Consumers' Experience of Home Infusion Therapy: A Phenomenological Study

submitted by

Sarah Breier, RN, BN

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Tasmanian School of Nursing
University of Tasmania
Launceston, Tasmania, Australia 7250

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DECLARATION

I declare that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief, it does not contain any material previously published or written by another person where due reference is not made in the text.

Sarah Breier

ABSTRACT

This thesis presents a phenomenological exploration of the meanings and experiences of home infusion therapy from the consumer perspective. Using a phenomenological research methods (as described by van Manen 1990), the study draws on the stories of five people who are recipients of home infusion therapy. Through semi structured interviews the participants in this study describe what this experience has been like. A discussion of themes has been structured according to the everyday experiences of home infusion. The participants describe a process that includes: 'the journey home' and 'having a life'. The impetus of this work is to heighten nurse's understandings and awareness of home infusion therapy from the consumer perspective.

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Chapter 1

THE QUESTION OF HOME INFUSION THERAPY

The Home Bodily Dimension - a Starting Point

Importantly for me, the home bodily dimension (within high acuity health care) provides a context for all other aspects of nursing. Nurses and patients are embodied beings. As I reflect on my experience in this respect, I am very aware that being embodied means far more than just having a body. In my experience of people being infused at home, and nursed at home, and those involved in the journey home, they do not appear merely as people who have bodies. Rather, they are their bodies. Modern health care has been criticized considerably, and no doubt justly, for its overemphasis on physical causes, physical symptoms and physical outcomes (Lawler 1991). Nursing has borne its share of such criticism. During my own progression through practice and change of practice, I have been constantly reminded of my own tendency toward labeling patients according to their diagnoses and/or the medical and surgical procedures for which they have been scheduled. I have heard myself (and my colleagues) refer to a patient not as a person, but rather as 'the appendix in bed six'. This kind of attitude stems from a reductionist approach; it is a perspective wherein the physical is separated from the psychosocial and the spiritual and from the totality of the person. When the primary focus of nursing is somatic, there seems to be no separation of that kind. The totality, the home bodily dimension, and the 'real' are not overlooked or downgraded. They are definitely there and are genuinely taken account of.

This study had its origins in my professional experience as a nurse and as an enquiring yet novice academic. As a nurse I have had a deepening interest over the past several years in home health care and the impact that these types changes within health service provision might be having on the consumer. I have cared for and observed people undergoing infusion therapy in various treatment settings, and practiced as a certified intravenous therapy nurse in the United

States between 1990 and 1993. On returning to Australia I was unable to resume this type of practice, in particular home infusion therapy, as home nursing care was considered to be non-acute domiciliary nursing care primarily for the frail aged. My academic interests became directed towards changes within the traditional health care delivery system in Australia and preparedness for the imminent introduction of Casemix and Diagnostic Related Group (DRG) based funding and classification systems. Having had experience with home treatment modalities elsewhere, I pondered as to whether acute home nursing provision would gain community acceptance in Australia and how it might be experienced by local health consumers.

As 'high acuity health care', 'hospital in the home' programs (HITH), and 'PATCH' (Post Acute Treatment and Care in the Home), have become virtual 'buzz' phrases within health care in Australia in recent years, the remarkable gap in the evaluative literature focusing on the consumer perspective became the initial impetus for embarking upon this research project. I chose the area of home infusion because it was of significant personal and professional interest and also in so much as it is the most sought after treatment within high acuity home care in Australia (Montalto and Dunt 1993). I have limited the scope of this project to home infusion therapy from the consumer perspective, in an attempt to contain it within the specified thesis word limit. This approach however is certainly not limited to this particular clinical area of high acuity home health care, and I am certain that the insights gleaned from this research could be transferred and appreciated within other home health treatment regimens and their outcomes.

Methodological Considerations

In commencing this research I was therefore reflecting on my past practice experiences entering the homes of patients and their families. While these experiences occurred within a different country and embraced a different health care delivery system, similar developments were beginning to occur in Australia. I had certainly pondered over the experiences of people for whom I had cared whilst abroad. This reflection continued upon my return home when I discovered

that similar treatment modalities were being discussed and trialed, apparently without consumer input. This question of the experience of home infusion therapy thus became the essence of my project.

The methodology employed in this study is drawn from phenomenology. Unlike positivistic inquiry where the question stands apart from the activities of those who carry out the research, the phenomenological question is said to be lived by the researcher (van Manen 1990). The general description of qualitative methods in research is part of the horizon or background that phenomenology (as an approach) has been contained within (Munhall 1994). The question therefore became part of the very fabric of my being and as such, I was unable to stand outside the question in a detached way. As Crotty (1996:16) explains 'researchers cannot deny that they all come armed with prior knowledge, their own beliefs and judgment, preconceived ideas and theories, or personal and theoretical bias'.

An initial exploration of the literature on home infusion therapy and other similar modalities has revealed that the majority of articles seem to focus on evaluating cost savings, treatment effectiveness of different drug preparations between the HITH setting, and hypothesizing consumer benefits. Recent evaluative research of hospital in the home programs within Australia, report high patient satisfaction without detailing specific patient responses and experiences, or the methodology used to elicit these responses (Montalto 1996). Capturing the true life experience of home infusion therapy has not featured in the contemporary literature reviewed for this project.

The First Person

I have elected to write mainly in the first person in recognition that within my experience lies the possible experiences of others (van Manen 1990). I was involved in the research process in such a way that it challenged the tradition of objectivity in academic writing (Webb 1992). To write about what it might have been like to experience home infusion therapy in the third person would have

been to distance myself from the participants, and depersonalize their stories. To talk of myself as the 'author' or the 'researcher' would not have been consistant with the use of the research method of phenomenology and would also distance you the reader from the research process. This process would not do justice to the researcher and participant relationship that has developed. This way of separating the knower from what is known resembles scientific writing whereby, 'knowledge is treated as something outside, rather than inside the minds or brains of individuals' (Chalmers 1982). I acknowledge that I have been an active agent in the construction of knowledge and I agree with the following comments by Webb:

> Writing in the third person is therefore a form of deception in which the thinking of scientists does not appear, and they are obliterated as active agents in the construction of knowledge (Webb 1992:749).

The Organizational Framework for the Study

The study unfolds as follows. This first chapter introduces the study and places it within the context of my professional and personal interest as a nurse and as an academic. This first chapter also situates the question of the experience of home infusion therapy within the changes currently underway in the health care system and outlines the significance of the study. Chapter Two outlines a historical perspective on the phenomenon of consumer experience and home infusion therapy and indicates the significance of the study to nursing. Chapter Three provides an overview of the methods of hermeneutic phenomenology (van Manen 1984, 1990), the methodology employed within the study. Chapters Four and Five outline the thematic analysis, exploration and interpretation of the stories respectively. The final chapter comprises reflections on the research process, and a discussion of the relevance and importance of the study for nursing. The dissertation ends with a reflection on the issue of consumer experiences of home infusion therapy.

Chapter 2

CONSUMERS' EXPERIENCE: AN EXPLORATION OF THE LITERATURE

As Rhomberg has recently commented, the postive aspect of the consumer movement in healthcare is that "...finally somebody is paying attention to what patients want" (1996:67). Exploring the question of to what it is like to be infused at home has required investigation into what is already known about home infusion therapy in general, and the impact on the consumer in particular. In what follows definitions of home infusion therapy are presented followed by a discussion concerning service provision and consumer perspectives. The notion of consumer experience as explained by Draper and Hill (1995) is also explored thus providing some indication of the identified gaps in previous research. The assumptions of consumer feedback as a process are presented as an introduction to the research methodology underpinning this thesis.

The Trend Towards Home Based Acute Care

With increasing pressure on hospital beds, the trend in Australia and overseas towards home health care has been tipped to grow, and growing it is (CIG 1994). As Heffernan suggests, shifting the hospital into the home is a huge break from Florence Nightingale's push for institutionalized nursing (1996). When Casemix of case payment was introduced in hospitals in the USA in the early 1980's, pressure increased on hospital administrators to contain costs. Thus began the shift from patient care in high cost acute hospitals to sub-acute, low-cost care centres, usually the home. That shift now appears unstoppable not only due to the cost benefits, but also because patients have come to demand it as their preferred option (Bernstein 1992).

In the United States home care agencies have more than doubled in the last five years and the total cost of products and services has also doubled since 1985 to $20 billion in 1993 (CIG 1994). Several Australian hospitals have recently

implemented HITH projects in line with US practices. The introduction of one such scheme at the Royal Prince Alfred Hospital resulted in the freeing up of hospital beds while also keeping people out of hospital because of the unique opportunity that the home environment offers for educating patients about their illness (CIG 1994).

Patient satisfaction is said to be a major driving force behind HITH programs. Patients value the one-on-one attention, advice and education they get because it is not always available in a ward. Repeat patients are now starting to request the HITH option (Royal Prince Alfred Hospital in CIG 1994).

The International Experience - Early Discharge Programs

Early Discharge Programs and HITH Schemes have been in operation for many years in countries such as Sweden, France and the United States of America. Other countries have implemented variations of Early Discharge Programs such as an extension of acute hospital services, in an endeavour to reduce the length of hospital stay, and contain costs. The Canadian HITH Scheme and the Petersborough HITH Scheme in England are well documented examples of this approach. Long term benefits have been reported, including the reduction of hospital beds needed to service patients and in the facilitation of safe discharge (Moody 1994).

In the United States 'Caremark', a subsidiary of Baxter International, operated a Home Infusion Therapies Service which catered for more than 75, 000 patients annually - at home, work, school, or when traveling through the network of over 80 service facilities (Torr 1994). Healthdyne Inc., another North American company is a private for profit provider of high technology home health care and alternate site infusion services (Torr 1994).

The Australian Experience - 'Hospital in the Home'

Since the mid 1980's there has been a great deal of attention paid to alternative methods of service delivery in Australian hospitals. Several key factors have influenced the move toward investigating early discharge programs and overall case management. These include the growing waiting lists for elective surgery that began to be a political issue in the 1980's, and the impending introduction of Casemix funding in public hospitals. Such considerations played an important role in promoting a review by State and Federal Governments and hospital administrations, of length of stay data and cost analyses directly related to this, in order to cap health expenditure (Moody 1994).

In the 1980's a Medicare Incentive Program allocated funds to public hospitals to allow them to investigate the development of new procedures and to improve existing ones related to reduction of length of stay and decreasing elective surgery waiting lists. Several participating hospitals devised programs aimed at decreasing waiting lists for elective surgery and targeting patient groups with a high length of stay. A wide range of conditions have been deemed suitable for early discharge or home management, including the administration of intravenous antibiotics, diabetes, midwifery management, paediatric, orthopaedic and respiratory problems (Moody 1994). Home treatment, encompassing the administration of intravenous antibiotics, is predicted to become a developing industry in Australia in the coming years, with technological improvements facilitating the process (Moody 1994).

The feasibility of early discharge programs for orthopaedic patients has received considerable attention in Australia. The Prince of Wales Hospital (Brown 1990) in Sydney, has conducted a Post Acute Orthopaedic Rehabilitation Service (PORS) since September 1989, with funding provided under the Medicare Incentive Program. The objectives of the program were:

- to care for elderly orthopaedic patients at home (if possible) rather than in hospital;

- to treat hip fractures by early operation and mobilization, plus early discharge to community support and rehabilitation; and
- to reduce length of stay for all elderly orthopaedic patients through the provision of immediate community support and rehabilitation.

The ultimate goals were to reduce the average length of stay for patients with hip fractures by 50% and increase the throughput of elective surgery orthopaedic operations while simultaneously decreasing waiting list or waiting time (Brown 1990).

St. George Hospital in Sydney likewise received funding in 1989 under the Medicare Incentive Program to implement an Early Discharge Program (Moody 1994). An extensive program was established with a staff of twelve. Again a large financial outlay was made on capital works, equipment, cars and staffing (Colbourne 1990). Initially only orthopaedic patients were accepted, but this was later broadened to encompass surgical patients. In the period between January 1992 to October 1992, a total of 512 patients were accepted into the program with an average saving of 2.5 bed days. This program provided home nursing services 'on-call' 24 hours a day, and physiotherapy cover seven days a week. Pre-admission assessments were undertaken on all elective surgery patients. Other services provided included occupational therapy, social work and home help. The coordinator of this program estimated that the throughput in the Orthopaedic Unit had increased by 43%. The other objective of decreasing length of stay had also been accomplished.

Similar projects and services have been implemented at the Preston and Northcote Community Hospital (Hill 1992); the Rapid Transit Scheme in Western Australia (Sikorski 1985); Box Hill Hospital (Schloss 1993); and the Mornington Peninsula Hospital (Montalto & Dunt 1993). Montalto and Dunt (1993) examined the potential application of such programs in Australia and concluded that for a select number of conditions, in a select group of patients, home hospital services will become a reality in this country. They also emphasize that structures for maintaining inclusion criteria and quality assurance must be rigidly enforced in order to maintain clinical standards and public

confidence. Britain-White (1995) similarly points out that many pilot programs have been instituted, mirroring results of previous trials. She states the need to accept these programs as a reality and create a uniquely Australian early discharge program that can be delivered on a nationwide basis with national standards.

Overall the literature generally supports early discharge as an effective method of treatment, with few criticisms reported in relation to cost-effectiveness, patient and carer satisfaction, and medical or physical outcomes. Variations are experienced in the program outcomes according to the method of implementation. Again the literature evidences a lack in consumer evaluation compared to the financial and medical outcomes that dominate the evaluative methods published.

Home Based Infusion Therapy

While it was known that medications could be injected into a vein as early as the 1600's (Millam 1996) modern intravenous (IV) therapy is less than a century old. Because of a lack of scientific methods, original attempts to deliver IV fluids and drugs met with little success. The two world wars undoubtedly accelerated the advent of IV therapy. However, the greatest advance in drugs, equipment and procedures has occurred in the past 25 years (Millam 1996).

Over the past fifteen years in the United States an increasing variety of IV therapies have been administered to patients both at home and in the outpatient setting (Williams 1991). Anti-neoplastic and chemotherapeutic agents, analgesics, blood products and coagulation factor replacement can be safely and effectively administered at home according to the recent literature.

'Alternative Site Infusion Services' are one of the most rapidly growing segments of the American health care system and are beginning to have considerable impact on our own health care practices in Australia. United States industry survey reports show revenue growth of approximately 20% over the past

few years with this growth expected to continue in the years ahead (Anrusko-Furphy and Wright 1995). The current interest locally in high quality, cost effective, health care has highlighted the role alternative site providers play in the health care delivery system. Other factors influencing this strong growth include the relative cost efficiency of home therapies, new technological advancements, and the aging population (Moody 1994).

'Alternative Site Infusion Services', 'Hospital in the Home Services', 'Advanced Home Health Care Services', and so on, are organizations which provide the services necessary to administer nutrition solutions, antibiotics and other medications to patients either through a venous access device or a feeding tube. The complexity of therapies provided in alternative sites and acuity of the patient's diagnosis have increased since the inception of home infusion services (Anrusko-Furphy and Wright 1995). Alternative site infusion services have truly become hospitals without walls. Therapies that traditionally required hospitalization, are now routinely administered at home, in nursing homes and in ambulatory infusion centres (e.g. oncology outpatient clinics, dialysis units). Pharmacists, nurses, physicians and other health care professionals must work closely together to provide continuity of care for these patients. It has been suggested that the provision of a successful infusion service providing safe and effective care for patients and demonstrating more efficient utilization of resources, requires the components of pharmacy/operations, multidisciplinary healthcare team, equipment/supply, marketing, and management (Anrusko-Furphy and Wright 1995).

These components must be provided in a complete infusion service according to the common themes arising from the related literature. A patient focused approach to care will encourage the team members to work together. With patient focused care, the patient's outcome is the primary goal of the service. The services are provided by the person which is most qualified for that particular patient and roles and responsibilities are not necessarily defined by discipline or training (Anrusko-Furphy and Wright 1995).

The Consumer Perspective

There is no doubt that the literature implies that home infusion therapy has the potential to improve the health outcomes and quality of life of many people. It is a well established modality used in several chronic and in some time-limited illnesses (Weinstein 1993). For the patient with a non-functional gastrointestinal system, or with cancer cachexia and subsequent malnutrition, parenteral therapy may represent the only chance for a normal life. For the patient in an immunosuppressed state secondary to cystic fibrosis or intractable cellutitis, IV antibiotic therapy may be the only clinical intervention that counteracts systemic infection. Weinstein (1993) suggests that home therapy has the potential to provide a patient with a greater deal of control over his or her life. As long as adequate and technically competent home infusion providers exist to coordinate the level of care needed, home infusion therapy is a feasible alternative and often a patient's first choice (Weinstein 1993). A successful program is one that incorporates coordination of resources, a team approach, and sound resources, and one that truly sets the standards for quality of patient care (Weinstein 1993).

Mahmood and Rubin (1992), two American authors, argue that patient advocate organizations feel patients are better cared for and feel more comfortable in the home environment. Well developed hospice programs have already shown great success in bringing home based care to the advanced and terminal cancer patient. The major advantages of delivering IV care at home are the convenience and comfort of the home environment. Transportation also is an advantage for those patients who do not travel easily (Mahmood and Rubin 1992).

A benefit for the elderly clientele is the ability to be surrounded by a familiar home environment in comparison to the often stressful hospital surroundings. This benefit is a major factor in the management of many patients, specifically those suffering with carcinomas (Mahmood and Rubin 1992). Furthermore, hospital schedules are often geared toward a different type of patient who will remain in the hospital for several days. The scheduled short-term IV therapy

patient may be lost in the "...bustle of emergencies and urgencies common to hospital systems..." (Mahmood and Rubin 1992:43).

According to the American literature, it is assumed that home care is more cost effective because patients only pay for the care they receive. The cost of therapy for a day in the hospital is based on a complicated procedure that takes into account many other factors such as hotel services (catering, linen, domestic) and infrastructure costs (McCue 1988). Home IV antibiotic therapy apparently generates additional savings by having the patient or the patient's family/caregiver administer and monitor therapy. This avoids hospital overhead expenses and reduces labor costs. It is important to recognize here that although the above explanations of home infusion therapy and their associated benefits read as being very positive, they reflect the American experience - a healthcare delivery system which is very different in comparison to our own.

Of considerable concern to the consumer is the issue of safety. Home IV therapy should be as safe as hospital therapy; one could argue that patients trained to assume responsibility for their own therapy might do a better job than would harassed and distracted nurses in a busy hospital (McCue 1988). Poretz (1984) concluded that home IV therapy was as safe - if not safer than - antibiotic treatment in the hospital.

It seems reasonable to expect that physical and emotional comfort for people receiving IV therapy at home will most likely be accomplished if they feel confident with their therapy. Understanding and exercising control over treatment - which, although complex, is considered to be safe and effective - is of critical importance (Wood 1991). Being at home on such important and complex treatment can be overwhelming, however maintaining access to someone who understands the problems and treatment can alleviate many of these anxieties (Wood 1991).

Identifying a Gap

Much of the local and international literature concerned with the development of high technology health care provision in the home has focused primarily on the issues of cost effectiveness, legal considerations, applications, organization and broad themes in consumer evaluation. The evaluative information gleaned from the related literature has been associated with health economics and the efficacy of home based treatments as compared to their pharmacokinetic effectiveness in hospitals. Despite home infusion representing a new practice trend within Australia, there appears to be a significant gap in the literature, in that the impact of such service delivery to the community based consumer has not been sufficiently explored.

Exploring the Assumptions

A review of the home infusion therapy literature highlights a number of assumptions concerning the 'benefits' of this form of health service to patients and their families. These assumptions include:

- treatment in the comfort and security of home
- continuity of family relationships
- individualized plan of treatment
- continuing relationship with a familiar institution
- freedom to participate in their plan of treatment at home
- caring, personal service by experienced qualified health care professionals working toward the success of the patient's plan of treatment (Lifeway Home Health Care Inc 1994).

The above points may follow logically from a marketing perspective yet these points are simply just that - marketing generalizations that regularly appear in journal articles supporting home care for complex treatments. The majority of formalized and fundamental assumptions regarding home infusion are based on clinical outcomes. For example, a recent investigation of outpatient intravenous antibiotic therapy concluded that out of 608 patients, of whom 567 completed the course of therapy (93%), two patients died (0.25%), five were considered poor compliers (0.75%) and thirty four were hospitalized during therapy (6%). By

way of evaluative data it was reported that 519 patients (92%) had improved at the end of therapy, 12 (2%) had not responded to therapy, and 32 (6%) were not available for follow up (Tice 1995). Other similar investigations review the microbiological outcomes of therapy, whether patients experience an adverse event such as anaphylaxis, and what types of disorders had been treated within the home setting.

The question of patient experience is rarely addressed in the home infusion literature. When mentioned it is usually towards the end of the report offering little or no true indication of what it actually like to be infused at home. Available evaluative data on home infusion therapy omits the impact on family members and caregivers. What we find instead, are loose generalizations such as "...results showed a high level of patient satisfaction with home IV therapy, with 95% of patients saying they would definitely undertake PATCH therapy again and 4% saying they would probably do it again" (Anti-Bacterial Chronicle 1995).

Another recent evaluative study focusing primarily on drug efficacy and cost effectiveness did mention that all participants "...expressed a strong preference for home IV therapy compared with hospital treatment" (Grayson et al 1995: 253). Why they expressed a strong preference was not fully explained apart from the comment that "...many of the patients reported a sense of improved self esteem associated with 'ownership' of their illness and involvement in their treatment" (Grayson et al 1995:253). This indistinct 'ownership' is also mentioned in a 1994 report on the Australian College of Health Service Executives:

> Many people will prefer care in the home because it gives them a greater sense of control (Torr 1994:39).

Even with a 'strong preference' it may well be possible to further our understanding of and responses to consumer's experience of home infusion. Vinen (1995) similarly offers generalized information stating that 99% of patients undergoing home infusion therapy (specifically intravenous antibiotics) endorse outpatient treatment in preference to inpatient treatment. The question as

to 'why' these patients would opt for home based care is not clearly articulated, and the reasons as to 'why' are often speculated on but not carefully followed up by the researcher. In a recent research report evaluating home chemotherapy for cancer patients it is stated that "(we) hypothesized that patients would benefit because of reduced traveling and waiting time, the ability to receive treatment in familiar surroundings and a decreased risk of acquiring nosocomial infections" (Lowenthal et al 1996:184). Despite this hypothesis being the impetus which originally prompted the research, the final report fails to address these consumer issues.

Similar research undertaken by Poretz et al (1982), Grizzard (1985), Barget and Zink (1989) and Bernstein (1990) also fails to offer an in-depth exploration and explanation of what it might be like to be, and/or to be involved with, being infused at home.

The 'patient' does warrant consideration in the literature when discussing the assessment of patient suitability and selection criteria for treatment. These considerations include whether or not the patient's home environment is conducive to successful therapy? Is the disease treatable at home? Is the patient suitable mentally? physically? attitudinally? Does the patient reside within a designated catchment area of service delivery. Nolet (1995) elaborates on individual considerations from a nursing perspective:

> The nurse, in conjunction with the physician and pharmacist, has an important role in deciding whether the patient is suitable for PATCH. The patient's physical limitations should be considered. Home IV therapy, particularly when the patient administers their own medication, requires a certain amount of manual dexterity, that older or injured patients may not have. In addition, some patients may not be mentally capable of treating themselves or undergoing outpatient therapy at an infusion centre. There is also the possibility of substance abuse. This is necessarily a contraindication to therapy, but in these patients, the team should try to avoid leaving an IV line in the patient. Alcoholics may not be suitable for outpatient therapy because they may have difficulty complying with therapy (Nolet 1995:1).

Explanations of service delivery, individual considerations, and patient support expectations are expressed in the related literature in retrospective terms more so

that outcomes. Thinking of the role of the patient, their family and/or caregiver as the consumer(s) is largely overlooked as a quality tool or indicator in the reviewed literature. The lack of consumer participation in this area underscores the research reported in this dissertation.

The Methodology of Consumer Experience

There has recently been a shift in thinking about the role of the consumer as patient. It is more likely now that researchers want to know what consumers think; that they accept what the patient tells them is an accurate reflection of what happened; and that this information can be used to improve the quality of patient care and shape policy. Coinciding with this shift, and related to it, is a serious questioning of the conception of experience as a unitary concept whose causal variables can be measured (Draper & Hill 1995).

There is some research into the relationships between satisfied patients and improved health outcomes which has shown that satisfied patients may be more prepared to seek help, comply with treatment and maintain an on-going relationship with their doctor (Carr-Hill 1992). More recently there has been an interest in satisfaction as an outcome in itself, which tends to be linked to economic appraisal of the costs and benefits (broadly defined) of particular treatments (Draper & Hill 1995). This is particularly the case in the available literature on home infusion therapy as an economical alternative to inpatient care. For example, local studies by Vinen (1995), Grayson et al (1995), Lowenthal et al (1996) and Montalto & Dunt (1993) all state that patients were satisfied with their home treatment and would prefer this approach compared to receiving the same form of treatment in a hospital setting.

The most frequent method of obtaining consumer feedback in the health sector has been by self completion patient satisfaction questionnaires, despite doubts over the value of the method in obtaining genuine consumer opinion, and concern about the passive role this method often assigns to consumers (McIver 1992). Patient satisfaction surveys appear to value consumer opinion, but are

often used to justify services, given that satisfaction levels are usually high in these surveys, where 85% satisfaction is standard according to McIver (1992). The challenge for such investigation therefore is to explore the covert information about dissatisfaction and other experiences and investigate the reasons behind these.

Assumptions About Consumer Feedback

Both the patient satisfaction literature and the newly emergent health outcomes literature as typified in the Medical Outcomes Short Form 36 (SF-36) contains similar debates over the type of information obtained from quantitative methods compared to qualitative methods. In other words, does the method of gaining access to the user's experience and views lead to an accurate reflection of what they think, and do structured questionnaires capture the meaning of people's experience as well as less structured interview methods? The consensus view seems to be that quantitative prescriptive methods reduce the complexity of the experience and thus do not adequately capture the meaning of that experience (Draper & Hill 1995).

Patient feedback surveys frequently treat consumers passively, as impersonal sources of information (Steele 1992). Market research, it seems, is rarely participative in its execution. Patient satisfaction surveys often provide a form of consumer feedback that is as patronizing in its application as the traditional health relationships that consumers have criticized. While assumptions about the value of consumers' ideas and experiences derive from democratic participative approaches, patient satisfaction surveys derive from both scientific and market approaches (Draper & Hill 1995). By and large these approaches do not involve consumers in planning or evaluation, nor do they involve consumers in discussions and decisions about solutions.

Summary

This chapter has outlined a selected review of the literature on consumer's experience of home infusion therapy and identified a gap in this literature. It has been argued that there is no single universally accepted method for obtaining information for obtaining feedback from consumers.

The most widely used form of consumer feedback has been that of closed choice questions administered as self-completion questionnaires usually undertaken after the episode of care. However, recent developments would seem to endorse the use of different methods; methods which are appropriate to the needs of particular groups of consumers and to the area of research requiring the development of a body of knowledge (Draper & Hill 1995). The limitation of previous research into the experiences of consumers undergoing home infusion therapy therefore stems from the methodological shortcomings of patient satisfaction surveys; their limited ability to get at peoples' experiences of home infusion therapy.

It is worth noting, therefore, that considerations of consumer's experience of home infusion therapy are almost completely overlooked, despite the rapid and widespread implementation of such health services. The urgency that hospital managers seem to have felt in relation to cost cutting measures, the reduction of waiting lists, and reduced length of hospital stay, seems not to have carried over into anything more than relatively superficial concerns regarding the impact of new treatment modes on those who are on the receiving end of care. The question of how health consumers experience home infusion therapy is thus surely of interest to those who have a stake in the delivery of quality health services. The present study is intended as a contribution to such a project.

Chapter 3

RESEARCH METHODOLOGY: EXPLORING THE PHENOMENON OF BEING INFUSED AT HOME

The previous chapter outlined a selective review of literature available on home infusion therapy and introduced some concepts of interpretive research and discussed their application to the study of consumer experience. The purpose of this chapter is to discuss the chosen methodology, outline the research design and the process used for data collection and interpretation. This chapter also introduces the people who participated in this study.

The Chosen Method of Inquiry - Phenomenology

> Phenomenology is that kind of thinking which guides one back from theoretical abstraction to the reality of lived experience. A phenomenologist asks the question, "What is it like to have a certain experience?" (van Manen cited in Morse 1985:27).

As a research methodology phenomenology concerns itself with gaining access to the outer world (life-world) from the inside of human experience (consciousness). This is achieved through reflection leading to transcendental subjectivity (unmeditated intuition) of the meaning experience through the enrichment of existential (being-in-the-world) and hermeneutic (interpretive) thought (Wagner cited in Parker 1992).

My reasons for selecting this method of qualitative research instead of quantitative methods was as follows. An important assumption of the empirical-analytical paradigm - natural science - is that the world is structured by law-like generalities that can be identified, predicted, manipulated and controlled. The empirical-analytical paradigm endeavours to present a formalized account of the nature of scientific knowledge that will enable prediction and control. Indeed, nurses need theory, knowledge of relationships, and identified interventions to help forecast and control human responses to specific situations (Munhall 1994). However, this knowledge, when and if applied, is not always sufficient. There

are many other considerations in the world of human life experience. As an alternative and a historical reaction to the prevailing hegemony of the positivist perspective, phenomenology construed itself as a philosophy, a perspective, and an approach to practice and research (Munhall 1994).

Phenomenologists speak of going back to the things themselves, to begin with phenomena and the experiences, not theories, in an attempt to move science away from positivist and reductionist views of the world (Parker 1992). The word 'phenomenon' in phenomenology pertains to the objects, events, situations, and circumstances as they appear to a participant in original perception, prior to any interpretation. 'Experience' on the other hand refers to the living through of an event, situation, or episode. The intention of phenomenology is to reveal lived experience, though it is recognized that the closest one can come is to disclosed perception (Oiler cited in Parker 1992).

The term 'perception' has a distinguishing meaning in phenomenology and warrants elaboration. Perception is the elementary awareness of what one lives through in experience. Meaning emanates from the embroiled interrelationship of person-world as a person gives meaning to experience. The reality of an experience cannot be known apart from a person's experience and interpretation of it. It is important in phenomenology that an understanding of the notions of experience, perception, and meanings be illustrated and clarified (Parker 1992).

Since phenomenological methods can be classed as a type of qualitative methodology, they have much in common with all qualitative methods. Distinct differences in this methodology do exist, however. One such difference is the mandate of phenomenology that no preconceived perceptions, expectations, or frameworks be present or guide the researcher as she/he gather and explore the data (Omery cited in Parker 1992). The practicality of this particular mandate is somewhat questionable. Second, the phenomenological method makes no conjectures. It does not deny that such things as process might be discovered, but phenomenology does not assume that processes exist before they are described (Wilson cited in Parker 1992). Third, with the phenomenological

method, the researcher approaches the participant and experience with an open mind, accepting whatever data are given. Phenomenology accepts all experiences as valid sources of knowledge for the participants living the experience. Each experience made known to the researcher is beheld as valid (Ray cited in Parker 1992). Fourth, the philosophical basis for this methodology is distinct from other qualitative approaches. This philosophical foundation originates with an existential phenomenological view, emphasizing a person as unique, possessing potential and experiencing opportunity for change (Appleton cited in Parker 1992).

Describing one form of phenomenology is not to deny the breadth and diversity of the phenomenological movement. The scope of phenomenology extends from the transcendental phenomenology of Edmund Husserl to the existential phenomenology adopted and expanded by philosophers such as Satre, Merleau-Ponty, Ortegay Gasset, Marcel and Riceour. In many instances, the figures historically associated with the phenomenological movement prevail within much ambiguity (Crotty 1996), Nevertheless, while phenomenologists are a very disparate group, they continue to subscribe to a basic approach in pursuing their understandings and inquiries.

At the very least, phenomenology serves to emphasize the realm of experience, and to 'affirm subjective experience' (Zerwekh cited in Crotty 1996:13). Its methods articulate the importance of the subjective experience and accordingly focus attention on our experiences. Crotty suggests that the purpose of studying experiences is 'to understand, their meaning, their essential structure' (1996:13). In short Crotty explains:

> A phenomenological method will uncover meaning and provide hermeneutic interpretation of human experience in its situated context. In short, phenomenology seeks to render lived experience intelligible (Crotty 1996:13).

After reviewing the number of approaches to doing phenomenological research, I have chosen a hermeneutical approach that is essentially Heideggerian phenomenology as outlined by Crotty (1996) despite his criticism of

inappropriate utilization of this method by nurse researchers. Phenomenology for Heidegger is 'to let that which shows itself be seen from itself in the very way in which it shows itself from itself' (Heidegger cited in Crotty 1996:79). This is also Heiddeger's hermeneutics (Crotty 1996). This phenomenology as defined by Heiddeger involves letting lived experience be revealed as it exists without predetermined divisions. It affirms subjective experience, and it is in opposition to the objectivity and reductionism sought through a positivist perspective. As Zerwekh explains, the nurse-researcher using this approach 'seeks to elucidate through dialogue turned into written text the clinical wisdom embedded in the everyday practice stories of nurses' (1992:16). Although Zerwekh speaks of nurses here, there is no reason why this concept can not be generalized into the everyday experience of patients and their families/caregivers.

Rather (1992) more generally explains that Heiddegerian phenomenology holds that our foundation mode of existing as persons is in interpretation and understanding. Understanding is maintaining one's own possibilities for being, within the context of the world in which one lives. Everyday experience as it is lived is the focus of attention in this interpretive research approach. The consideration for Heideggerian phenomenology is to render lived experience intelligible as 'this is the place where meaning resides' (Rather 1992:48).

The hermeneutical position of Heidegger's phenomenology is defined simply as understanding being rendered explicit by interpretation, that is, in language. Rather (1992:48) explains that language does not solely represent our way of being, it discloses what it is to 'be'. Language is a method of human being which exposes Being (Rather 1992).

Heidegger (cited in Rather 1992) stated that everyone exists hermeneutically, finding significance and meaning everywhere in the world. Heidegger understood that hermeneutic methods could consequently be applied to our understanding of life and other persons, the everyday world of practices, and lived experience.

Why Phenomenology ?

Phenomenology as a method in this research project seeks to describe and unfold the experience of home infusion therapy before the eyes of the researcher and reader, so that the essence of what it means for these people can be understood. The professional literature (i.e. nursing, medicine, allied health) is comparatively silent with regard to the experience of home infusion therapy. An understanding of this phenomenon of human experience has not been sufficiently elucidated using qualitative methods of inquiry as discussed in the preceding chapter. What one believes or hypothesizes to be the benefits of home infusion therapy may not in fact accord with the experience of those who are receiving it at home. The aim of the study is thus to continue to develop an understanding of what it might be like to be infused at home.

Philosophical Underpinnings of this Study

Paterson and Zderad (1976) view nursing as an existential human experience of being and doing with another. According to these authors:

> Phenomenology involves an openness to nursing phenomena, a spirit of receptivity, a readiness for surprise, and the courage to experience the unknown (Paterson and Zderad cited in Parker 1992:284)

The act of caring increases the humanness of both patient and nurse. The phenomenological approach has been endorsed as the most appropriate for studying the richness and complexity of nursing phenomena by Parker (1992).

Ray (1992) declares, for nurses, phenomenology extends a means by which the lived experience of the 'life-world' or historical phenomena (mental, social and historical) of the nurses and persons to whom they are responsible can be studied and understood (cited in Parker 1992:284). Oiler (1982) stated that 'phenomenology is a philosophy, an approach, and a method. Possessed by a reverence for experience, it confirms to nursing valuing' (cited in Parker 1992:285). She continues by explaining that the phenomenological approach is

appropriate because the 'nursing profession emphasizing a reverence for clients' experiences, is concerned with the quality of life, and the quality of the nurse - patient relationship' (Oiler in Parker 1992:285).

According to Munhall (1988) phenomenological studies are needed in current theory formation and reformation to ascertain which researcher biases have influenced world views and as a result have assisted in establishing norms and standards that may be inappropriately generalized. A qualitative perspective then, according to Munhall, 'becomes essential from the philosophical perspective of nursing not only as a research design but also for actual implementation of a holistic, empathic, individualized delivery of nursing care' (1988:27).

Research Design

The selection of an appropriate research design has involved difficult choices. While the literature on interpretative research methodologies is extensive, it is also diverse, contradictory and ambiguous. As Christensen argues, 'there are few certainties and many bounded options for the researcher' in this post modern era of doing and writing interpretive research (1996:48). This is particularly the case with the conflicting assumptions throughout the literature regarding hermeneutical phenomenology.

In candid terms, I understand the fundamentals of phenomenology in its various forms in similar terms to those expressed by Judith Christensen (1996:49):

- we live our lives embedded within a situation, both constituting and being constituted by our world
- we perceive ourselves to be in an intersubjective world
- our interpretations shape what we are
- our understanding embodies our practices
- practices are models of social action
- there is no outside, detached standpoint from which we can examine others

- there is no privileged, absolute or timeless perspective
- phenomenology goes beyond translating the shared meanings people give to their world
- phenomenology seeks to explicate the nature of phenomena to which people give meaning (Christensen 1996:49).

Doing phenomenological research for Crotty (1996) quite simply is identifying subjective experience, describing it and understanding it. In nursing research what the phenomenological approach calls for is a method of inquiry that will not influence the subjectivity of the experience under the study. It demands a method of data collection and data analysis that will expose the participants' experience accurately from their perspective: that is, in terms of the significance it has for them personally (Crotty 1996).

I have drawn upon van Manen's four hermeneutical procedural activities (1984) of understanding phenomenological work as cited in Munhall (1994:259), as the basis to my research endeavour. van Manen's approach (1984) of turning to a phenomenon that seriously interests us, and commits us to the world; investigating experience as we live it rather than as we conceptualize it; reflecting on the essential themes that characterize the phenomenon and, describing the phenomenon through the art of writing, provide the methodological 'plan' from which I have approached the present research project.

van Manen's Approach of Phenomenological Research

During his time at the University of Alberta, Max van Manen (1984) described the particular phenomenological approach that will be used in this study. Van Manen was heavily influenced by Merleau-Ponty's philosophy (Parker 1992) and described phenomenological research as a dynamic interplay among four procedural activities. The aim of these procedural activities is to assist the researcher to accomplish a deeper understanding of the nature of meaning of our everyday experiences. This heightened awareness will ultimately help us become more humanistic and caring as we learn the difficult skill of how to act tactfully

in situations based on careful thoughtfulness (Parker 1992 cited in Munhall 1994:292).

By employing van Manen's procedural approach, we not only can learn about lived experience but we can gain insight into the lived experience of particular phenomena, as van Manen (1984) states:

> Phenomenology differs from almost every other science in that it attempts to gain insightful description of the way we experience the world. So phenomenology does not offer us the possibility of effective theory with which we can now explain and/or control the world but rather it differs us the possibility of plausible insight which brings us in more direct contact with the world (van Manen 1984:37-38).

Phenomenology is, according to van Manen, 'a philosophy or theory of the unique; it is interested in what is essentially not replaceable' (1990:7). This is in contrast to traditional, experimental research which is largely interested in knowledge that is generalizable. van Manen also theorized that a person could only really begin to understand phenomenology by actually doing it. This view seems to have originated with Merleau-Ponty (Parker 1992). In reading phenomenological research, van Manen asserts that the significance of the final description is only understood when we understand the quantity of work, time, reflection and rewriting that is requisite to this type of study, 'it all seems somewhat absurd until we begin to discern the silence in the writing (van Manen 1984:37).

In hermeneutic phenomenological research, as described by van Manen (1984), the first procedural activity involves turning to the nature of lived experience, which entails a thoughtfulness and questioning of a phenomenon of interest that is important to the investigator (Parker 1992). The topic of this study comes from both my personal and professional experiences. There is a passion in my quest for an increased understanding of the meaning of this experience of home infusion therapy.

Turning to the phenomenon that seriously interests me and commits me to the world

The phenomenon of interest in this research is experiencing home infusion therapy. van Manen states that turning to the nature of the lived-experience means that it is a 'driven commitment of turning to an abiding concern, a quest, a true task, a deep questioning of something which restores an original sense of what it means to be a nurse, or a teacher, a patient, a theorist, or a researcher' (cited in Bartjes 1991:253). Central to this quest is the recognition of one's own contribution to humanity - 'that which renders fullness or wholeness to life' (van Manen cited in Bartjes 1991:253).

For me, investigating, exploring and developing an understanding into the lived-experience of being infused at home is most definitely a quest of interest for two main concerns. Firstly, the obvious deficit in the consumer focused exploration as identified in the previous chapter and secondly, a personal questioning of 'what it is like' from the consumer perspective, so as to develop a better understanding of how this experience can inform both medical management and nursing practice as well as policy and quality improvement from a consumer focused perspective.

The phenomenon of interest was approached by asking what the experience of home infusion therapy is like. The emphasis was on the meaning and experience of home infusion therapy through the examination of the context in which the experience is lived.

Obtaining sincerely subjective data from the research participants and safeguarding its subjective character throughout the process of analysis may be the principal concern to phenomenological research. However, as Crotty (1996:16) explains 'researchers cannot deny that they all come armed with prior knowledge, their own beliefs and judgment, preconceived ideas and theories, or personal and theoretical bias'. A crucial part then of turning to the nature of lived experience involves explicating assumptions and pre-understanding (Parker cited in Munhall 1994). With the use of phenomenological inquiry, a common

problem is that the researcher has too much information about the phenomenon under study. According to Parker (1992) 'a researcher must state clearly her or his assumptions prior to and throughout the study so that he or she can bracket them' (cited in Munhall 1994:293).

In this research I have somewhat renounced the idea of withholding assumptions and preconceived ideas acknowledging that complete objectivity is impossible as the researcher is part of the research process, and thus undeniably influences the development of that research. This assertion is defended by Sir Peter Medewar (1990) who states:

> There is no such thing as unprejudiced observation. Every act of observation we make is biased. What we see or otherwise sense is a function of what we have seen or sense in the past (cited in Davey 1992:43).

Other authors who query whether one's presuppositions can be put aside or suspended include Hauck (1991) who is content to identify 'investigator assumptions' rather than rid herself of them (cited in Crotty 1996:20). Montbriand and Laing (1991) acknowledge that researcher's frames of reference are embedded in the interpretations, while Zerwekh (1992) acknowledges that the author's frame of reference influences the process.

Investigating the experience of home infusion therapy as it is lived rather than as it is conceptualized

The second procedural activity as suggested by van Manen (1984) entails investigating experience as it is lived (existential investigation). This is the data collection or data general stage. It is here that I will ask, "What is the meaning?', "Can you give me an example?" My approach to interviewing has involved semi-structured questions and personal journalling to gather information about the lived experience of receiving home infusion therapy. A copy of the interview schedule is included in the appendices.

Investigating the experience of home infusion therapy as it is lived is therefore accomplished by being immersed in the consumer's world as it is lived, not

conceptualized. The approach I have taken draws on Minichiello's description of in-depth interviewing, that is, the repeated face-to-face encounters between the researcher and participants directed toward understanding the participant's perspective on their lives, experiences or situations expressed in their own nature (Minichiello et al 1991). The in-depth interviewing activities were of a semi-structured nature which allowed a conversation to elicit social interaction, not a predetermined question and answer procedural activity.

The first step in data collection was for the researcher to reflect on personal experiences of home infusion therapy. This was done at the beginning and during the process of this study, with the intention being to minimise the impact of researcher bias. Each of the interviews began with a discussion of the nature of the experience of home infusion therapy. The discussions then turned to the nature of home based care and how it compared to institutional care. This shift in focus was initiated by the participants themselves thus shaping the conversations to more of a comparative nature.

I met with the participants at a mutually agreed location. Three of the interviews took place in the participant's homes and two in a clinical setting. At the first face-to-face meeting informed consent was obtained. Each conversation lasted for approximately one hour. A return visit was made to discuss individual transcripts with each of the participants; this also lasted approximately one hour. The age of research participants ranged from 28 to 62 years. Each participant had a differing diagnosis, also of differing acuity. Copies of the ethics approval application and consent forms for the study are included in the appendices.

The conversations between the participants and myself were recorded verbatim and preserved as text through the use of a dictaphone and interview transcripts. By this method the lived-experience of home infusion therapy was captured in the text and preserved for interpretation. According to Gadamer, text is located within a world that embodies historical, social and cultural dimensions as a segment of time. It is by way of language that understanding occurs, through the process of interpretation (Gadamer 1975).

The indications and implications for considering home infusion therapy are many and different encompassing most clinical specialties in varying stages of acuity and duration. Consumers of this new trend in infusion therapy management are by no means a homogeneous group. To recognize contrast, and to appreciate the participants as individuals, I have chosen to introduce them so that they can be kept alive in the pages of this text as their stories merge with my understanding for the purpose of this thesis. I have chosen to refer to these people using pseudonyms - June, Will, Jennifer, Melissa and Cathy. They are introduced on page 35.

Reflecting on the essential themes that characterize the phenomenon

The third of van Manen's procedural activities, phenomenological reflection, involves two major steps: conducting thematic analysis and determining essential themes. The ultimate phenomenological description, which will be the end point of this study, will be established on these themes. According to van Manen (1990:87), "(a) theme is the experience of focus, the meaning, or point. Themes describe an aspect of the structure of the lived experience." When attempting to disclose thematic aspects, the researcher asks, "What statement(s) or phrase(s) seem particularly essential or revealing about the phenomenon or experience being described?" (van Manen 1990:93). The analysis of themes begins with the descriptions of the participant's experiences. From these participant descriptions, the researcher begins to reflect on the lived experience. A clarification of themes begins to evolve as the researcher begins to understand the meaning of the experience as a whole. Developing themes describe an aspect of the structure of the lived experience and allow the researcher to determine meaning from the lived experience data (Parker 1992).

Employing van Manen's approach as described by Munhall (1994) I have utilized a thematic analysis to make sense of the research. This thematic analysis has been achieved by reading and rereading the interview transcripts numerous times in order to gain a deeper appreciation and perception of the entire research.

This process occurred in conjunction with ongoing data collection, thereby providing the means to ask more structured questions in the follow up interview. Whilst the transcripts were read and reread, essential themes of the experience of home infusion therapy were identified and subsequently highlighted as suggested by van Manen (1984). Adjunct themes were also highlighted as the transcripts were revisited in a continual rechecking process. This rechecking process, whilst revisiting the transcripts, assisted in keeping the findings close to the original data and allowed the reader to participate in the method of interpretation through the medium of language.

I began the analytical process while transcribing the tape-recorded interviews. This chore provided me with the opportunity to really listen to the material, a chance for 'first reflection'. No attempt was made to spell out any themes per se during the first listening. The intent was simply to validate the transcriptions and to let the material 'in' to my mind. Several days passed between the initial reading of the transcripts and the time when I highlighted, line by line, all the material that seemed to be describing experiences of what it was actually like to be infused at home. This material was then outlined and taken back to the participants for feedback.

Once it was clear that the experiences were authentic portrayals of the experience, thematic analysis began on what turned out to be four innate themes of what it was like to be infused at home. The following themes were identified, in order of frequency mentioned, with the most often mentioned being listed first. Participants described their experiences of home infusion therapy in terms of:

- going home
- control
- having a life
- the hazards of hospitalization

Following much reflection and thought on the four themes as identified by the participants, I began the phenomenological writing-up of the experience of home

infusion therapy. What emerged over time was essentially the fourth procedural activity in phenomenological research as purported by van Manen (1984), phenomenological writing.

Describing the phenomenon through the art of writing and rewriting

The fourth procedural activity, the phenomenological writing, is good if:

> ...it reawakens our basic experience of the phenomenon it describes...in such a manner that we experience the more foundation grounds of the experience (van Manen 1984:65).

van Manen (1984:41) specified this process of writing as a 'poetizing activity'. The phenomenological writing should be both an illustration containing examples, as well as a description of this human experience. The intention of phenomenological description and interpretation as described by van Manen (1984; 1990) is to empower us to behold the deeper structures and significance of the lived experience of the particular phenomenon under investigation. In describing the phenomenon of home infusion, I have attempted to use examples and descriptions that hopefully elucidate its deeper structures. van Manen (1984) proposes that phenomenological description is an 'example of examples'. Every example is an interpretation of the original experience although it is not absolute.

The structuring of phenomenological writing may be organized in several ways, although it is beneficial to relate to the phenomena it is describing (Mezquita cited in Munhall 1994:306). Alternative ways include patterning around the themes; writing analytically; generating the essence of the phenomena by illustrating examples as to how they were determined; an engaging in a dialogue with another phenomenological author. A combination of these approaches is acceptable according to van Manen (1984). The process of writing and rewriting is characterized by back-and-forth careful pondering that allows for the meaning of the experience to emerge. In essence, the methodological process seeks to illuminate the meaning of the lived experience and to convey this to readers in an

intelligible manner (van Manen 1984). In this research, the text has been hypothesized and poetized with four lifeworld themes interwoven.

Participant Selection

The main objective of participant selection for the study was to involve those people who had a direct knowledge of the experience of home infusion therapy. People known to the researcher through professional contact were invited to participate. Five participants were invited because they had undergone home infusion therapy for various medical and surgical conditions. At the time of data collection none of the participants were undergoing active therapy. The reason completion-of-treatment was selected over treatment-in-progress was initially one of convenience for the participants. However, I also believed that the ability to be truly reflective regarding the experience of home infusion therapy came as a result of being able to look back to the initial treatment. I believed that while undergoing home infusion treatment, the focus for the participants was on their illness, treatment and prognosis. The all-consuming and at times tedious nature of the respective therapies may have meant that outside interests or concerns were considerably lessened.

In phenomenological research, the researcher 'lives' the question by a process of returning to the question or the thing itself (the experience of home infusion therapy), until one begins to feel a sense of the nature of the topic being studied (Parker cited in Munhall 1994:188). This process is in contraposition to simply stating the questions as in the case of other research methods. The researcher, in this instance, according to Parker (1992), also understands that she will function as a 'tool' or part of this study as data are filtered through her, read, written, or tape-recorded during this study.

June

June 36 was diagnosed with breast cancer two years ago and has undergone both surgery and chemotherapy for the treatment of her illness. Currently in remission June has undergone several treatments of chemotherapy via a centrally implanted infusion device. June was approached by her physician last year if she would like to try home infusion instead of traveling one and a half hours to the hospital for treatment. Since then June has undergone the last two chemotherapy treatments in her own home. June is married and has two young children.

Will

Will 28, has suffered cystic fibrosis and related illness since his diagnosis shortly after birth. He has undergone infusion therapy for treatments of respiratory tract infections, bronchospasm and total parenteral nutrition. Will has forgotten how many hospitalizations he has endured and cannot remember how many times he has received infusion therapy over the years. Normally he would be hospitalized for approximately two weeks at a time. As he said *probably hundreds of drips and drugs and all the bugs to go with them.* Will requested earlier this year if he could go home earlier to have his infusions performed at home by a visiting nurse. Since then he has had two weeks of home infusion therapy altogether and one hospitalization. Bill lives with his parents about 30 minutes drive from the main hospital.

Jennifer

Jennifer is 62 and has been treated for lymphoma since her diagnosis two years ago which has been treated by both chemotherapy and radiotherapy. These treatments were administered in both Launceston and Burnie although Jennifer lives in neither of these areas. Jennifer was approached by her chemotherapy nurse whether she would be interested in receiving her remaining chemo treatments at home. Jennifer agreed as she was becoming very tired with the traveling that was necessary in getting to the various treatment centres. Jennifer

lives with her husband of forty years and has two children who both live in the same town.

Melissa

Eighteen months ago Melissa's daughter was diagnosed with leukaemia and had a lengthy hospitalization of just over three months. This resulted in the family relocating some 100 kilometres to be closer to the hospital and the treating physician. Melissa's daughter Katie is twelve years old now, and since being approached by specialist nursing staff regarding a new service for paediatric home oncology care, she has been able to have her chemotherapy treatments at home. Having her daughter's leukaemia treatments transferred from the hospital to home has significantly impacted on Melissa's life. Melissa lives with the partner Shane and younger son Ben.

Cathy

Cathy is 30 years old and has suffered with recurrent pelvic inflammatory disease after a complicated ectopic pregnancy three years ago. She is a single mother of one and works full time in an administrative position. After repeated hospitalizations for intravenous antibiotic therapy, Cathy negotiated with her physician to coordinate home care for the remainder of her treatments. Cathy was initially under the impression that this kind of treatment was only available in a hospital setting which made keeping her job very difficult as well as the need for more child care. Since hearing about home infusion therapy from a visiting gynaecologist, Cathy has not been admitted to hospital for further care.

Establishing the Determinants of Rigor

It is generally accepted that phenomenological research operates under a different set of criteria for precision, exactness, and rigor than quantitative research (Sandelowski 1993; Koch 1994). In the latter form of research, the terms 'precision' and 'exactness' usually pertain to the reliability of a measurement

tool used to collect data and the overall research design (van Manen 1990). In comparison, phenomenological research uses 'precision' and 'exactness' to refer to the interpretative descriptions being as full and complete as possible, remaining faithful and as close as practicable to the phenomenon under study (van Manen 1990). van Manen (1990) also indicates that phenomenological research is rigorous in that it is sensitive to the fact that our lifeworlds are remarkably more complex than can ever be fully or ultimately revealed and that at best, an interpretive description can only ever be an approximation. Furthermore, he suggests that objectivity and subjectivity are not 'mutually exclusive categories', as they are in quantitative research (van Manen 1990:20). Objectivity for the phenomenological researcher refers to the ability to remain loyal to the object under investigation without being averted or misled into other directions. In contrast, subjectivity involves upholding a strong familiarization to the phenomenon being researched. This is achieved by the researcher being perceptive, intuitive and discerning throughout the course of the research.

Lincoln and Guba (1985:300) suggest that there are four premises involved in interpretive inquiry that replace the more conventional research terms of internal validity, external validity, reliability and objectivity. These are the premises of credibility, transferability, dependability and confirmability. A number of authors have used these criteria in attempting to establish rigor in qualitative research (Koch 1994; Porter 1994; Beck; 1992).

Lincoln and Guba (1985) propose that the credibility of the research study turns on the possibility that believable findings and interpretations will be produced as a result of the research. According to these authors the most incisive step in the establishment of credibility is member checking, through the return of the transcripts to the participants for clarification of meanings. Member checking was undertaken informally by returning the transcripts of the research conversations to the participants, and asking them to read and discuss the interpretations derived from the text. At the follow-up interview, the participants were given the opportunity to add anything resulting from readings of the transcripts. It was also an opportunity for debriefing.

Transferability replaces the notion of external validity, or the probability that the results can be transferred over time and across different contexts. Sandelowski (1986) employs the term 'fittingness' as part of the evaluation of qualitative research findings. I have included as much detail as possible, including the time and the contexts in which the interviews took place, to assist potential readers of this research to make judgments about its transferability.

Dependability and confirmability replace the notions of reliability and objectivity. According to Lincoln and Guba (1985) a number of approaches are possible to determine the dependability and confirmability of the inquiry. The technique used in this project was the keeping of a reflexive journal (Lincoln and Guba 1985). A journal of personal experiences and reflections was kept and often referred to in recording my thoughts and feelings regarding to the interviews and the decisions concerning method that were made along the way. Revisiting and reviewing this journal has provided me not only with a source of data, but also an opportunity to reveal some of the assumptions and biases which were influencing my interpretation. I found that keeping such a journal was helpful, especially in that it offered a concrete way of reminding me where my particular biases might lay. As the phenomenological reflection and writing began, I found that journal entries stopped; this was as if the writing became my personal expression of all I had collected - a synthesis of sorts.

According to Munhall (1994:189), evaluating research from a phenomenological perspective for rigor and merit involves, first of all, assessing the affirmation - 'the phenomenological nod' - of the participants. This occurred when the participants upon first reading the interpretations nodded in agreement. This is a critical process of substantiating phenomenological research. As Munhall (1994) explains:

> The participants are the only ones who can answer the questions as to whether you have captured their telling of the experience and meaning the experience held for them (Munhall 1994:189).

Summary

In this chapter, van Manen's hermeneutic phenomenological research approach has been described and specific methods for data collection and analysis have been discussed. It is my hope that the inclusion of the information contained within this, and subsequent chapters, provides an invitation to the reader to be part of the validating process for this research (Benner 1984).

Chapter 4

THE JOURNEY HOME - EXPLORING THE INTERPRETATIONS

Capturing the real, rich and undistorted life experience of people undertaking infusion therapy at home has culminated in a process of exploring the essence of what it means for the participants to be at home and 'having a life' while also undergoing home infusion. As basic and colloquial as this may read, it has been validated by the participants as being at the heart of the overall experience, or as Cathy (1996) explains, 'the nuts and bolts of it...'.

> *A good part of being at home for your treatment has to do with the satisfaction and security that comes from being in a situation that is familiar, or, having an arrangement that you know about ahead of time and know pretty well what to expect, and know this in an unthreatened and comfortable manner. This is probably why it is also natural to think of 'being at home' as 'being at ease', which I guess can be compared to dis-ease - or in a sense a feeling of relaxation. Another way of looking at home infusion therapy on a somewhat deeper and more powerful level is the feeling 'I am where I can be myself', so, 'I have my treatment where I can be myself'. There is no need to explain my actions to anyone or no need to feel on guard towards the misperceptions of the visiting nurses, as, for example, when getting home tired in the late afternoon after work, I feel free to kick off my shoes and lie down on my back in the middle of the living room with my kid, hook up with the nurse and have my treatment (Cathy).*

This chapter and chapter five employ van Manen's (1984) approach to phenomenological writing as the basis to a thematic analysis and interpretation of the participants' stories.

> *When I had my treatment in the hospital, my life outside the hospital walls was never considered...but I didn't really consider it either. I just donned my nightie and accepted it as gospel that I was a patient being treated by the doctors and nurses and that they would make me better (Cathy).*

These powerful words of submission and acceptance speak to a mind and body separation that arose for Cathy as a result of being hospitalized for infusion therapy. The actual experience of hospitalization for Cathy objectified her body as a 'thing' to cure, placing it outside the realm of her real life needs. She also talked about the labeling of her hospital diagnosis by becoming '*the PID - IV antibiotics in bed 11*' (Cathy 1996). The process of labeling the diagnosis and treatment may

have displaced Cathy from being a person to being a patient. Cathy's body could then be spoken of and treated as something disassociated from the woman who was living the experience with an outside life of individual wants, needs, desires and attributes. Of course for the medical and nursing staff, Cathy's body manifested symptoms of an illness requiring parenteral therapy. However, a medical understanding of her infirmity had little to do with Cathy's life outside the hospital - one that she wanted 'back'.

Originally a hospital nurse, I once exemplified what Lawler (1991) has described as a body worker. I worked primarily with the outside of people's bodies, objectively measuring physiological parameters of a person's physical illness. Of course, this was not the entirety of the activities that I might perform in the course of a nursing shift. Nevertheless a large component of any day was taken up in such a manner. I remember wondering what it must have felt like for the person in the bed, to have so much attention given to the physical body. The body that was subjectively feeling my nursing care, lay beyond the labeling diagnosis and the physical interventions it endured.

At times I felt I was objectifying the body with the labeling diagnosis and treatments prescribed in an attempt to cope not only with the occurrence of the illness, but also the need to keep everything as uncomplicated as possible. This regimentation and list of tasks served to order what was a very heavy workload. I believed that time did not allow me to delve into anything more that just getting my work done, completing all the prescribed tasks in an orderly fashion, reporting abnormalities as necessary, and completing my shift on time. I appreciated that there was life beyond the hospital walls because I 'had' one myself, yet I also held the notion of a separate mind and body in my work within the hospital walls and I wondered if this practice of objectifying the body occurred for the person in the bed. Seymour (1989) indicates that this practice of objectifying the body may precede to a bodiless conception of self; a hampering of the unity between the body and the mind. More candidly, I explain my previous objectifying of the body in terms of the inability to conceptualize patients and people in their own homes,

living their own lives. Essentially I was not 'personalizing' the hospitalized patient.

This separation of mind and body has characterized Western thought for hundreds of years. The 17th century philosopher Descartes extended this assumption of a separate mind and body by proposing that the mind was not only separate from the body, but from nature as well (Grosz 1994). The body could be interpreted to be like any other object in the natural world and subject to the same physical laws. Consequently, the body as mechanical metaphor prospered. This has resulted in the body being thought of as an object which could be 'tested experimentally and blueprinted in detailed anatomical study' (Leder 1984:30). Cartesian Dualism, the legacy of Descartes, postulated that there were two dissimilar and reciprocally exclusive categories - mind and body. The outcome of these categories was that the mind was ministerially positioned outside the body and a gap existed between the two (Grosz 1994). Since Descartes these ideas have structured Western understandings of the body.

Merleau-Ponty (1962) developed the view of the 'lived body'. He critiqued the Cartesian representation of a disunited mind and body saying that our bodies cannot be reduced to the mere workings of a machine (Leder 1984), for it is the 'lived body' that ultimately constitutes our being in the world (Merleau-Ponty 1962). There is no mind that is housed in a mechanical body, for the body is not a container for 'things'.

The English language accommodates only a lone word for the body and that is 'the body'. It does not differentiate in language between the body as it is lived, whereas in both the German and French languages there are separate words for the differing realities of the body (Emden 1991). Thus the term 'lived body' has been used to represent the body through which and in which the world is experienced.

A remarkable personal and professional confrontation occurred when I commenced my practice as a home infusion nurse in the United States some six years ago. I made a transition from various emergency rooms in tertiary care facilities to the

living rooms, bedrooms, kitchens and verandahs of people of all ages and ethnicities with many and varied needs. These people did not wear pajamas, nor did they exhibit the 'reluctant acceptance' as described by Cathy, of hospitalization for infusion treatment. These people all had families, pets, mail boxes at the front of their houses, and rooms filled with history, stories and piles of dirty laundry - much the same as in my house. I would visit these people in their homes, on their terms, and consequently the overall reality of communication was vastly different to that I had previously experienced as a hospital nurse. The other striking contrast was the ownership and control these people had over their illnesses and varied treatments. I existed in their normal lives as another person who visited their homes, not one who participated in the 'labeling' and 'fixing' that was discussed previously in this chapter.

Making the transition as a 'patient' from hospital to a 'person' at home may not sound particularly complex, yet the nursing style was considerably different and so were the outcomes for these people. They seemed happier, more independent, healthier and 'at ease.' I too was far happier, healthier, independent and at ease despite facilitating identical treatments and assessments that I would have performed for the same people in a hospital setting. This confrontation is more simply explained in terms of considering patients as being personalized in their homes. My nursing practice changed significantly because of this elementary realization - one which I had taken for granted for so long. This realization was the beginning of my true appreciation of consumer experience - in this case, consumer experience of home infusion.

Being in Hospital

Home infusion therapy has become a possibility only recently for those people who fit specific selection criteria. Restrictions in the past have mainly been associated with the lack of service availability; a lack of necessary skill level in nursing personnel; and the reluctance of the overall health care team to consider alternatives to acute hospitalization for intermittent infusion therapy. The participants in this study all received their initial treatments as inpatients in an acute care facility. The choices these people had regarding place of treatment was

solely that of the hospital. For the people in this study, being a patient originally meant being hospital bound. For June, this awareness meant that her labeling diagnosis of cancer necessitated hospitalization:

> *They didn't do any of that kind of treatment at home, and anyway, we lived over an hour's drive away from the hospital. I had to go into the hospital to actually have it done and...um...was just a piece of um on the factory line type of thing, that's another one sort of thing and it wasn't very comfortable being so far away from my family. So after that came all the one day trips back to hospital...wait your thing sort of gotta go along like a doctors appointment, wait your turn, wait till they're ready to do you. You know there is three, four or five other people around you doing exactly the same, um...so you just sort of, you're just a number, really, I mean the people are nice but when its all said and done you are just another number that they have got to get through the day.*

For Jennifer hospital-based treatment meant a time of anxiety, distress and fatigue from travel:

> *When I went into the hospital I was very uptight and it used to upset me seeing the other patients having their chemo, ah, I know there was curtains you could pull but I didn't like to suggest that cause you would probably make the other patients feel uncomfortable. Ah, it just distressed me seeing the others hooked up, I didn't like it and it was sort of sterile...real clinical. And traveling I found awkward...mmm...plus I went through the, got further into the treatment, um, you sort of felt sicker and traveling made you feel worse.*

Will's awareness of hospitalized treatment manifested itself in boredom and disassociation; one that he had accepted for most of his life:

> *I'd go in for two weeks at a time so I guess I know it all pretty well, you know, hospital stuff. It just gets really boring...not so bad the first few days cause you're sick but when you start to feel good again, you know, you've got nowhere to go, can't go home, it just gets so boring. You'd just get a bit angry at first but then you'd just put up with it...kind of ignore your anger and just put up with.*

For Melissa, whose daughter Katie was initially hospitalized for three months, the experience of hospitalization necessitated a move for her family away from their established home, and resulted in the stresses and fears associated with an intensive hospitalization and the isolation of relocation:

> *I hate being away from home...we all hate it. All our family's down the coast, I hate it. If I say to Katie's Dad anything about being up here he gets a bit*

> *ago with me so I just sort of grin and bear it I suppose. I mean I've got no friends up here...I don't know anyone apart from staff and that here and I miss my friends and I miss my family. I've just got to put up with it.*

Like Will, hospitalization for Cathy meant boredom and a feeling of imprisonment with loss of income while also adding to expenses for child care resulting from her inpatient status:

> *I got PID several years ago and it was pretty bad and I had to, my doctor said I had to come into hospital, cause I had a really bad fever and I was in a lot of pain and that I needed to have um, intravenous antibiotics, and I had to have a course that went over seven days and it all cleared up and I was OK to go home...and then several months later I got the same symptoms back again and I was, well basically, just in and out of hospital having the treatment and when I had to go into hospital I had to leave my work, um, and then I had to get someone to look after my kid, um...I lost money. I ended up almost losing my job.*

June felt labeled and numbered; Jennifer was distressed and uncomfortable; Will was bored; Melissa was angry and missed her family; Cathy felt imprisoned. All of these people expressed a certain disassociation between their needs as people and their experiences as patients. This disassociation was experienced itself as a submission to the 'hospital way'; a kind of a reluctant acceptance of the 'institutionalized norm'.

This reluctant acceptance is more simply described in the words of the participants as something that is treated as gospel (in this case hospitalization for infusion therapy), yet something that is also inconvenient, boring, distressing, and imprisoning. The depersonalizing loss of control over one's illness and one's life on the 'outside' occurred when these people relinquished the territory of their bodies, for a short while at least, to a hospital culture for treatment. The objectification and passivity that results is described by Cathy in the following terms:

> *No-one saw me as a professional woman supporting her child with a house to maintain and a job to keep. I know this because at handover outside my room I overheard one of the nurses referring to me as the PID - IV antibiotics...a single mother you know. This pissed me off so much because it was so judgmental...they did not realize that I had feelings and needs and a home with a beautiful daughter that I wanted to go back to. I told them this all the time but they said that the doctor would make the decision as to when I was OK to go home.*

Cathy is here speaking to the separation between her body as an object, and the feeling and personal part of herself. June spoke in similar terms of a separation and described how this is experienced as a complete change of routine:

> *Coming into hospital changes your routine totally different to what you're used to at home...I mean the nurses are there to help and everything but they know nothing of where you've come from and what you are like as a person...like I really need my privacy, but this isn't an option for them because they're; looking after you and half a dozen people and with all the crap from everyone else and the doctors, it just isn't a priority.*

The anger, resentment, and self reproach that Melissa exhibited when describing her reluctant submission to the customary treatment for her daughter's illness reveals a similar negativity:

> *They [hospital medical and nursing staff] would try and console you, yeah I mean like the drugs they'd give Katie and yet they say they are doing her good and this is the best place for her. I don't know if any of them were parents but you'd hate to see your child just vomit after vomit and cry to go home and no, there is nothing you can do but yet it's good for her. I would just sit there and cry and hate myself for not being able to whisk her away to somewhere safe...it was just horrible...a bloody nightmare...and I'm sure Katie hated me for it too.*

The compulsion and passion with which Melissa described the experience of hospitalization surprised me. She experienced her daughter's illness as a nightmare; being trapped within a vicious circle of resentment. The potency of this resentment is not clearly appreciated until the stories of the participant's transition from hospital to home are explored. The degree of dislike, even hatred, of hospital will be more thoroughly explicated in the following chapter. Suffice it to note for the time being how the experiences of these people offer a glimpse into a somewhat rebellious journey back home and the liberation encountered in the process.

Going Home

For the people in this study living in a body means not only that they initially experienced the feeling of separation between mind and body, but also that 'going home' for their treatment involved retrieving a sense of feeling whole, being at ease, and becoming a person again. Going home for these people signified reinstatement of an 'embodied' state. *Embodiment* encompasses an intimacy between the body as an object and the body as it is lived. The body as 'lived' body enables us to experience situations, interpret them, and interact with the world in a meaningful way (Benner and Wrubel 1989). Alternatively, *disembodiment* refers to the division between the body we *have* the body we *are*, a separation between 'the body' and 'the self' (Seymour 1989). This relationship between 'the body' and 'the self' (or the mind) may be disrupted by major changes to the body's appearance or functioning state, leading to a feeling of disembodiment.

The concept of *embodiment* has been used to explain how it is that through consciousness we are aware of being-in-the-world, and it is through the body that we gain access to this world. Our feeling, thinking, taste, touch, hearing, and consciousness are mediated through the opportunities presented by the body. At any point in time, and for each individual, a particular perspective or consciousness exists based on the individual's history, knowledge of the world and perhaps openness to the world. Phenomenology's focus on the individual and on the meaning events may have for an individual, reflects the recognition that experience is individually interpreted (Munhall 1994).

Each participant had a differing reason for making the journey home. June was approached by her physician to ascertain if she would agree to a trial of home infusion care as a new discharge planning initiative of the hospital to which she was admitted. Jennifer was similarly approached by the chemotherapy nurse who had been providing her care during the past three treatments. When his boredom became unbearable, Will asked his specialist if he could go home and have his care attended to by a community nurse known to his family. Melissa, and her daughter Katie, were informed by the ward nursing staff of the commencement of a home oncology care service for children and whether they would consider participating. Following discussion with a visiting Canadian gynaecologist regarding her repeated hospitalizations, Cathy learnt that home infusion treatment was happening

in other parts of the world and promptly sought discharge and access to this mode of service delivery.

Each participant wanted to make the journey home, yet for one, Melissa, this journey initially proved to be somewhat unsettling:

> *This kind of treatment freaks me out...it freaks me out anyway - at home or in hospital. I hold Katie's hand, and I bury my head in the bed when they're doing it. Yeah, but I mean I haven't got the stomach for that sort of thing. At the beginning I was a bit worried that something could happen and they [the nurses] wouldn't have the stuff here [at home] to back them up, but after the first week I realized that they knew what they were doing...they've got a job to do and they know what they're doing...no I was a bit scared, sure, well I suppose after the first week but after that I had no doubts whatsoever with it.*

Melissa was speaking generally of the transition from hospital to home, but when asked specifically about the experience of having Katie treated at home, without access to twenty four hour on site medical and nursing coverage, the response was different

> *I was a bawling mess. I didn't like Shane to go away for too long in case something happened and like I'd just go into a frenzy and I guess if I went anywhere I needed to be constantly, all the time, ringing up saying "the kids haven't been sick have they?"*

The experience of the transition for June, Jennifer, Will and Cathy was completely different. All commented on the relaxed nature of commencing home treatment, the absence of fear, and the feelings of control and freedom associated with 'being liberated' from hospitalization. For June, the transition was made comfortable by the treatment taking on the normality of the home environment, as compared to the complexities of the hospital environment:

> *When I first got it at home, I mean, it didn't worry me at all. It just fitted right in. We got a coat hanger out and put it up in the wall unit to make for the drip to drip down...all of this just took place in the sunroom. When the nurse left it wasn't scary...it was fine, fine, because I mean I would normally just get up and go home anyway, after I finished the treatment at the hospital...I was fine and plus I knew the phone numbers to ring if at any stage of the day or night, so you know there was no problem worrying about anything.*

For Jennifer, far from the initial home treatment being a source of fear, she found this to be:

> *Not having the staff about, that did not worry me. Well, I felt that the visiting nurse had done what she had to do, and I was relaxed and she was only a phonecall away if I did need her like they always said to ring and like a couple of times I did have to ring and they were very helpful...no, no worries at all.*

Will explained that his initial home treatment felt safer than those experienced during his past hospitalizations. He *'just felt more comfortable ... knowing that there was less chance of infection at Mum and Dad's house than in the ward...that's the scariest thing for me, you know, getting another infection.'*

For Cathy the initial home treatments involved no more concern than those which she experienced in hospital:

> *To begin with I guess it was a bit of a concern, but no more that what it was like when I was in the hospital...but, you see, everything was explained to me, well I was like an expert, I am an expert now about it, so if I had any problems with my device, I'd already been given all the information about what to do...all the signs and symptoms of complications to be aware of yeah.*

To some considerable extent the participants' stories of their subsequent experiences of home infusion were constituted as comparisons with the experience of hospital based treatment. The journey home for these people signified a regaining of control and ownership. Along with this control and ownership came the feeling of being 'at ease', a feeling that was largely absent in hospital.

For Jennifer, regaining control meant regaining her privacy which in turn relieved her distress:

> *At home the infusion was more relaxed...the whole thing was..and I could sit on my chair and, ah, everything familiar around me, you know, you could see the cat on the mat and the time seemed to go quicker. That half an hour seemed to go quicker at home and also, ah, I used to have trouble, well I think almost all chemo patients do...if you want to or need to go to the toilet straight away afterwards you sort of had continual diarrhoea and um I would get myself worked up that I would be wanting to go before that half hour was up and cause you can't go, they can't take the needle out and ah, when I was having it at the hospital for once they removed the needle I would find myself racing up the corridor to go to the toilet and then often on the drive home we would have to find a toilet at least two or three times and that was very embarrassing.*

Recall Melissa's hatred of hospital and the separation from the family home. This was coupled with her daughter's own distress in the hospital setting which manifested in anorexia and subsequent weight loss. For Melissa, the comparison of relaxation at home and anxiety in hospital structured her sense of being at ease at home:

> *Everyone in the hospital seemed pretty stressed out too you know, I mean, when they would come out home they [the nurses] seemed to be more relaxed. Katie is more relaxed and they'll sit and have a coffee and chat, you know, I think that there should be more of it, yeah. And it's more of a, doesn't seem to be a duty for them, you know, cause, while they're doing Katie they're chatting, you know they're just so relaxed and it's a lot easier cause we've got a seven year old as well and he hates coming in hospital and, you know, when the nurses come out home he'll chat away to them, and they chat to him. You know...to me, it's no different in having your friends around or your brothers or your sisters visit, yeah, it's no different.*

Will's ownership of his illness and subsequent treatment in the home setting meant having control over how his treatment was delivered and thus minimizing the chances of infection. An expert in relation to his lifelong illness and differing treatments and therapies, Will explained how a sense of being in control was comforting:

> *I feel better at home, cause I'm pretty fussy, you know, hygiene, you know, you sort of, you feel like probably there is a much bigger risk of getting another infection when you're in the hospital...I mean, all the illnesses, infections, sick people, and people don't always wash their hands...and you hate having to be on guard to all the staff - making sure they was their hands and do the infusion right, you know, I mean it doesn't take too much and I've phlebitis or worse pneumonia. I'm just real careful, well I just, I know with myself I'm real careful...you see, I've grown up with this so I do know...you see, if I get a bug in the hospital...well...that could be it for me...hasta la vista baby.*

Control for Cathy essentially means independence. This independence is described not only in terms of ownership of her illness but also the ability to take control and return to a more familiar lifestyle:

> *I'd heard that could get, you know, infection of your infusion device, so I didn't want to get any more infection that I already had, so I took really good care of it, plus you know I mean its not as if I'm dumb or anything. I, I, they taught me in the hospital how to take care of it, so I took care of it, an um, you know, I um can actually perform my treatments myself because I've become independent.*

and

> *I could look after myself and my daughter, carry on with all my normal household duties, go grocery shopping, and go to work. Well, it's not as if it's an executive position or anything, but we gotta eat you know...and by the time I used up all my sick time, you know, if I had to have weeks off or stuck in hospital, they [employers] didn't really like it that much so I'd lose, I wouldn't have any sickness benefits, so I'd lose money, and then I'd have to spend more money having someone look after my daughter, because I have no family here in Tassie, so I had child care...you know, it would be really difficult.*

For Cathy home infusion therapy meant that the treatment could also be administered at alternative sites, for example, at her place of employment. This complimented the independence and control she was regaining after discharge from hospital:

> *Well, like what I'd arrange with my nurse and at my job, with my boss I used to say can I take my lunch break between 10 and 11 in the morning or 2 and 3 in the afternoon depending on when my 24 hourly dose was due, and there's a little room out the back of the offices that we would prepare a clean area, set up there and just hook up like I would at home.*

Travel was another theme which encompassed a kind of liberation for the participants in the study. Whether this represented ongoing outpatient visits to the hospital; or a distance to be traveled by family; or coping with the issue of relocating; travel was an issue for all participants. I reflected on my experiences as a hospital nurse and again realized the taken for granted assumptions that existed around the outside lives of patients. The provision of treatments, therapies and care were administered solely within the bounds of the hospital walls, and an appreciation for the external circumstances of patients did not seem to be a priority, especially in the midst of a busy outpatient department. Listening to the stories of the participants regarding the issue of travel again awakened me to the reality of 'having a life' outside the hospital and the disembodiment associated with ignorance of the same:

> *There was a hell of a lot of travel...a lot of travel, um, backwards and forwards...at one stage there were weekly visits to Burnie, backwards and forwards...um, about an hour and a half one way so you can imagine how totally stuffed you'd be, plus the winding road...got so sick and then it would take longer cause you'd be throwing up. Sometimes it even took longer, sort of depending in Winter, some time you can actually be blocked and not*

> *actually be able to get there so there was one trip I had to, cause it snowed I couldn't go to the check up on the day, so, yeah...(June 1996).*

Similarly for Jennifer, traveling to and from treatments was further complicated by the effects of the treatment itself. The anxiety Jennifer encountered also seems to have filtered into the lives of her family. Rereading her words I also gained a strong sense of her fatigue and distress. Her body was not behaving as she wanted it to, perhaps reinforcing the separation between the body she *has* and the body she is *living*:

> *The traveling itself was really inconvenient...yeah, yes it was...traveling from, well, from Ulverstone to Burnie, probably somebody that lives in Burnie it wouldn't be quite so bad they wouldn't live so far away but for me it's almost an hour away from the hospital, and, ah, yes, I found that awkward, mmm, plus as I went through the, got further into the treatment, um, you sort of felt sicker and didn't feel like going out anywhere, so it was an effort to get in the car and go anywhere, so it was allot better for the nurses to do the traveling...I mean...they weren't sick from chemo. And for my husband it was also really hard - you see I can't drive when I'm in the middle of treatment so he had to get time off work to ferry my around, back and forth to the hospital. He also found that pretty awful cause I'd get so sick in the car...you know...like I was telling you about the diarrhoea. A couple of times my kids had to help out cause he wasn't coping very well. They didn't cope that well either, you, know...got real upset.*

As discussed earlier in this chapter, the issue of travel for Melissa and her daughter Katie, involved a move some 120 kilometers from their family home to establish a new residence closer to the hospital. While traveling for Melissa was not so much an inconvenience, it nevertheless represented a frightening obstacle that often resulted in panic - panic that was relieved by the resiting of the treatment centre to her home.

> *I don't that drive that much...I hate driving, you know, I used to think oh God, I've got to back in there again today. You see, I've never driven around here before and I just panic...I mean, I don't know the streets...all the bloody one way streets. But, no, the nurses coming out to us, that is so much better. I feel allot better with them coming out, out I feel safer anyway.*

Melissa also speaks of the relief associated with having the therapy conducted in the family home with particular reference to the affects of hospitalization on her daughter:

> *I'd take her in to hospital - she used to carry on a real heap... wouldn't let them do anything without me or Shane being there. I mean I could be there but I was no good...It was Shane, you know her was the tower of strength and then they started coming out home and Katie, she just sort of changed, there was no screaming, there was no squealing and that you know...she just used to lay on her bed and let them do what they had to do you know. I think she got over her fear or what, but she just seemed to over the fear of the needles and all that in her own bedroom. You know it used to take three or four of them to hold her down in hospital.*

With the obstacle of travel removed for Will, and his family, a more relaxed treatment scenario became possible. Will spoke of his treatment being a part of his family's life for as long as he could remember. In this sense, being in the hospital or at home made no appreciable difference. The real difference for his family was felt to be in the absence of travel and subsequent separation from home:

> *Like it's a fair way in there and back...you know, to the hospital, and sometimes I wouldn't see my family for days cause it's not like you can just jump in your car and be there in ten minutes or something - I mean, it's a bit of a haul and all the traffic and trucks and that on the highway kind of freaks Mum out a bit I guess. I think me being at home now, well the biggest benefit I think is for my family - I mean, we're all here together, not separated.*

When asked if travel was an issue both Will and Jennifer felt that taking the nursing staff out of the hospital environment, into the home environment, resulted in the nurses being more relaxed, more friendly and less remote. While their demeanor remained professional, this was a more personable professionalism:

Jennifer: *They [the nurses] seemed happier...well possibly at home they were, they'd talk about the garden, the view...we've got a nice sea view here and they, ah, probably had more time to me cause it was one whereas at the hospital they had the others to care for as well and, um, they could talk to you, not that that is great thing but it does help, you know, they have more time, and the travel's a good break for them, you know, gets them away from the hospital.*

Sarah: *Did you find it more personal then, with nurse traveling out to you?*

Jennifer *Yes. It's nice, it was nice...but yet I understand that at the hospital when there was others such as me, they, you know they would have to go from one to the other, you know, to check things but at my place it was more relaxed for them as well as me.*

Moreover, as Melissa suggests:

Melissa: *The nurses are always more relaxed and they'll sit and have a coffee and a chat, you know, I think there should be more of it, yeah. And it's more of a,*

> *doesn't sort of seem to be a duty for them, you know, while they're doing Katie they're chatting, you know they're just so relaxed and it's a lot easier like cause we've got a seven year old and he hates coming into hospital you know. When they come out he will chat away to them, and that, and they chat back.*

As the participants settled back into their home lives and continued with home treatment, they resumed activities that had fallen away due to the need for hospitalization. Although weak from chemotherapy, June continued to perform the household duties and child raising activities that fulfilled her life before her illness. Jennifer tended her beautiful seaside garden. Melissa was able to help Katie at home, with her school work, and have family and friends to visit. Returning home for Will meant returning to his hobbies and seeing his mates. Cathy returned to work and to the side of the daughter she so dreadfully missed whilst hospitalized. The benefits of being at home for these people were reinforced when the occasional visit to hospital was required. As June explained:

> *It's not until you have to come back in here, sort of thing, for something else that can't be done at home, you know, like ray treatment, that you realize how bloody awful it is and wonderful home is sort of thing - like it makes you really appreciate the stuff at home and good the home nurses are.*

The need for a hospital visit compounded the feelings of disassociation in June's case. For Will, his infusion device served as a reminder of hospitalization, yet only in a liberating sense in that it enabled him to have treatment on an ambulatory basis. For Cathy and Jennifer, regaining a sense of embodiment through avoiding hospitalization meant regaining a sense of looking and feeling normal. It is, after all, the outside of our bodies that exists as a visible covering for all to see. The outside of Cathy's body revealed her infusion device - something that was not uncommon within the hospital, yet outside the hospital walls she initially experienced its presence with the same intrusiveness and disembodiment that she encountered as an inpatient:

> *The only time I felt embarrassed was when...mmm...I first went back to work and had a dressing on my arm covering my PICC line and everyone was asking 'oh, what's that?'... 'Oh, it's my PICC line...my infusion device'...and they said that oh, have you got AIDS or something, and I went no...I've , I have to have intravenous medications for an infection that I've got, and then they all thought I had cancer. But no, I only work with a few people anyway, and already all I said was, look , you know it means that you can have this*

> *stuff at home now. They all thought that was really cool, they said oh that's excellent, you know, and some of them had known of some people like, one of them had an uncle on the mainland who had his chemotherapy at home. Yeah, so at first I felt a bit self conscious, maybe a little embarrassed...but now, you know now I kind of feel really proud.*

The regaining of a sense of self in embodiment for Cathy in particular may not have been an easy thing initially. Feeling whole again, normal and proud, for the participants also involved recovering a sense of being in control over a body that had previously been given up to medical treatment and institutionalization. Loss of a sense of control over one's body is not an uncommon response to serious illness according to some authors (Eakes 1993, Frank 1991). Frank (1991) suggested that control is a much valued attribute in our society. Advertisements advocate control over the body by diet, or exercise, or some other form of prescription. To relinquish bodily control, as happened with the people involved in this study, could be seen as a failure both socially and morally.

Sacks (1984:154) proposes that the world of illness can be a contracted world, 'with each step, each advance, one's horizons expanded, one stepped out of a contracted world - a world one hadn't realized was so contracted'. Initially, Cathy considered hospital to be a place she could not venture beyond. Likewise for Will, Jennifer, Melissa and June, this contracted space may be related to the feeling of disembodiment, for as Merleau-Ponty (1963) suggests, the body is our means to the space around us, and it haunts space like other objects:

> It applies itself to space like a hand to an instrument, and when we wish to move about we do not move the body as we move an object. We transport it without instruments...since it is ours and because, through it we have to access to space (Merleau-Ponty 1963:5).

For these people the restoration of embodiment, the regaining of bodily control, and the resurrection of a normal life in their 'real world', all converge around the significance and the symbolism of making the journey home. Making this journey home involved living in a body with all that that entailed. Out of their prior disassociation came a new appreciation of their experiences of illness and treatment prior to the introduction of home infusion therapy. Being at home and being at ease coincided with being in one's body and living one's life. Part of the

process of reconstituting a sense of embodiment may have involved regaining a sense of control over one's body and the situation within which one found oneself. Essentially the journey home meant having their life returned to them.

A life 'returned' is one that is treasured and unwillingly given up. For these people having a life meant avoiding hospitalization and more plainly, staying home. The issues surrounding this avoidance of hospitalization are explored in the following chapter.

Chapter 5

'HAVING A LIFE' - THE ESSENCE OF AVOIDING HOSPITALIZATION

The somewhat colloquial notion 'having a life' was fundamentally employed by the participants in maintaining a sense of control, choice, and a quality of home life, that is far removed from the hospital milieu. When this theme was more thoroughly explored through the teasing out and rereading of the transcripts, it was the actual reflection of the participants on their prior experiences of hospitalization that informed and enlightened their actual experiences at home. Thus, 'having a life' was related to their individual reasons for wishing to avoid further hospitalizations. Each participant had a different justification for wanting to stay home, yet these justifications were related to their individual reasons for not wishing to be hospitalized. These justifications were clearly tailored within two propositions, the physical and/or emotional, yet essentially came under the one umbrella. I have called this thematic umbrella the hazards of hospitalization.

The Hazards of Hospitalization

The hazards of hospitalization are well recognized. Ordinary aging and physical compromise due to various disease processes are often associated with functional alteration, such as a decline in muscle strength and aerobic capacity; vasomotor instability; reduced bone density; diminished pulmonary ventilation; altered sensory continence, appetite, and thirst; and a tendency toward urinary incontinence (Creditor 1993). Hospitalization and subsequent bed rest, whether indicated or not, superimpose factors such as enforced immobilization, reduction of plasma volume, accelerated bone loss, increased closing volume, and sensory deprivation (Vetter 1995). Any of these elements may drive vulnerable patients into a state of marked, and at times irreversible, functional decline. The factors that contribute to a deluge of dependency are identifiable and can be avoided by modification of the usual acute hospital environment, and considering

ambulatory alternatives such as home infusion therapy where practicable (Creditor 1993).

The hazards of hospitalization frequently centre around immobility (Vetter 1995). Some consequences of impaired mobility encompass 'decreased joint range of motion, loss of muscular strength and endurance, loss of bone mass and strength, cardiovascular deterioration, respiratory problems, metabolic imbalances, pressure ulcers, decreased urinary function, and psychological effects' (Hamilton and Lyon 1995:30).

As I listened to the individual stories the participants shared over the course of the research, I was repeatedly reminded that their awareness and appreciation of these hazards (which varied for each participant) were very well informed. It was as though they were familiar with the research conducted around these issues. For example, Will knew of the risk hospitalization would have not only for his illness but for his very survival. Melissa knew very well of the associated anorexia and malnutrition that hospitalization meant for her daughter Katie. Jennifer and June both knew that 'hanging around' in hospital resulted in decreased fitness, bone loss and clotting problems. The hazard that struck Cathy the most was not so much the effect on her physical body, but the effect that prolonged hospitalization had on her ability to secure and maintain her job and thus on her ability to continue providing for her child.

Prior to undertaking this research I had not fully appreciated the significance of these hazards. It was through the participant's sharing of their fears, their concerns, and their overall knowledge of hospitalization, that information seemed to shape their individual stories of what it really meant for them to stay at home and receive their treatment at the same time as living their lives. Again I underwent a personal and professional confrontation in relation to the taken-for-granted assumptions that I had experienced in one of my prior nursing roles. I began to reflect back on the time I practiced as a nurse in an acute hospital setting, attending to various parenteral therapies for different people, yet obviously misreading the nature of their respective anxieties and the importance

of their home bodiliness that was overshadowed by the experience of hospitalization and subsequent acute treatment.

Each participant spoke of how draining and uncomfortable these anxieties could be. The most common hospitalization related anxiety that featured throughout all participant's interviews was the impact that hospitalization had on their functional abilities - those abilities that were restored to them immediately upon making the journey home.

Functional Decline

Hospitalization can result in complications unrelated to the problem for which the patient was previously admitted. Apart from increasing susceptibility to nosocomial infection, thromboembolic disease and adverse incidents, functional decline and functional morbidity lead to prolonged length of stay, need for institutionalization and increased costs of health care. Functional decline becomes more conspicuous the longer the length of stay (Creditor 1993).

Functional decline, be it enforced bed rest, or the bed rest and immobility that occurs when one is confined to a hospital ward, occurred for Will. Will compared his experience at home as being liberating and free whereas in hospital his freedom was compromised:

> *Hospital is so boring anyway, I mean there really isn't that much to do, and the nurses don't like you going too far cause the doctor might come and do a round or you gotta go and have a test somewhere...kind of drives you up the wall a bit...anyway, I know it's bad for me, you know, just hanging around. Anyway at home it's up to me, you know, to get my work out...usually get a fair bit of fresh air out the back at Mum and Dad's, wander down to see my mates, you know...I mean I can't overdo it with my lungs pretty weak and all, but I just don't get to do it at all when I'm admitted.*

The mechanics of respiration are altered with aging and illness. Costochondral calcification and reduction in muscle strength diminishes rib cage expansion, and the residual capacity increases and occupies a greater proportion of total lung capacity (Druz and Sharp cited in Creditor 1993). Will knew perfectly well how

functional decline could compromise his illness, and perhaps contribute to prolonging his hospitalization. As explained in the previous chapter, Will's fear of hospitalization was essentially a fear of additional complications and perhaps death. This anxiety was alleviated when his home life was returned:

> *It's not much of a life in there (hospital)...I mean, I can't do anything except sit around and wait for a visitor, whereas I can kind of do what I like at home. The scariest thing is getting another infection on top of my CF which isn't that unusual in the ward.*

Illness related changes in the cardiovascular system predispose patients to orthostatic hypotension, which is also one of the most common complications of functional decline (Hamilton and Lyon 1995). Immobility also impacts on urinary function. Potential complications include impaired renal drainage, renal calculi, and urinary tract infections. Functional decline can also lead to functional incontinence and constipation (Hamilton and Lyon 1995). Cathy's experience of functional decline in hospital always resulted in constipation and she endured several urinary tract infections in her initial hospitalizations. Cathy explained her altered digestive habits as a consequence of ingesting different foods, and not eating or drinking what she normally did at home - a situation that was rectified upon discharge:

> *Whenever I went into hospital I got really badly constipated and that really hurts when your tummy's all blown out and you've got enough troubles down there anyway...I think it was the food mainly, cause I don't eat that kind of food at home, but it was also really difficult to eat anything else because I didn't have anyone really to bring stuff in. Here (home) it's just normal, and I go to the fridge and fix what I need, and drink what I like...that's another thing, because I was just lying down and not drinking enough my urine got really concentrated and I ended getting a couple of bladder infections which were just the pits. So I guess that's not really critical or anything but...well, for me, it wasn't that enjoyable. I used to sit on the loo in hospital and I remember thinking of how I would never take for granted my own loo at home ever again...I know that sounds really silly but it's true.*

The issue of food, appetite and nutrition was also significant for Melissa and her daughter Katie. The freedom to prepare and eat the food that one normally eats when healthy, or otherwise, became of crucial importance to Katie's well-being, and the anxiety which Melissa experienced in relation to her daughter's malnutrition:

> *Katie never eats in hospital. She either has takeaways or I cook it at home and bring it in. Katie just hates the food...the first time she came in she lost so much weight...she wouldn't eat....she would go two or three days and would not eat no matter what you got her she just wouldn't eat. She was so thin and frail that one of the specialists said that she might not make it... so one of the nurses...he's great by the way... you know, he organized a barbecue, and we all had a barbecue for Katie in the ward courtyard...but you can't expect that every day in the hospital.*

At the time Melissa was sharing her story with me, her daughter Katie peered through the doors, overhearing our conversation, and though shy, she walked up to her mother, put her arms around her, and referred to the hospital food as "*It's horrible...Mum's the best cook....especially her apricot chicken, that's the best... and roast's*". This situation was really quite moving, as healthy and happy Katie embraced her mother, complemented and thanked her at the same time for helping her to regain an appetite and more importantly, her health. This mother and daughter relationship was another issue of confrontation for me as I reflected on my past nursing experiences and realized the importance of what I was witnessing and which up until now I had failed to appreciate within the context of a child's admission to hospital. The freedom and relaxation exhibited by Melissa and Katie during this conversation characterized the very thing they had wanted, that is, to return to their home and their lives together.

The employment of home infusion therapy in treating children can result in a reduction in hospitalization by as much as four weeks for those for whom parenteral antimicrobial therapy is indicated (Vinen 1995). The provision of this kind of service results in improved psychological well-being and decreased risk of nosocomial infection. Children also have improved appetite at home and are less fearful of medical care. Avoidance of hospitalization for children is likely to result in lessened psychological impact on the child in addition to reducing the extent of wage loss for parents (Vinen 1995). According to Bradley (1994), children were happier and returned to a normal life more quickly if discharged early from hospital to receive parenteral therapy at home after major illness or surgery. Outpatient parenteral antibiotic therapy in particular improved children's psychological well-being and also reduced their risk of nosocomial infection (Bradley 1994). The case of Melissa and her daughter Katie provide an

instance of how the life of a patient (and of her/his family) changes when parent(s) and child(ren) are able to return to the familiar, comfortable and healthy home life.

Montalto (1996) reports that the vast majority of carers/family members approve of outpatient treatment and comment favourably on the companionship and involvement associated with at-home treatment. This contrasts with the relative loneliness and worry experienced by carers in having a loved one in hospital as well as the organization required for hospital visits and the hazards associated for getting to and from the hospital. Melissa's anxiety regarding her daughter's admission encompassed a range of problems she encountered including sleeplessness, loss of appetite, and a strain within her relationship with her partner:

> *I was a total monster the whole time Katie was in hospital...just worrying about her the whole time, not being able to eat and getting sicker. I couldn't sleep, I couldn't eat and it almost tore our house apart. I don't really think that kind of thing is considered in hospitals anyway, you know, that you might be having a hard time at home with your kid in hospital.....well I know that things have been a lot better since the nurses have been coming out and we don't have to go in there anymore....well, at least if we can help it you know.*

Nosocomial Infections

Functional decline associated with hospitalization dramatically alters the way people live and how they contend with their environment. Enforced immobilization, accelerated bone loss, and other physiological changes associated with sensory deprivation, commonly result in irreversible functional decline and intensify the risk of developing life-threatening complications. Given the problems associated with the hospital admission of immunosuppressed and physically compromised patients (e.g. nosocomial infections), and given that the safety and efficacy of IV therapy is now well established, home treatments , either as an alternative to hospitalization, or in association with early discharge, have become a viable option (Vinen 1995). This issue of nosocomial infections appeared throughout the interview transcripts as the most feared hazard of hospitalization. Melissa's daughter Katie, Will and Cathy all experienced

secondary infections whilst hospitalized. For them, the reality of remaining at home meant not placing themselves at risk of additional infection-related and other medical complications. Will especially approached this issue with a somewhat impassioned resentment of hospitalization:

> *A few years ago I was in hospital having IV antibiotics through a drip in my arm and got blood poisoning cause I had a drip that was left in me for two weeks. It stuffed up my vein so bad that that arm's no use now...you know, for drips and stuff...all the veins are really weak and scarred. If I knew then what I know now, well, it wouldn't have happened, but then I didn't sort of know.*

A number of studies (Stiver et al 1978; Graham et al 1991 cited in Vinen 1995) have demonstrated that parenteral agents can be safely and readily administered in the home environment with fewer complications than for patients treated in hospital. The study by Graham et al (1991) revealed a significantly lower rate of bacteraemia in patients treated at home compared to patients treated in hospital. This is particularly so in Will's case. Since his treatment has shifted to the home environment he has not experienced any further infection associated with infusion therapy. Infection control in the home is nevertheless very important; provided patients and their families are appropriately trained in basic hygiene and know what complications to watch for (e.g. phlebitis), the home environment is much safer than that found in hospital (cited in Vinen 1995). Will explained that his experiences have shaped his understanding of infection control in the home and the realization of the need to maintain the highest standard. With such understanding has come a marked reduction in anxiety in comparison to that he had experienced in hospital:

> *I'm real careful with my care at home and my family's really supportive of this. It's just a real relief to be able to do your own thing with your tubes and it makes you more active too...yeah, so that's better for you.*

Will's fears of acquiring a nosocomial infection were discussed in the previous chapter, as he explained how a hospital-acquired infection could be fatal to him. He appreciated the need to receive home based treatment as the chances of acquiring a fatal infection in the home were far reduced compared to that in hospital. According to Graham et al (1991) there are fewer deaths associated

with home infusion therapy compared to deaths associated with hospital acquired nosocomial infections in conjunction with IV therapy (cited in Vinen 1995). Serious adverse effects are uncommon in home intravenous therapy and most are minor and similar to the minor adverse reactions seen in hospitalized patients (Morales and Snead cited in Vinen 1995). Within the context of Will's experience, home infusion therapy meant more chance of actually having a life and keeping it, rather than having it endangered by the hazards of hospitalization.

Approximately 5 - 6% of all patients requiring hospitalization will develop one or more hospital-acquired infections (Boyce et al cited in Vinen 1995). In the United States, bacteraemia associated with intravenous catheters and intravenous monitoring was estimated to occur in at least 35 000 patients per year, with a mortality rate of 20 - 40% (Stamm in Vinen 1995). The additional length of stay and costs associated with the hospital based management of such infections far exceeds the cost of outpatient antimicrobial therapy (Haley cited in Vinen 1995).

Because the home is bacteriologically a less hostile environment, with its lower incidence of complications as a result of avoiding the hazards of hospitalization, patients should, where possible, be treated entirely as outpatients, or following early discharge (Gross et al; Mulligan cited in Vinen 1995). Stable, otherwise healthy patients, can be safely and effectively treated entirely as outpatients, provided they are cautiously selected, that is, if they do not fulfill admission to hospital criteria. Patients admitted for infusion therapy should be considered for early discharge with continued outpatient parenteral therapy. This will reduce not only overall costs of treatment, but also the likelihood of developing complications associated with the hazards of hospitalization (Vinen 1995).

Safety

The safety of home infusion therapy is determined by the following factors: type and severity of the illness/infection; efficacy of the medication; possibility of clinical deterioration; concurrent medical problems; development of allergic reactions; patient selection and training; the level of monitoring/supervision during therapy; the patient's compliance; and problems with the intravenous line/infusion method (Vinen 1995). The most important factor is ensuring safety of an outpatient parenteral program is the establishment of an integrated team of professionals who are responsible for all aspects of the patient care.

Home infusion therapy should be as safe as hospital therapy; one could argue that patients trained to assume responsibility for their own therapy might do a better job than would harassed and distracted nurses in the hospital (McCue 1988). Complications have included drug toxicity (only as often as would have been expected, regardless of the locations of treatment) and phlebitis. Researchers have concluded that home infusion therapy was as safe - and probably safer - than infusion therapy in the hospital (McCue 1988).

The Stress Of an Admission

According to Wilson-Barnett (1979) many people have maintained that admission to hospital is a key event which is frequently accompanied by emotional reactions on the part of patients. Rachman and Philips (1975) listed five commonly encountered manifestations of this stressful event, namely anxiety or fear, increased irritability, loss of interest in the outside world, unhappiness and preoccupation with one's bodily processes (cited in Wilson-Barnett 1979). While these may be considered as reactions to illness as well as hospitalization, the events which occur during the admission process are thought to add to the distress and thus deserve exploration in their own right.

If one pictures the events which often precede admission to hospital, it is not surprising that negative emotional reactions, such as anxiety and stress occur. A period of illness or suspected disease is likely to reduce the individual's resistance to further life stress, as coping with the onset of illness can be seen as

a major adjustment. This fatigue and lowered coping ability is then not the ideal condition for facing the added stress of hospitalization (Wilson-Barnett 1979). This was particularly the case for Jennifer who battled with pre-admission anxiety over the consequences of her hospitalization and treatment sustained in the process:

> *I just used to get so uptight beforehand...it felt, ah...like I was leaving my house for the last time. The drive in was the worst and I started to panic about the side effects before I even got to the hospital. Once I was there it got a little better but you got to sit with everyone else which was very distressing. Hospital just gets me uptight. I know at home you can rest more, ah...whereas when I'm in there, there was just so much noise with the cleaners, you know, the ones that have to stay in. It all just got me very upset in the stomach.*

Not knowing what to expect; anticipating the worst, yet hoping it will not happen; wanting to fit in and feel comfortable; yet not knowing what to do, must all combine to lead to anxious feelings. For Jennifer, the hospital surroundings created an anxiety that could only be relieved by avoiding hospital altogether. June and Cathy also found the hospital surroundings distressing and disturbing to their convalescence. Their dislikes included having to use bed pans, noise - especially nurses walking about the ward, the pan-flusher, doors banging, call bells ringing, alarms going off, other patients moaning or coughing, the rigid routine, so many new faces, not knowing which nurse to ask for what, having doctors talk over them using technical terms, and seeing other people equally distressed or critically ill:

> *It is all very unsettling, you know...can't relax, can't sleep, and basically can't wait to get out of the place and get back home (Cathy 1996).*

and

> *My privacy...or lack of, was really bad sort of thing, you know...can't hold a private conversation with my husband or one of the nurses cause it could be overheard...you know, just felt sort of trapped (June 1996).*

Other factors which produced anxiety for the participants included being concerned over the illness and treatment; what the treatment might entail and what treatment might be required. It seemed that this anxiety was compounded

by the hospitalization (in an acute care setting) which served as a constant reminder of illness. For Melissa, regard for her daughter's condition was relaxed and comfortable within the home environment. This regard was completely reversed when an admission to hospital was indicated:

> *It's funny to realize how much different you feel at home, you know, about Katie's leukaemia...because we cope really well at home and it had just become a part of our home life...yet when we come in to hospital all that just flies out the window and you're back to square one - panic struck you know.*

In addition, learned fear of hospitals and concern over what health care professionals and other patients will be like, and a lack of knowledge about the hospital environment, can also lead to feelings of insecurity and distress (Wilson-Barnett 1979). The presence of hospital induced complications does not, in itself, guarantee that a community-based alternative will be better. It does suggest however, that hospitals are not entirely safe, even without the effect of illness.

Saving Money

Reduction in overall costs of treatment of serious illness requiring parenteral therapy is an obvious advantage to the payer. It has been suggested that both direct and indirect costs are lower for home infusion care than compared to inpatient care (Vinen 1995). Despite this, reimbursement policies continue to obstruct the expansion of the practice. In many cases, prior approval is necessary for coverage in many situations and only certain aspects of the treatment program are covered (Balinsky cited in Vinen 1995).

Home infusion treatment and care has not only resulted in improved care of people with serious infections, debilitating respiratory illness, and neoplastic disease processes, as experienced by those participating in this study, it has also provided one of the most cost effective advances in health care (more specifically high acuity home health care) in a world characterized by spiraling health costs and an increasing aging population placing great demand for hospital beds

(Popkess and Watkins 1992). Being at home or simply being ambulant can also result in cost savings for the recipients of home infusion therapy themselves. As Cathy explained in the previous chapter, this modality of treatment enabled her to return to work and keep her job. The hazard of hospitalization that distressed her most was the dissatisfaction and anxiety associated with her inability to return to work for an extended period of time and the consequences of possible unemployment:

> *Just lying there not being able to do anything while someone else is probably trying to do your job better is pretty nerve wracking when you have a child to feed and clothe, and plenty of bills to pay. I used to make myself sick with worrying over my job, especially when I wasn't really doing much in hospital than just hang around. So, you know, this is so important to me...I mean, its given me back my life.*

According to Popkess and Watkins (1992), as educated consumers, patients can take a more active role in meeting their own health care needs. Many patients prefer to be treated at home, where they feel more in control of their bodies and the circumstances leading to recovery. The same authors explain that in a fast-paced world of work, many people are reluctant to spend time away from careers and other obligations. Often, the provision of high-technology services at home, including infusion therapy, allows patients and their families to participate in the recovery process with less disruption in their lifestyles.

When Cathy mentioned the concept of having her life 'given back' to her, it awakened my realization that the whole essence of having a life was the essential theme of what the people in this study were essentially revealing through their shared experiences. Despite their constructing an understanding of 'at home' experiences largely in relation to past experiences of hospitalization, the participants were only able to truly express their experiences of being at home, by firstly making the journey home from hospital. If this journey meant having a life returned, a life that was now given a new appreciation, then the lived experience of home infusion therapy was essentially encompassed within the reflection of hospitalization.

The negative effects of hospitalization began immediately and progressed rapidly for the people who participated in this study. It was these effects that informed

and shaped their experiences of home infusion therapy. This has been demonstrated throughout this chapter by exploring participants' anxieties and referring to the associated literature which indicates that people recover more rapidly and usually more comfortably when receiving their prescribed therapy at home. The participants validated this conclusion by basing their own conclusions on their own experiences. The notion of 'having a life' is very much associated with being at home; or as Cathy explained, this is "(because) hospitalization is no life..".

Chapter 6

PHENOMENOLOGICAL WRITING ABOUT THE EXPERIENCE OF HOME INFUSION THERAPY - A FINAL REFLECTION

According to Munhall (1994) a powerful phenomenological description will undoubtedly reawaken the primary experience in others who have lived it. This study set out to uncover the lived experience of home infusion therapy for the health care consumer. Broadly speaking, the findings revealed that having the infusion treatment at home meant having one's needs met within the comfort and familiarity of one's own environment. The findings also indicated that the lived experience of home infusion therapy can be understood in relation to the themes of having control and ownership over one's life. For nursing (especially hospital-based nursing), this points to the need to develop a greater understanding of how to identify, acknowledge and appreciate the importance to the consumer of having a life and being in control. The importance of consumers having a life and being in control pertain equally as much to families and/or carers of consumers.

Importance and Relevance of the Study

In the area of clinical practice, nurses need to be encouraged to identify ways in which those in receipt of nursing care can maintain their control, ownership and comfort within the context of health. While meeting all the needs of a patient is perhaps not possible, it is important to be able to respond to those the individual believes to be most important. Health care professionals must be cognizant of all aspects of 'dehospitalization' and strive to make it as painless and positive as possible for all involved. As Heffernan (1997:12) argues, nurses do not own patients. This may be problematic for many nurses, since they often seem to have an 'innate' need to provide care and to feel needed. Heffernan (1997:12) continues by suggesting that '(giving) the patient some control over treatment and environs is symbolic of cutting the umbilical cord'. To recognize this

departure from the traditional hospital provision of infusion therapy will deliver a far smoother and individually respected transition home for all involved.

According to Munhall (1994) the Health Care Financing Administration reported in 1990 that the United States spent $660 billion on health care and further projected that the cost of health care will rise to $1.8 trillion by the year 2000. Phenomenological research is rarely (probably never) the first choice for those considering issues pertaining to the healthcare budget. The conventional literature here characteristically places overwhelming emphasis on health-economic and pharmacoeconomic empirical data analysis. I believe however, a phenomenological uncovering of the lived experience of home infusion therapy can provide useful data which may cause us to rethink certain therapeutic and economic assumptions surrounding the 'benefits' of hospital care versus home care. The phenomenological findings reported in this study may assist in shaping the direction, accessibility, quality, efficacy, and affordability of service provision. While this study was not intended as an exercise in the cost-effectiveness of home-infusing, an enhanced understanding of what individuals feel, and why they feel it, when experiencing a new service modality within health care provides critical background knowledge to those who must make decisions about the costs and benefits of health care practices and treatments. The insights learnt about consumer satisfaction with home infusion therapy is by far the most important contribution of this research project.

Home infusion care is an evolving modality. The number of health care consumers receiving high acuity home health care is growing rapidly, due to the twin pressures of growth in numbers of persons needing care and cost control measures that seek to minimize use of institutional care. The emergence of high acuity home health care demonstrates that the devices used in the care of home patients have become increasingly complex, reflecting both patient acuity and efforts to minimize dependence on skilled nursing labour (de Lissovoy and Feustle 1991). Home infusion therapy has the potential to give a patient and their family/carer a greater degree of control over his or her life. As long as adequate and technically competent home infusion providers exist to coordinate the level

of care needed, home infusion therapy is a viable alternative and may reasonably be expected to become the first choice for many (perhaps most) consumers. Nevertheless, Heffernan (1997) suggests that there will always be people who prefer to stay in hospital, where they feel safe, surrounded by traditional medicine. This may reflect the wishes of carers, when the difficulties of caring for someone at home becomes too much of a burden.

Though it is not necessarily the intent of a phenomenological research project such as this to change the practices and expectations of health care professionals and consumers, there is nevertheless an intent to understand individuals' experiences in ways that reflect the interpretation of the individual rather than our superimposed interpretation - in this case the hypothesized consumer experience as discussed in chapter 2. With this in mind, we must aim to heighten our awareness of the consumer perspective and thus provide to patients, and their families and carers, what they want and need, rather than that which is hypothesized from the (all too often) paternalistic perspective of the health care professional.

Reflection on Method and Meaning

I began this study in an attempt to contribute to our understanding of the experience of home infusion therapy from the perspective of the consumer. A method of study was sought that would allow me to, as Greene (1988) put it, 'break with the cotton wool, of habit, of mere routine, of automation to seek alternative ways of being, to look for openings' (cited in Munhall 1994:247). This stemmed from a desire to employ other ways of knowing in order to gain insight into a consumer experience. The wish to break away from the restrictions of traditional methods of inquiry led to a phenomenological approach which allowed for the collection of personal stories with all the embellishment, richness and serendipity that these might encompass. The nature of phenomenology is such that although commonalties can be asserted, there may be no such thing as a single meaning. There are instead, different vantage points, different stories, different voices.

I chose the method described by van Manen (1990) to explore the phenomenon of consumer experience of home infusion therapy. This was an intentional choice, and it is timely to now reflect on the limitations and strengths of this choice. I have used the major thematic headings of 'the journey home' and 'having a life' as the basis for this reflection. The identification of themes is, at best, only ever a simplification of the whole, and is therefore perhaps inadequate when being used solely to interpret the phenomenon under study. In this respect I have perhaps drifted a little from van Manen's method in that participants' stories have not been reduced to abstract generalizations in deriving themes. The participants remain alive in the text, as their stories and personal moments are intertwined throughout the discussion. Moreover, my voice has been purposefully added to their voices in the creation of the text.

In considering the conversations with the participants in this study, I am aware that there are a range of possible interpretations. I have developed but one interpretation; as van Manen (1990) suggests:

> A phenomenological description is always one interpretation, and no single interpretation of human experience will ever exhaust the possibility of yet another complementary, or even potentially richer or deeper description (van Manen 1990:31).

As a nurse drawn into the practice domain of high acuity home care, my knowledge and experience have been important influences in interpreting the conversations reported herein. My own experience has consequently been added to the data collected. Rather than considering my own subjectivity a limitation, as would be the case in empirical-analytical research, in phenomenological research this becomes a strength. The voices and stories of the five people became six as I also participated in the narration of this experience. I believe that these collective interpretations and understandings have closed the distance between myself as a researcher and the people with whom I was researching. The method has allowed me to explore the phenomenon under investigation from within an interpretative paradigm which has these shared understandings (Habermas 1971).

The narration of the experience of home infusion therapy has been of particular significance to the participants. They all spoke of how helpful it had been to be able to tell of their experiences. It was as if this type of conversational opportunity had not been previously available to them for various reasons. Perhaps the telling of their stories has provided a sense of validation of experience for June, Jennifer, Will, Melissa and Cathy (and perhaps also for myself).

Identifying one definitive statement, or 'phenomenological writing' about the experience of home infusion therapy as a kind of essence or 'truth', may be to nullify the phenomenological premise that the meaning of an experience is embedded in the life of the person and the experience being investigated. Having made this qualifier of sorts, it is true nonetheless that I did identify themes in the participant's interviews and was able to distinguish a number of global themes that were subsequently validated by the participants themselves. All of this points to the likelihood that while some generalizations can be made about research from a consumer perspective, the best way to understand an experience may be to read or hear about it from an individual 'who has had it' (Munhall 1994:248).

This study has indicated that the phenomenon of the consumer's experience of home infusion therapy can be afforded the status of an entity, or a 'reality', in the lives of the participants. The participants did describe many experiences and feelings, yet I believe that all the experiences shared by them are best understood in the context of their lives. Is it phenomenologically sound to arrive at one general statement about such experiences? Surely it must be acknowledged that in writing one final phenomenological description the researcher is using a speculative shorthand of sorts (Munhall 1994). The danger lies in the possibility that in attempting to simplify phenomena so that they might be more easily shared with others, the results can be a dilution in which the complexity of meaning is lost (Munhall 1994).

If there is meaning in the findings of this study, it surely lies in the data, and not so much in the phenomenological writing about the data. It lies in the examples cited by the participants who at times struggled to recollect and then reconstruct their experiences for me. These experiences seemed to them to be so simple, and so personal, that they wondered aloud about how their experiences could help anyone else. But help they do! They help us recognize how very important the familiar home environment and the associated sense of control is in the overall experience of health care. They help us realize that home is where the heart is; where a familiar environment exists. Home is about ownership, responsibility, control, family relationships, and being 'at ease'. These are paramount to a positive experience of high acuity home care such as infusion therapy. If we wish to understand this experience, we must ask people about their own stories; their own felt needs; their own ways of feeling safe, secure, supported, in control, respected and recognized as individuals who live their lives in their own homes together with their families.

Change is inevitable and always in progress. The implementation of home infusion therapy within health service provision is one of those changes. As health care providers, we should direct our energies so as to ensure that the consequences of such change is positive, and that at the same time, the caring focus of the past is retained. Making the journey home is an opportunity for us as carers to validate the experience of health care consumers and allow these people to make their own choices. Surely this choice is among the greatest gifts we can bestow.

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APPENDICES

UNIVERSITY OF TASMANIA ETHICS COMMITTEE

(HUMAN EXPERIMENTATION)

APPLICATION TO UNDERTAKE AN INVESTIGATION INVOLVING HUMAN SUBJECTS

1. TITLE OF PROPOSED INVESTIGATION

Home Infusion Therapy – Consumer Perspectives ?

2. APPLICANTS

Title/Name	*Position*	*Department*
Assoc. Prof. M. J. Hazelton	Associate Professor	Nursing
Ms Sarah J. Breier	Student (Masters - thesis)	Nursing

3. TEACHING/RESEARCH

Is the proposed investigation for teaching or research? Research

4. AIMS

This study represents an investigation into the lived experiences of those patients undergoing home infusion therapy. Home Infusion is a recent initiative in health service provision which represents a significant marked departure from traditional hospital based health care which has necessitated lengthy hospitalisation.

The aims of this research are:

- to expose the lived experience of those patients receiving home infusion therapy
- to determine the efficiency, safety and suitability of home infusion from a consumer perspective
- to evaluate the effects of a new treatment modality on the patient
- to evaluate whether the reported benefits of early discharge practices from the associated literature can infact be replicated in our own community

5. JUSTIFICATION

(i)
This study will contribute to an understanding of the lived experiences of patients receiving home infusion therapy as a result of expedited ' acute' discharge. It will facilitate an appreciation into those perspectives of early discharge that health care professionals find essential, and those which they (might) perceive have a negative impact on work practices, and the ability to provide high quality care for patients. This research shall make a significant contribution in the field of advanced home health

nursing and early discharge planning from the acute care settings in the Northern region of the State. It is anticipated that the understandings gleaned from this research endeavour will reveal patient attitudes and ideas that will assist in improving the facilitation of continuity of care. Through this process better connections will be established between patients, the hospital, community providers and health care professionals.

(ii)
The main advantage of undertaking this research will be the exposure of issues patients experience regarding the effectiveness of early discharge, home infusion and the complexities in assuming an innovative role in their own health care that has historically been located within a medically defined task domain. By investigating patients' experiences first hand, certain quality indicators specific to home based infusion therapy will be uncovered. These patient focused indicators will thereby act as quality tools to assist in shaping the most successful and satisfactory home infusion service for the Northern Region. This process will simultaneously provide an insight into the complex realities of hi tech home care from a consumer perspective that will foster an appreciation for health care professionals to acknowledge.

6. BRIEF DESCRIPTION OF INVESTIGATION - RESEARCH PROCEDURES

This research will be undertaken over a 6 week time frame

ethnography - in-depth interviewing

sample - patients of the LGH referred for Home Infusion

7. EXPECTED DURATION OF THE INVESTIGATION

From July 1996 to September 1996

8. SUBJECTS AND SELECTION

(i) Between 3 and five patients referred to the Home Infusion Service in the Northern Region. Male and Female participants ranging from 22 - 59.

(ii) Participants will be approached directly and invited to partake in this study. Participants will be patients referred to the newly established Home Infusion Service at the Launceston General Hospital.

9. REVIEW OF ETHICAL CONSIDERATIONS

Has this protocol previously been submitted to the University Ethics Committee ? YES/NO

Has this protocol been submitted to any other ethics committee ? YES/NO
(Launceston General Hospital Ethics Committee)

UNIVERSITY OF TASMANIA

Tasmanian School of Nursing

THE STATEMENT OF INFORMED CONSENT

Title of Project: **CONSUMERS' EXPERIENCE OF HOME INFUSION THERAPY**

SUBJECT

1. I (the participant) have read and understood the 'Information Sheet' for this study.

2. The nature and possible effects of the study have been explained to me.

3. I understand that the study involves the following procedures:
   A number of interviews which will be tape recorded with my permission and the information so collected will be used for the purposes of the study. I acknowledge that fictitious names only will be used.

4. I understand that there are no anticipated discomforts involved in the study.

5. Any questions that I have asked have been answered to my satisfaction.

6. I agree to participate in this investigation and understand that I may withdraw at any time without prejudice.

   I agree that research data gathered for the study may be published provided that I cannot be identified as a subject.

Name of Subject.....

Signature of Subject.....Date.....

INVESTIGATOR

7. I have explained this project and the implications of the participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation.

Name of Investigator.....

Signature of Investigator.....Date.....

Should you have any query concerning this research project please feel free to contact:

Associate Professor Mike Hazelton — Tasmanian School of Nursing, University of Tasmania, Launceston Campus; phone (003) 243318

Sarah Breier — Manager, Medicare Incentive Projects, Launceston General Hospital
phone: (003) 327924
Master of Nursing student, University of Tasmania