

Spinal cord compression secondary to cancer: disability and rehabilitation

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Abstract

Introduction

This thesis describes a research study designed to examine the consequences of disability arising out of spinal cord compression secondary to cancer, and to examine the rehabilitation services available to patients.

Research aims and questions

The study was intended to achieve the following:

1. To ascertain what might constitute effective rehabilitation interventions for patients with metastatic spinal cord compression.
2. To identify the conditions in which these intervention might be delivered.
3. To ground proposals in spinal cord compression patients' experience of disability.

The following research questions were posed:

1. What are the consequences of disability for patients with metastatic spinal cord compression?
2. What strategies do patients themselves use to manage disability?
3. What do health care staff, particularly rehabilitation professionals, understand to be the consequences of disability for this patient group, and correspondingly, what are their views on the significance and provision of rehabilitation?
4. To what extent is rehabilitation being provided to these patients, and with what effect?
5. Where rehabilitation is not being provided, why is this the case?

Study design

The study had two components:

- A series of nine in-depth interview-based case studies, which involved talking to patients about their experiences of living with spinal cord compression, as well as gaining the perspectives of family members and the health professionals who provided care and services.
- A retrospective audit of the medical records of 73 spinal cord compression patients admitted to a radiotherapy in-patient unit (the Frank Ellis Unit at the Churchill Hospital in Oxford) over a two year period (July 2003 – June 2005), identifying disability-related problems and the measures taken to address them.

This was a Phase I modelling study in terms of the Medical Research Council's framework for evaluating complex interventions, with Pawson and Tilley's (1997) Context-Mechanism-Outcome configuration adopted as a conceptual basis for data collection. Within-case analysis was informed by George and Bennett's (2004) account of process tracing, and between-case analysis was modelled on the constant comparative method of Glaser and Strauss (1967) with an analysis of narrative as a variation on that theme.

Results

Disability is a serious problem for patients with spinal cord compression, but it is one problem among many others, not the least of which are the physical and emotional consequences of life-threatening illness. In response to disability, patients 'twin-track' their attitudes to it, acknowledging but also resisting the idea of themselves as disabled, and adopting a series of psychological devices to manage the tension.

In effect, patients recognise that something significant has changed and that, as a consequence, new self-management skills must be learned, functional boundaries must be explored, useful information must be sought. At the same time, they display a determination to hold on to an established identity, associated with a sense of normality. This identity embraces the idea of competence and resourcefulness, the events, activities and pleasures that one looks forward to, and the wish to avoid burdening others. It is not a 'disabled' identity. To some extent, these two attitudes are in tension, as one acknowledges disability while the other, implicitly or explicitly, resists it. Consequently, patients try to find ways of resolving this tension, by 'revising downwards' their expectations, by constantly deferring the anticipated pleasures, and by avoiding situations in which their abilities might be put to the test, or the sense of normality be disconfirmed.

Health care professionals are likely to construe the patient's response as indicative of a certain type of character – 'realistic' on one hand, and 'unrealistic' on the other. They do not see 'acknowledging / not acknowledging' as twin facets of a complex response to circumstances, or as something which every patient engages in to one degree or another.

Patients are motivated not to recognise rehabilitation as something they need, a view which is confirmed by the cursory form of rehabilitation experienced in hospital, and by the marginal significance attributed to it by nursing and medical staff. On discharge, hospital staff assume that rehabilitation needs will be identified in the community, although the way in which community rehabilitation services are organised virtually guarantees that this will not happen, unless a specific referral is made (as it is in only 5% of cases). The patient, meanwhile, remains unaware of the potential value of rehabilitation, and has no incentive to request rehabilitation if no-one offers it. They are

consequently unprepared for life post-discharge, and assume that they (and their families) must manage on their own.

Conclusions

Like the patients, health care professionals may have to 'twin-track' if they are to provide rehabilitation in a way that is acceptable to patients with metastatic spinal cord compression. Instead of categorising patients as 'realistic' or 'unrealistic', they should work towards sustaining patients' 'positive illusions', while at the same time taking whatever opportunities arise to enhance the patient's day-to-day ability to function in a 'safe' space. This entails revising some deeply entrenched ideas about working with patients who have a disability: patient-centredness, the importance of goal setting, and the need for adjustment.

Prologue and Acknowledgements

This study developed out of my work in rehabilitation with adults with physical disabilities. I qualified as an occupational therapist in Cape Town in the mid-1980s, at a time of social and political upheaval in South Africa, with the ruling Nationalist Party making a last-ditch effort to preserve its policy of Apartheid in the face of an increasingly well-organised and determined resistance movement. While the main focus of political activism was on a change of government, the mood of increasing political empowerment created a climate where many minority groups, including people with disabilities, began to take a stand against discrimination. 'Disabled People South Africa' (DPSA) was formed in 1984, and campaigned energetically for the social, political and economic rights of disabled people.

An active local DPSA group met regularly in the gym of the spinal injuries unit where I began working in late 1985, and they brought with them a new perspective on disability: one where disabled people themselves were the experts on their bodies and on their needs and priorities, presenting a contrast to the professionally-driven agenda that dominated the unit at the time. I saw the necessity for rehabilitation to contribute to a person's sense of autonomy, self-worth, social participation and economic self-sufficiency, in a process led by the disabled person. Two decades of clinical practice persuades me that this is easier said than done; nevertheless, I remain committed to the notion that key to the effectiveness of any rehabilitation intervention is a person's sense of him or herself as a worthwhile human being.

At a very early stage in my career, then, I observed the influence of what I later came to recognise as the Social Model of disability in providing a positive framework for disabled people. A disabled person was not inferior, inadequate or pitiable, nor, for that matter, courageous or heroic; but rather had the potential and capacity to make a meaningful contribution given a societal acceptance of difference and an accessible environment. Disability was not a tragedy; it was a social problem. Psychologically, this was a powerful message, both to disabled people, and to the staff who worked with them.

Moving into cancer and palliative care rehabilitation some years later, I was struck by a number of interesting – and puzzling – contrasts. Instead of a professional paternalism, the palliative care rhetoric was very much around partnership working, patient-centered practice and patient choice; yet patients seemed more passive, less demanding, more grateful to staff. There was virtually none of the angry determination in response to disability that I had encountered in people with longer-term disabilities. It seemed that disability was seen by patients as the ultimate tragedy: ‘not only am I dying, but my enjoyment of life is curtailed by immobility, dependence and indignity’. The combination of helpful professional and grateful patient appeared to produce a situation in which creativity and ingenuity were stifled. In this context, I wondered whether the Social Model of disability had anything to contribute. Would a more rights-based approach to disability be congenial to people at the end of life? Conversely, were there situations in which a disability could legitimately be seen as a tragedy, and what were the theoretical implications of this for the Social Model? I had some practical questions as well: I wanted to ascertain what kinds of rehabilitation interventions (if any) were acceptable and beneficial to people whose last months of life were complicated by disability.

The choice of patients with metastatic spinal cord compression as a group to study was largely pragmatic. In my experience of working in cancer and palliative care, there are two groups of patients who pose a particular rehabilitation challenge: those with brain tumours, and those with spinal cord compression. People with brain tumours are a difficult group with whom to carry out research, not least because of the cognitive and personality changes that often result from the illness. With a background in spinal injuries, the contrast between rehabilitation in spinal injury and in metastatic spinal cord compression interested me greatly.

I would like to make a brief observation about terminology. Throughout this thesis, I refer to 'patients' and 'carers'. 'Patient' is, of course, a problematic term, but the alternatives ('client' or 'person with spinal cord compression') have their own disadvantages. This study was carried out in a hospital, where 'patient' is accepted currency, both by those providing treatment and care, and by those receiving it; and it is on this basis that I use the word in this study. The terms 'disabled people' and 'people with disabilities' are, likewise, contested. 'Disabled people' is preferred by some, on the grounds that it emphasises that disability is imposed by the environment and social attitudes. Others argue for 'people with disabilities' which is seen to place emphasis on the 'person' rather than the 'disability'. In the United Kingdom, 'disabled people' is the term preferred by most activists in the disability movement, and it is the term I use in this thesis.

I am grateful to a number of people for their thoughtful, kind, constructive and critical support in carrying out this project. Primarily, I owe a debt of gratitude to the nine patients and their carers who were willing to be interviewed, and who spoke candidly about some often painful experiences. I am also extremely grateful to the staff who spent

time talking to me, and to the oncology and palliative care consultants and senior ward staff who not only gave permission for me to approach their patients, but who also did a great deal to facilitate the research process.

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I was fortunate to have a number of opportunities throughout the study to present preliminary thoughts and findings to various audiences who provided very useful critical feedback, helping me to strengthen (or discard) lines of thought. The Stirling-Dundee Seminar Series, the South African Palliative Care Congress, the Oxfordshire Occupational Therapy Research Group, and two study events at St Christopher's Hospice – one on palliative care rehabilitation, and one on narrative – stand out in particular.

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PART I
INTRODUCTION AND LITERATURE REVIEW

Chapter 1

Metastatic spinal cord compression

1.1 Introduction

This research takes as its starting point the consequences of disability resulting from metastatic spinal cord compression. A detailed account of the diagnosis and clinical management of metastatic spinal cord compression is not relevant for this review; however, there are issues that are significant for rehabilitation, and I begin this chapter with a brief background to these. They include aspects of prevalence, aetiology, diagnosis and treatment which shape patients' experience of illness. I then move on to a critical discussion of the literature on rehabilitation in metastatic spinal cord compression, posing a number of questions related to the operationalisation of rehabilitation, the patient's role in rehabilitation and the relationship between life-threatening illness and disability.

1.2 Overview of metastatic spinal cord compression

1.2.1 Incidence and aetiology

The onset of a metastatic spinal cord compression is an oncological emergency, necessitating immediate intervention to minimise damage to the spinal cord and preserve neurological function. Estimates of incidence vary from 2.5% (Loblaw *et al.* 2003) to 6% (Bach *et al.* 1990) of all patients with systemic cancer, the variation reflecting the lack of comprehensive epidemiological studies of this condition.

Nearly half of all metastatic deposits in the spinal cord arise from one of three types of primary cancer: prostate, breast and lung. They are also found in patients with lymphoma, melanoma, renal cell carcinoma, thyroid carcinoma and sarcoma (Abraham 2004; Cowap *et al.* 2000; Hicks *et al.* 1993; Byrne 1992). Thoracic lesions are the most

common (70%), followed by lumbosacral (20%) and cervical lesions (Loughrey *et al.* 2000; Hill *et al.* 1993; Gilbert *et al.* 1978), the location of the metastases being roughly proportional to the mass of bone in each region (Abrahm 2004).

The neurological symptoms found with metastatic epidural tumours arise from compression rather than invasion of the spinal cord. Most commonly, tumours develop between the dura mater and the periosteum, with the spinal cord being compressed anteriorly (Belford 1997). This compression leads to oedema and ischaemia, distorting and damaging the neural tissue, and giving rise to symptoms such as pain, limb weakness, sensory loss and sphincter disturbance (Abrahm 2004; Eriks *et al.* 2004; Cowap *et al.* 2000). Pain may be local or radicular (Levack *et al.* 2002; Husband 1998). Local pain occurs particularly with metastatic deposits inside the vertebral body. Radicular pain is the more common, and is an indication of disease in the epidural space, arising from tumour compressing the nerve roots.

1.2.2 Diagnosis and treatment

Early diagnosis of spinal cord compression is of paramount importance, since this provides patients with the best chance of a good functional outcome post-treatment. Patients who are able to walk on diagnosis are much more likely to preserve this ability following treatment than immobile patients are to regain it (Levack *et al.* 2002; Hacking *et al.* 1993; Kim *et al.* 1990; Sørensen *et al.* 1990). Several reviews and studies report unacceptable delays in diagnosis and emphasise the need for early warning signs (particularly pain) to be taken seriously and acted on immediately (Prasad and Schiff 2005; Levack *et al.* 2002; Husband 1998; Hill *et al.* 1993). Where a spinal cord compression

is suspected, magnetic resonance imaging (MRI) is the diagnostic investigation of choice (Levack *et al.* 2002; Husband *et al.* 2001; Loughrey *et al.* 2000).

In the absence of data from prospective randomised controlled trials, there is no definitive strategy for the treatment for metastatic spinal cord compression, but accepted best practice includes three components: steroids, radiotherapy and surgery (Prasad and Schiff 2005; Loblaw and Laperriere 1998). There has been considerable debate about the desirability of surgery as a first-line treatment (in preference to the widely accepted practice of steroids and radiotherapy) following a controversial paper by Patchell and colleagues (2005), published in the *Lancet*. While this is of undoubted importance in determining the optimal management of metastatic cord compression, for the purposes of this study, the medical or surgical treatment is significant only in so far as it affects the way that patients move through the hospital system, and the consequences of this on referral for rehabilitation, and I will elaborate on local practice in Chapter 2.

1.2.3 Prognosis

The prognosis for patients with metastatic epidural spinal cord compression is poor, with a median survival of 3.1 months, and a one-year survival rate of less than 20% (Sørensen *et al.* 1990). The two main determinants of a good outcome (measured in terms of survival and preservation of function) are tumour biology and, as mentioned earlier, the degree of neurological deficit at the time of diagnosis (Loblaw and Laperriere 1998; McKinley *et al.* 1996; Sørensen *et al.* 1990). The site of the primary tumour is significant, with patients with haematological, breast and prostate cancers surviving longer than those with lung cancer. The likelihood that a patient will recover mobility following treatment is inversely related to the degree of impairment on diagnosis; fewer than 30% of patients regain lost

functional capacity (Sørensen *et al.* 1990). Attempts have been made to develop prognostic indicators (Tokuhashi *et al.* 2005; Eriks *et al.* 2004; Hacking *et al.* 1993; Tokuhashi *et al.* 1990). The system proposed by Tokuhashi and colleagues, which uses six parameters (performance status, extraspinal bone metastases, quantity of metastases in the vertebral body, metastases to internal organs, primary site, and the severity of neurological damage), has received some attention in the literature. It has been recommended as a tool in assessment for surgery (West of Scotland MSCC Guidelines Development Working Group 2006; Ulmar *et al.* 2005; Enkaoua 1997), and may have potential in predicting patients' suitability for rehabilitation (Tang *et al.* 2007).

1.2.4 Consequences of spinal cord compression

Understandably, given the factors described above, the main focus of the medical literature on metastatic spinal cord compression is the need for early diagnosis and on recommendations for optimal treatment in order to prevent or minimise disability (Levack *et al.* 2002; Husband 1998; Sørensen *et al.* 1990; Barcena *et al.* 1984; Constans *et al.* 1983; Gilbert *et al.* 1978). The point is clearly made in the literature that this is a condition associated with compromised quality of life for patients and for their carers. As Lobblaw and Laperriere (1998: 1613) summarise: 'malignant spinal cord compression is one of the most dreaded complications of metastatic cancer. Its natural history, if untreated, is one of relentless, progressive pain, paralysis, sensory loss, and sphincter incontinence'. For patients, the threat of physical disability and carer dependency are among the most distressing aspects of illness (Breitbart *et al.* 1998).

An alternative view is offered by Levack *et al.* (2004), reporting on a substantial study which correlated spinal cord compression patients' quality of life with ability to walk,

finding no significant association. Patients rated their quality of life overall as good to very good. On the basis of their results, Levack and her colleagues suggest that patients might not share medical professionals' rather bleak outlook on life with spinal cord compression.

In general terms, however, disability resulting from spinal cord compression is seen to cause significant disruption to patients' lives. While rehabilitation might not be much more than a footnote to medical and surgical treatment in the medical literature, it is nevertheless acknowledged as an important component of management, where it can 'engage patients and families in constructive purpose such that decline is not experienced with helplessness' (Cheville 2001: 1040). Additionally, there is a small body of literature that focuses on rehabilitation interventions in metastatic spinal cord compression, and it is to this literature that I shall now turn.

1.3 Rehabilitation in metastatic spinal cord compression

1.3.1 Approaches to rehabilitation

Patients with spinal cord compression encounter a range of disability-related problems: altered mobility, impaired skin sensation, pain, spasticity, incontinence, sexual dysfunction, and the emotional consequences of a sudden loss of independence (Kirshblum *et al.* 2001; Cowap *et al.* 2000; McKinley *et al.* 1999b). These are problems which in other conditions, such as traumatic spinal cord injury, would merit an individual's participation in some structured programme of rehabilitation.

Staas *et al.* (1998) list the difficulties encountered by people with a traumatic spinal cord injury as follows: mobility problems, sensory deficit, pain, spasticity, bladder and bowel

incontinence, sexual dysfunction, difficulties with activities of daily living, and depression. The similarities between spinal cord compression and a traumatic spinal injury are clear. Benefits of specialist rehabilitation for people with traumatic spinal injuries in terms of independent function and psychosocial adjustment have been reported (Inman 1999; Smith 1999; Staas *et al.* 1998; De Vivo *et al.* 1991), and the existence of highly specialised spinal injury units worldwide is evidence of the accepted need for the funding of such specialist rehabilitation programmes. These are delivered in in-patient units where stays of between three and six months are the norm. Such programmes would typically include the following aspects (Sipski and Richards 2005; Department of Health 2004c):

- Detailed information on managing (for example) incontinence, pressure care, sexual function.
- Achieving maximum independence.
- Full equipment evaluation.
- Counselling for patients and their families.
- Peer support.
- Planned management of transition to community living.

Of course, there are also some significant contrasts between the two conditions; the most profound being the difference in life expectancy. Given the poor prognosis of spinal cord compression, the majority of these patients will be obliged to cope not only with a disability, but also with the implications of a life-limiting disease (Eva and Lord 2003). Age and general health are additional factors, with traumatic spinal injury occurring

predominantly in healthy younger men (Staas *et al.* 1998), while metastatic spinal cord compression is seen in an older age range (50 – 70 years) with a more even gender distribution (New *et al.* 2002), and is associated with a significant degree of co-morbidity (Cowap *et al.* 2000).

Even taking these differences into account, a reasonable question at this point is whether the disability-related problems arising from a spinal cord compression are met with a structured and co-ordinated approach similar to that which has been shown to be effective in spinal injury rehabilitation. A comprehensive literature search¹ identified 28 papers which either evaluated or commented on rehabilitation in metastatic spinal cord compression. These are listed in Table 1.1. (Papers that reported on measures of disability evaluating medical or surgical treatment in the absence of rehabilitation were excluded.)

Table 1.1: Literature on rehabilitation and metastatic spinal cord compression

¹ Searches of AMED, ASSIA, BNID, CINAHL, EMBASE, OTseeker, Pedro, PsychINFO and PubMed were carried out between January 2003 and March 2007, with the following search terms (used singly and in combination) bone, cancer, disability, epidural, malignan*, spin*, cord, compression, metasta*, non-traumatic, injury, palliative care, occupational therapy, physiotherapy, and rehabilitation.

Prospective surveys			
	Aims and Setting	Results and Conclusions	Sample size
Levack <i>et al.</i> 2004	Survey of quality of life in relation to disability of metastatic spinal cord compression patients admitted to 3 oncology centres (UK) between 1998 and 1999. <i>Outcome measures:</i> Schedule for the Evaluation of Individual Quality of Life (SEIQoL-DW); Karnofsky Performance Scale (KPS); Barthel Index; Hospital Anxiety and	Median SEIQoL-DW score = 66 (out of possible 100). SEIQoL-DW correlated with KPS but the range of scores for each level of performance was very wide. No significant association between SEIQoL-DW and ability to walk. SEIQoL-DW adversely affected by emotional distress measured by HADS.	<i>n</i> = 180

	Depression Scale (HADS).	Quality of life as determined by the patient may not coincide with health professionals' opinions.	
McKinley <i>et al.</i> 2001	<p>Longitudinal study with matched block design, comparing length of stay, functional gains, costs incurred and discharge rates of non-traumatic spinal injury (including metastatic spinal cord compression, number not specified) against traumatic spinal cord injury patients admitted to spinal injury units (USA) between 1992 and 1999.</p> <p><i>Outcome measures:</i> Length of stay; Functional Independence Measure (FIM); Rehabilitation charges; Discharge to home rates</p> <p><i>Admission criteria:</i> Not stated.</p>	<p>Non-traumatic SCI had shorter inpatient stays (22 vs. 41 days), and lower discharge FIM scores, FIM change and rehabilitation charges. No difference between two groups in discharge to home rates.</p> <p>Patients with non-traumatic SCI can achieve comparable rates of functional gains to TSCI. Patients with TSCI had greater overall functional improvement but longer rehabilitation stays and higher rehabilitation charges.</p>	<p><i>n</i> = 172</p> <p>TSCI = 86</p> <p>Non-traumatic SCI = 86</p>
McKinley <i>et al.</i> 2000	<p>Prospective comparison of demographics, injury characteristics and functional outcomes of metastatic spinal cord compression and traumatic spinal cord injury patients admitted to a spinal injury unit (USA) over a five year period.</p> <p><i>Outcome measures:</i> Length of stay; Functional Independence Measure (FIM); Discharge rates to home.</p> <p><i>Admission criteria:</i> Prognosis > 3 months; able to tolerate 3 hours rehabilitation per day.</p>	<p>MSCC were older, more often female, more often unemployed. MSCC more often paraplegia and more often incomplete lesions. MSCC had shorter inpatient stays and comparable discharge rates.</p> <p>MSCC patients achieved comparable rates of functional gains. TSCI had greater functional improvement overall but MSCC patients had shorter inpatient stays and achieved similar discharge to home rates.</p>	<p><i>n</i> = 193</p> <p>TSCI = 159</p> <p>MSCC = 34</p>
McKinley <i>et al.</i> 1999a	<p>Case-controlled comparison of functional outcomes, length of stay and discharge to home rates of traumatic spinal cord injury and metastatic spinal cord compression patients admitted to a rehabilitation centre (USA) over a five year period.</p> <p><i>Outcome measures:</i> Length of stay; Functional Independence Measure (FIM); Discharge rates to home.</p> <p><i>Admission criteria:</i> Prognosis > 3 months; able to tolerate 3 hours</p>	<p>MSCC had significantly shorter rehabilitation inpatient stays. Rates of functional improvement similar for both groups. TSCI achieved greater functional improvement overall. Similar discharge to community rates.</p> <p>Patients with MSCC can achieve comparable rates of functional gain. While patients with TSCI achieve greater functional improvement, patients with MSCC have shorter rehabilitation</p>	<p><i>n</i> = 58</p> <p>TSCI = 29</p> <p>MSCC = 29</p>

	rehabilitation a day.	stays and can achieve comparable success with discharge to community.	
McKinley <i>et al.</i> 1999b	<p>Prospective survey to compare incidence, epidemiology and functional outcome of non-traumatic spinal injury patients (including metastatic spinal cord compression) with traumatic spinal cord injury patients admitted to a spinal injury unit (USA) over a five period.</p> <p><i>Outcome measures:</i> Demographic and clinical data; Level and completeness of injury; Functional Independence Measure (FIM)</p> <p><i>Admission criteria:</i> Not stated.</p>	<p>39% of admissions were non-traumatic SCI. Non-traumatic SCI significantly older, more likely to be married, female and retired. Significant FIM improvement for both groups and comparable discharge home rates. More paraplegia and incomplete lesions in non-traumatic group.</p> <p>Individuals with non-traumatic SCI represent a significant proportion of SCI rehabilitation admissions and, although differing from those with TSCI in demographic and injury patterns, can achieve similar functional outcomes and discharge to home rates.</p>	<p><i>n</i> = 220</p> <p>TSCI = 134</p> <p>Non-traumatic SCI = 86 (of which MSCC = 22)</p>

Retrospective reviews of clinical records

Tang <i>et al.</i> 2007	<p>Retrospective review of clinical records to explore functional gains made through rehabilitation, and predictive factors for functional gains, for metastatic spinal cord compression patients admitted to a neuro-oncology rehabilitation ward (Canada).</p> <p><i>Outcome measures:</i> Length of rehabilitation; Functional Independence Measure (FIM); Tokuhashi Score; Survival.</p> <p><i>Admission criteria:</i> Not stated.</p>	<p>Significant improvement in FIM scores. Median survival from start of rehabilitation = 10 months. High FIM gain and high Tokuhashi score predictive of longer survival.</p> <p>Rehabilitation improves functional outcome in MSCC. Tokuhashi score can help to identify patients with good prognosis and potential for improvement during rehabilitation</p>	<i>n</i> = 63
McLinton and Hutchison 2006	<p>Retrospective review of clinical records reviewing treatment (including rehabilitation) of metastatic spinal cord compression patients admitted to a regional cancer treatment centre (UK) between 2001 and 2002.</p> <p><i>Outcome measures:</i> Demographic and clinical information taken from case notes using pro-forma.</p>	<p>Areas of concern included poor assessment of pain, and the lack of clear plans for mobilisation and rehabilitation.</p> <p>Care of patients with MSCC is complex and involves multi-professional expertise. Guidelines should be developed and further research is needed to ensure good quality care.</p>	<i>n</i> = 174

Catz <i>et al.</i> 2004	<p>Retrospective review of clinical records to assess neurological recovery and factors affecting this in non-traumatic spinal injury patients (including metastatic spinal cord compression number not specified), compared with traumatic spinal cord injuries admitted to a specialist rehabilitation hospital (Israel) between 1962 and 2000.</p> <p><i>Outcome measures:</i> Demographic and clinical data; Frankl grades of neurological deficit.</p> <p><i>Admission criteria:</i> Not stated.</p>	<p>Neurological recovery was significantly affected by initial Frankl grade and by specific non-traumatic SCI pathology.</p> <p>Rate of recovery of function found to be higher for patients with non-traumatic spinal injuries.</p>	<p><i>n</i> = 1330</p> <p>TSCI = 250</p> <p>Non-traumatic SCI = 1085</p>
Eriks <i>et al.</i> 2004	<p>Retrospective review of clinical records to identify factors that predict survival more than 1 year after rehabilitation for metastatic spinal cord compression patients admitted to nine specialist spinal injuries units (Netherlands) between 1990 and 2000.</p> <p><i>Outcome measures:</i> Demographic and clinical data; Barthel Index; Rehabilitation goals; Discharge; Survival.</p> <p><i>Admission criteria:</i> Prognosis > 1 year; patient physically able to participate in rehabilitation; Potential for discharge home.</p>	<p>Barthel scores improved by an average of 4.8 points out of 20. Average survival after discharge was 808 days. 66% of patients were discharged.</p> <p>Patients meeting the admission criteria can benefit from in-patient rehabilitation in a specialist spinal injury unit.</p>	<p><i>n</i> = 97</p>
Garrard <i>et al.</i> 2004	<p>Retrospective review of clinical records of patients with neurological deficits secondary to cancer (including metastatic spinal cord compression, number not specified) admitted to a specialist neuro-rehabilitation unit (UK) between 1996 and 2000.</p> <p><i>Outcome measures:</i> Demographic and clinical data; Functional Independence Measure (FIM); Barthel Index; Goal-setting.</p> <p><i>Admission criteria:</i> Not stated.</p>	<p>All patients made significant FIM improvement. 19 were discharged home. An average of 18 short-term goals were set for each patient with an average of 15.8 being achieved.</p> <p>Patients with neurological deficits secondary to cancer can benefit from in-patient rehabilitation.</p>	<p><i>n</i> = 21</p>
Guo <i>et al.</i> 2003	<p>Retrospective review of clinical</p>	<p>No variables had significant</p>	<p><i>n</i> = 60</p>

	<p>records to identify the clinical and social variables impacting significantly on survival of metastatic spinal cord compression patients admitted to a specialist cancer centre rehabilitation unit (USA) between 1996 and 1998.</p> <p><i>Outcome measures:</i> Survival (Kaplan-Meier survival analysis)</p> <p><i>Admission criteria:</i> Dependence in activities of daily living or mobility, and requiring at least two of physiotherapy, occupational therapy, speech therapy and rehabilitation nursing.</p>	<p>influence on survival time (median = 4.1 months from rehabilitation admission), with the exception of gastro-intestinal cancer which had a poorer prognosis (median = 0.6 months). Average length of stay 16.7 days. One month gap between time of diagnosis and time of transfer to rehabilitation unit.</p> <p>Rehabilitation programmes for patients should be of short duration and early referral (i.e., on diagnosis) to the rehabilitation service should be encouraged.</p>	
Parsch <i>et al.</i> 2003	<p>Retrospective review of clinical records and public administration databases to analyse the clinical presentation, survival rates and rehabilitation outcomes of metastatic spinal cord compression patients admitted to a spinal injury unit (Germany) between 1979 and 1995.</p> <p><i>Outcome measures:</i> Clinical and demographic data; Functional Independence Measure (FIM); Frankl Scale.</p> <p><i>Admission criteria:</i> Not stated.</p>	<p>Higher FIM scores on admission together with age, neurological deficit were reliable prognostic indicators. Functional improvements were made with rehabilitation (FIM improvement from 60 – 87).</p> <p>Clinical and functional status is a valuable prognostic factor for survival. Institutional rehabilitative efforts are effective, and patients with metastatic spinal cord compression should be accepted into such programmes.</p>	<i>n</i> = 68
New <i>et al.</i> 2002	<p>Retrospective review of clinical records to investigate complications occurring during rehabilitation and to formulate a model to predict length of stay for non-traumatic spinal injury patients (including metastatic spinal cord compression) admitted to a spinal injury unit (Australia) between 1995 and 1997.</p> <p><i>Outcome measures:</i> Clinical and demographic data, co-morbidities and complications.</p> <p><i>Admission criteria:</i> Not stated.</p>	<p>Most patients had at least one complication but patients with non-traumatic spinal cord injury have fewer complications than patients with traumatic spinal cord injury. A multivariate model for length of stay was able to predict 52% of variances.</p> <p>Non-traumatic spinal cord injury patients have a difference demographic profile to traumatic spinal cord injury..</p>	<p><i>n</i> = 134</p> <p>MSCC = 27</p>

<p>Cowap <i>et al.</i> 2000</p>	<p>Retrospective review of clinical records to assess functional outcome and relevance to planning of subsequent care needs of metastatic spinal cord compression patients admitted to a specialist cancer centre (UK) between 1987 and 1995.</p> <p><i>Outcome measures:</i> Eastern Cooperative Oncology Group Performance Scale (ECOG); Neurological status (own measure).</p>	<p>No significant change in performance status or neurological status over the course of treatment. Median survival from diagnosis 82 days. Survival significantly better for those presenting with good functional status. 68% discharged; 32% died before discharge.</p> <p>Performance status and neurological status have prognostic significance in functional outcome may be helpful in care planning decisions.</p> <p>Care at home is possible for many of this group of patients, but will require considerable input from community services and family carers.</p>	<p><i>n</i> = 166</p>
<p>McKinley <i>et al.</i> 1996</p>	<p>(i) Review of clinical records to examine functional outcome and descriptive data of metastatic spinal cord compression patients admitted to a spinal injury unit (USA) over a five year period, with (ii) post-discharge follow-up telephone survey.</p> <p><i>Outcome measures:</i> Functional Independence Measure (FIM); Length of stay; Discharge rate and placement; Telephone interview.</p> <p><i>Admission criteria:</i> Able to tolerate 3 hours / day of intensive rehabilitation, and prognosis > 3 months.</p>	<p>FIM improvements in all areas. Average length of stay 27 days. 84% patients discharged home.</p> <p>75% of 20 responders to 3-month follow-up had improved or maintained discharge abilities.</p> <p>Patients with MSCC can make significant functional gains through rehabilitation. These gains can be maintained for at least three months post-discharge.</p>	<p>(i) <i>n</i> = 32 (ii) <i>n</i> = 20</p>
<p>Hacking <i>et al.</i> 1993</p>	<p>Retrospective review of clinical records to develop a predictor of survival and functional outcome of metastatic spinal cord compression patients admitted to spinal injury rehabilitation units (Netherlands) between 1985 and 1990.</p> <p><i>Outcome measures:</i> Length of stay; Survival</p> <p><i>Admission criteria:</i> Not stated.</p>	<p>Average stay 111 days. Average survival after discharge 423 days.</p> <p>Six factors significant for predicting probability of living for longer than one year after discharge: tumour biology, SCC as presenting symptom, slow progression of neurological symptoms, surgery and radiotherapy, partial bowel control on admission, partial</p>	<p><i>n</i> = 74</p>

		<p>independence on admission.</p> <p>The sum score can be helpful when selecting patients for intensive inpatient rehabilitation programmes.</p>	
Hicks <i>et al.</i> 1993	<p>Retrospective review of clinical records to describe motor function, medical complications, recurrent compression and survival, for metastatic spinal cord compression patients admitted to two hospices (UK) between 1990 and 1992.</p> <p><i>Outcome measures:</i> Motor function (own measure); Karnofsky Performance Scale.</p>	<p>Response to treatment was dependent on performance status. Overall median survival from presentation was 5 weeks.</p> <p>Karnofsky Performance score before onset of MSCC is a useful predictor of response to treatment.</p> <p>Patients who are not ambulatory at diagnosis have poor prognoses and experience multiple problems. Hospice care is recommended for this group.</p>	<i>n</i> = 34
Murray 1985	<p>Retrospective review of clinical records determine survival following rehabilitation for malignant (primary and secondary) spinal cord compression patients admitted to a spinal injury rehabilitation unit (USA) over a twelve year period.</p> <p><i>Outcome measures:</i> Frankl Scores; Occupational Therapy and Physiotherapy Assessments (non-standardised); Telephone interview</p> <p><i>Admission criteria:</i> Screened for rehabilitation potential by a physiatrist.</p>	<p>One year survival rate was 58%. MSCC does not invariably imply a poor prognosis.</p> <p>Patients with more severe neurologic injury have worse outcomes.</p> <p>Aggressive rehabilitation efforts are warranted in the group of patients with primary CNS tumours or radiation myelitis.</p>	<i>n</i> = 27
Audit			
Playford <i>et al.</i> 2002	<p>Evaluation of an integrated care pathway for rehabilitation of non-traumatic spinal injury (including metastatic spinal cord compression) patients admitted to a specialist neuro-rehabilitation unit (UK) between 1997 and 1999.</p> <p><i>Outcome measures:</i> Numbers and categories of goals set; Rates of goal achievement; Variance patterns; Functional Independence</p>	<p>Patients set an average of three new goals a week. 90% of goals were achieved. Patients with acute-onset disability have a higher rate of non-achievement of goals.</p> <p>The number of variances fell over the 3 year period. The ICP enables monitoring of the rehabilitation process.</p>	<p><i>n</i> = 85</p> <p>MSCC = 20</p>

	Measure (FIM).		
Pease <i>et al.</i> 2004	Report on the development and audit of a rehabilitation care pathway for metastatic spinal cord compression patients admitted to a cancer treatment centre (UK) between 1997 and 2000. <i>Outcome measures:</i> Demographic and clinical data; Tomita Scale.	Implementation of the care pathway enabled earlier mobilisation leading to fewer complications. Significant increase in survival rates at 60 weeks. Use of the pathway is recommended.	<i>n</i> = 148
Review articles			
Eva and Lord 2003	Review article of rehabilitation for metastatic spinal cord compression patients.		
Lin 2002	Review of rehabilitation management of cancer patients with bony pathology, including metastatic spinal cord compression.		
Kirshblum <i>et al.</i> 2001	Review article of rehabilitation in central nervous system tumours, including metastatic spinal cord compression.		
Bucholtz 1999	Review article of the management of metastatic spinal cord compression, noting need for rehabilitation.		
Kirshblum 1999	Review article of rehabilitation in metastatic spinal cord compression.		
Hillier and Wee 1997	Review article of the palliative management of metastatic spinal cord compression, with recommendations for appropriate rehabilitation.		
Opinion			
Baines 2002	Personal opinion on the importance of rehabilitation for patients with metastatic spinal cord compression.		
Michael 2001	Illustrative case study promoting rehabilitation interventions for patients with metastatic spinal cord compression (USA).		

In this table, I have categorised papers according to the strength of the evidence, from quasi-experimental studies through to reviews and opinion. It is noticeable that there is very little experimental evidence, with the majority of papers being retrospective reviews of clinical records and opinion pieces.

On the face of it, it would appear from this literature that the similarities between traumatic spinal injury and metastatic spinal cord compression are widely recognised, and that structured rehabilitation programmes are both offered and, to some degree, evaluated. A number of studies report on the potential for patients with metastatic spinal cord compression to benefit from participation in rehabilitation programmes in specialist in-patient units: the five papers by McKinley and colleagues, and those by Tang *et al.* (2007); Catz *et al.* (2004); Eriks *et al.* (2004); Guo *et al.* (2003); Hacking *et al.* (1993) and Murray (1985). In all of these studies, intensive rehabilitation is found to have substantial benefits in terms of functional gains made, and several papers comment on the very favourable discharge to home rates achieved by patients with metastatic spinal cord compression. The authors of these studies recommend that since institutional rehabilitation programmes are effective in these respects, patients with metastatic spinal cord compression should be provided with this type of rehabilitation.

However, these papers are not without flaws: sample sizes are small, with metastatic spinal cord compression often being evaluated as a subset of non-traumatic spinal injury. As with any study relying on retrospective data, those listed here are subject to inaccuracies in records. Only two of the studies provide follow-up data (McKinley *et al.* 1996 and Murray 1985): for the most part, we do not know whether functional gains were sustained. The majority of these studies were carried out in North America, mainland Europe and Israel, where specialist rehabilitation is more accessible than it is in the UK. For example, in the Netherlands (population 16.5 million), there are nine specialist spinal injury units. In the UK, there are twelve such units for a population of 60.2 million. Rehabilitation interventions are not specified and, given the substantial international

variations in service delivery (as noted by Eriks *et al.* 2004), results are not generalisable between countries. Also, there is no indication of patients' evaluation of the rehabilitation, a point which I shall pick up on later.

The problems to which I have just referred are eclipsed by a far more significant complication. The specialist rehabilitation centres reported on (with the possible exception of the cancer rehabilitation centre described in Guo *et al.* 2003) have admission criteria which would exclude the majority of patients with metastatic spinal cord compression: patients were required to tolerate an intensive programme of rehabilitation (three or more hours a day), to have a life expectancy exceeding three months (in one case, one year), and to have clear potential for discharge to home. Given a reported median survival of approximately 82 days from diagnosis (Cowap *et al.* 2000), and a one year survival rate of less than 20% (Sørensen *et al.* 1990), the studies listed above, which consider patients' suitability for admission to specialist units, inevitably exclude the majority of patients with metastatic spinal cord compression.

This problem is, to some extent, addressed by two of the UK studies: Cowap *et al.* 2000 and Hicks *et al.* 1993, both of which report on the consequences of disability for this patient group from a cancer treatment centre / hospice perspective. In contrast to the studies mentioned previously (which advocate intensive specialist rehabilitation in order to maximize independence and self-sufficiency), they suggest that patients with metastatic spinal cord compression are highly disabled and dependent, requiring a great deal of care:

Unfortunately, a large number [of patients] are left with significant neurological and functional handicap. [...] Care of these patients in the community will usually involve considerable input from community services, as well as that which the patient's family or carers can provide. This will usually entail frequent visits by social services carers for practical help such as getting patients in and out of bed (which may involve hoisting), bathing and feeding, as well as input from a district nursing service to provide a range of nursing care, such as care of pressure areas, urinary catheters, wound dressings, bowel and symptom control (Cowap et al. 2000: 263).

On one level, this is at odds with the more optimistic outlook presented by the rehabilitation specialists; but, taking account of the rehabilitation admission criteria (relatively good prognosis, good exercise tolerance and discharge potential), we can see this as an acknowledgement of the need for different interventions depending on the needs of the patient. The rehabilitation specialists (McKinley and colleagues 2001, 2000, 1999a, 1999b, 1996; Tang *et al.* 2007; Catz *et al.* 2004; Eriks *et al.* 2004; Guo *et al.* 2003; Hacking *et al.* 1993; and Murray 1985) are reporting on those patients with a better than average prognosis, while the UK's cancer/palliative care perspective incorporates patients whose level of disability and prognosis require hospice services. We could say that there are appropriately different approaches for selected groups of patients with varying needs: patients with a short prognosis are best cared for by hospices; those with a longer life expectancy should be referred for further specialist rehabilitation.

However, to leave the matter there would be to fail to take account of a more subtle but arguably more significant difference: that of the implied philosophy of rehabilitation in the two groups. As I shall illustrate in the next section, on the one hand professional provision of care is recommended; on the other patients are enabled to assert their

independence and given clear and practical ways to achieve this. The contrast that emerges strongly is the view that is taken of the patient's role in rehabilitation. Whatever we say about the precise nature of the population for whom rehabilitation is intended, this is a highly significant issue, and one which is fundamental to the whole rehabilitation project. It determines how rehabilitation is targeted and, correspondingly, how priorities are set.

1.3.2 Representations of rehabilitation

This contrast in approaches towards disability and rehabilitation is very neatly illustrated by two of the review papers I have referred to in Table 1.1: Kirshblum *et al.* (2001) and Hillier and Wee (1997), and I will use them to draw out these differences further. Both Kirshblum *et al.* (who are American) and Hillier and Wee (who are British) promote rehabilitation. Hillier and Wee propose that rehabilitation is 'the major issue' in the management of metastatic spinal cord compression. Kirshblum *et al.* agree, and point to the evidence for the benefits of inpatient rehabilitation for people with spinal cord compression, citing the studies by McKinley and colleagues. As can be seen from Table 1.2 below, however, there are some significant differences in the way that rehabilitation is conceptualised in the two papers, with Hillier and Wee's palliative approach emphasising the provision of care to highly dependent patients, while Kirshblum *et al.* focus on the importance of patients' independence and autonomy.

Table 1.2: Representations of rehabilitation in metastatic spinal cord compression

	Hillier and Wee 1997	Kirshblum <i>et al.</i> 2001
Setting	Hospital / hospice, aiming to discharge home as soon as possible.	Specialist in-patient rehabilitation unit.
Team	Specialist palliative care physicians Specialist palliative care nurses Physiotherapist (trained in palliative care) Social worker GP and community services	Patient Physician (rehabilitation specialist) Rehabilitation nursing specialists Physiotherapist Occupational therapist Psychologist Dietician Social services Recreation therapist
Activities of daily living	Need to offer realistic care packages to enable patients to return home quickly. Patients may require total care. It is difficult to provide this without sacrificing patient autonomy and control.	Need to establish level of independence on admission, and build on this. Emphasis on teaching compensatory techniques, providing appropriate equipment. Where an individual cannot perform tasks independently, they can learn to instruct others to assist.
Bladder and bowel management	Relative constipation managed with regular manual evacuations – requiring adequate analgesia and sedation. Urinary incontinence will require an in-dwelling catheter. Intermittent self-catheterisation is not an option.	Patients should be taught a bowel programme to allow them to have control over the time and place of bowel movements. Intermittent self-catheterisation should be taught to ensure effective bladder emptying.

There are clearly some noteworthy differences here, and they are more than just procedural (the setting in which rehabilitation takes place) or technical (the potential for self-catheterisation). Kirshblum *et al.* include the patient as a member of the rehabilitation

team, and strongly emphasise the rehabilitation team's 'enabling' role, in contrast to Hillier and Wee's 'provision of care.'

1.3.3 Questions arising out of these representations

In accepting the notion that the differences are simply reflections of patients' needs at different stages of illness, one is making the assumption that, at the end of life, patients need to be provided with care rather than to be encouraged to participate as fully as possible in daily life. This is a matter I would like to examine further, because it is crucial. I will examine it in the context of two other important issues, since it is one of three closely connected groups of questions, and they need to be considered in the relation to each other.

- Firstly, questions concerning the operationalisation of rehabilitation in palliative care generally, which will include its objectives, proposed interventions, settings, and so on.
- Second, the question of the patient's role, and in what sense the patient can be a participant or partner in the rehabilitation process.
- Third, the theoretical questions surrounding the relationship between a life-threatening illness and disability. Patients with metastatic spinal cord compression are unusual in having both: most people with a poor prognosis do not have an attendant substantial disability, and most people with a disability do not have a poor prognosis. Consequently, much of the literature on these two conditions fails to address the particular problems of this group of patients.

These sets of questions are all interdependent and, in Chapter 2, I shall address each of them in turn. As we shall see, the literature offers only very limited guidance on all three of them.

Chapter 2

Palliative care rehabilitation

2.1 Introduction

My examination of rehabilitation in metastatic spinal cord compression has raised three related questions. To address these, I now turn to the wider literature on rehabilitation in palliative care, and consider each of the three issues in turn: the operationalisation of rehabilitation; the patient's role in the process; and the relationship between life-threatening illness and disability. In the course of the discussion, I identify a number of empirical gaps in our understanding of the contribution of rehabilitation for patients at the end of life, and of the potential for its successful implementation. This will build towards the research agenda for the present study.

2.2 Operationalising rehabilitation in palliative care

Rehabilitation is generally described in terms of its objectives: it enables disabled people to regain function, to live independently and make decisions for themselves (Barnes and Ward 2005), and it facilitates the adaptation to disability seen to be fundamental to psychosocial well-being (Olney *et al.* 2004; Livneh 2001). A clear and comprehensive definition is provided by Wade and de Jong (2000), who describe it as a multi-disciplinary process which includes:

- Assessment to identify the nature and extent of functional difficulties, and the factors which will contribute to their resolution.
- Working with the patient to set goals.
- Identifying and implementing strategies to achieve these goals.
- Constantly monitoring progress and adapting plans to incorporate changes.

It aims to:

- Maximise social participation (role function and social status).
- Maximise well-being (physical and emotional).
- Achieve satisfaction (adaptation to disability).
- Minimise carer stress and distress.

It is a co-ordinated, team effort aimed at enabling people to be as independent as possible, and to participate to as full an extent as possible in all aspects of their daily lives. Crucially, this is as much about a patient's psychological resources as it is about their physical capacity.

Definitions of rehabilitation in palliative care are broadly similar, but are qualified by the recognition of limited life expectancy, for example:

'Cancer rehabilitation attempts to maximise patients' ability to function, to promote their independence and to help them to adapt to their condition. It offers a major route to improving their quality of life, no matter how long or how short the timescale' (NICE 2004: 134).

There is no shortage of desirable outcomes identified in the literature. Rehabilitation professionals in palliative care are engaged in a number of projects: enabling people to gain a sense of normality in their lives through their participation in daily activities; helping people to make functional progress; helping people to adapt to their illness and come to terms with deterioration and death; reducing physical, psychological and spiritual distress; giving people a sense of hope and meaning; and enabling people to construct a new self (Cheville 2001; DeLisa 2001; Hopkins and Tookman 2000; NCHSPCS 2000; Bye 1998; Hockley 1993). These are ambitious goals, and, if they are to be achieved,

then explicit mechanisms for accomplishing them are needed. Without workable methods for delivering rehabilitation, its aims will remain unrealised ideals.

Very often, however, the mechanisms which are offered in this literature are inadequate, for reasons that will become clear as we proceed. Rather than an overall strategy, what is frequently offered is a series of categories into which the different components of rehabilitation may fall. A notable exception is the National Council for Hospice and Specialist Palliative Care Services' (NCHSPCS) document on rehabilitation, *Fulfilling Lives*, which offers a fairly detailed strategy; but even this does not take into account the place of specialist rehabilitation services; nor does it include the patient as a member of the rehabilitation team (NCHSPCS 2000).

The components mentioned above generally fall under one of four headings: the settings in which rehabilitation might take place, the professionals involved in providing rehabilitation, the procedural arrangements for ensuring delivery, and the interventions that could be provided.

2.2.1 Settings

A number of suggestions are made regarding the settings for rehabilitation for patients requiring palliative care. We have already noted the proposals for rehabilitation in specialist rehabilitation centres by Kirshblum *et al.* (2001) and in specialist palliative care facilities by Hillier and Wee (1997). Hopkins and Tookman (2000), respectively a nurse and a doctor in a hospice day centre, propose that specialist palliative day care provides the ideal setting for rehabilitation. They compare day care with the shortcomings of other environments such as acute hospitals, where 'traditional departmental structures and

boundaries can make a co-ordinated and integrated approach difficult to achieve' (Hopkins and Tookman 2000: 124), and primary care, where staff lack specialist skills in palliative care. One cannot help but notice the way in which recommended settings correspond to the authors' places of work. These somewhat partisan proposals fail to take account of the fact that the settings in which patients find themselves are often dictated by the progression of their disease rather than being the result of positive choices about their ideal environment.

The NCHSPCS document (2000) comes closer to the mark, pointing out that patients move through a variety of services during the course of their illness, and that rehabilitation needs might arise at any time. It proposes that patients should be able to access rehabilitation in any setting, including acute or community hospitals, nursing and residential homes, hospices, and in their homes. This recommendation is endorsed in the National Institute for Clinical Excellence (NICE) Guidance on Cancer Services: 'all patients who need rehabilitation services access them when and where they need them [...] without undue delay' (NICE 2004: 136). What we lack, however, are explicit mechanisms for the way in which these services should be implemented and delivered across this range of services and settings.

2.2.2 Professionals

Various permutations of rehabilitation professionals are suggested in different papers. Perhaps the one that should be regarded as definitive is that specified in the NICE Guidance, since this is the document that is influential when it comes to commissioning and funding services in England and Wales. It proposes the following: appliance officers, dieticians, lymphoedema therapists, occupational therapists, oral health specialists such

as dental hygienists, physiotherapists, psychosexual counsellors, speech and language therapists, stoma therapists and therapy radiographers. Individual Cancer Networks are tasked with drawing on the expertise of these professionals to provide a rehabilitation service which is appropriate to the needs of the local population, including timely referral to rehabilitation specialists where required. It is not clear whether the specialists referred to here are rehabilitation specialists in palliative care, or whether this is a recognition of the need for collaborative working with non-palliative care rehabilitation specialists, such as those working in traumatic spinal injury units, or neuro-rehabilitation units.

It is interesting to note that no attempt is made by the NICE Guidance to describe this group of professionals as a 'team'. They are referred to as individuals who might, at various stages of a patient's illness, be required to provide a service. This contrasts markedly with the approach advocated by Kirshblum *et al.* (2001), and others such as Guo *et al.* (2003), Playford *et al.* (2002) and McKinley *et al.* (2001). As previously noted, these authors are writing from the position of specialist rehabilitation providers, and the process that is recommended for the effective provision of rehabilitation is dependent on a group of rehabilitation professionals who meet regularly and work together as a team. A rehabilitation team should work towards common goals for the patient, should have relevant knowledge and skills, should involve and educate the patient and family, and should be able to resolve most of the common problems faced by their patients (Wade and de Jong 2000). Various palliative care authors also emphasise the importance of team work (NCHSPCS 2000; Hockley 1993; Santiago-Palma and Payne 2001), but fail to operationalise this in any meaningful way. Hopkins and Tookman (2000) suggest a fairly

detailed model for team-working in palliative care rehabilitation, but have a tendency to see 'multi-professional' as a synonym for 'nurse-led'.

2.2.3 Procedures

There is agreement that the process of rehabilitation should include a period of assessment and goal-setting, the formulation of 'care plans' and 'care packages', and referral on to other services where necessary (Hopkins and Tookman 2000; NCHSPCS 2000; David 1995; Fulton 1994; Hockley 1993). Service evaluation is encouraged, but specific tools and methods for achieving this are not offered (NCHSPCS 2000). Broadly, the processes suggested in the palliative care literature mirror those of mainstream rehabilitation, but there is an interesting difference in expression. This is illustrated in the Kirshblum *et al.* (2001) / Hillier and Wee (1997) comparison in Table 1.2. Palliative care professionals conceptualise rehabilitation as the provision of *help* and *care* (Hopkins and Tookman 2000; Hockley 1993), which contrasts with the mainstream rehabilitation's emphasis on *maximising participation* (Cardol *et al.* 2002a; World Health Organisation 2001; Wade and de Jong 2000). This difference reflects the disparate ways in which the patient's role in rehabilitation is conceived, a subject to which I have already referred, and to which I will return in the following section on 'Partnership and participation' (section 2.3).

There is a greater degree of crossover between mainstream rehabilitation and cancer and palliative care rehabilitation in countries such as the USA and the Netherlands (as evidenced by the papers listed in Table 1.1, and reviews such as Mosvas *et al.* 2003) than is the case in the UK, where sources of reference in palliative care rehabilitation originate largely in the palliative care literature (exceptions would be Garrard *et al.* 2004 and Playford 2002). In the UK literature, where rehabilitation journals and texts are cited (as,

for example, in NCHSPCS 2000), they are used to draw attention to the evidence for the effectiveness of rehabilitation in other conditions like stroke and multiple sclerosis, rather than to highlight or learn from problematic issues such as the goal setting process and evaluation. Consequently, in the UK, discussions of rehabilitation in palliative care tend to be somewhat parochial, oblivious to the critical debates in the mainstream rehabilitation literature (Cardol *et al.* 2002a; Pfeiffer 2001; Kendall *et al.* 2000; Nocon and Baldwin 1998). A specific example of this is the paper referred to earlier (in section 1.2.4) by Levack and colleagues (2004), who report their surprise at spinal cord compression patients rating their quality of life as high 'despite' an inability to walk independently. That people with disabilities value relationships and social participation over physical independence is not a new idea in rehabilitation and disability studies (see, for example, Albrecht and Devlieger 1999).

2.2.4 Interventions

There is no shortage of suggested interventions, but frustratingly little attempt is made to describe these in any meaningful detail. Hopkins and Tookman (2000) note that a mixture of clinical, social and environmental interventions should be offered, but do not elaborate on what these might look like. In a widely cited source, Dietz (1981) proposes that rehabilitation for cancer patients comprises four categories or phases: preventative, to lessen anticipated disability; restorative, to return a patient to gainful occupation; supportive, to manage slowly progressive handicap; and palliative, to ameliorate complications associated with 'relentless progression of disease', such as bedsores, contractures and 'emotional deterioration secondary to inactivity' (1981: 24). While these four categories arguably provide a useful heuristic, Deitz's model is limited in at least two

ways. Firstly, it begs the question that the rightful task of rehabilitation is to restore a person to 'normal' function; and secondly, the notion that the palliative phase comprises care of the bed-ridden is dated. Indeed, Dietz devotes a chapter of his book to the rehabilitation of a person following hemicolectomy, a surgical procedure that would rarely (if ever) be considered now in the treatment of cancer. Doubtless in 1981, when Dietz's book was published, cancer rehabilitation was a novel and progressive concept, but the intervening 25 years have seen such rapid progress in cancer and palliative care that much of Dietz's approach is obsolete.

In a more up-to-date document, the College of Occupational Therapists (2004: 9) provides guidance on occupational therapy interventions in cancer and palliative care. Here is an example, under the heading 'Lifestyle Management':

The occupational therapist can:

- *Work with people with cancer and family/carers to achieve balance in life*
- *Help them assess what priorities are most important to them – including social and spiritual priorities*
- *Help them find occupation which is meaningful to them*
- *Take into account the influences of culture*
- *Provide a crucial link between care in hospital and living at home.*

This is unexceptionable, but, again, tells us nothing about the mechanisms by which these interventions might be delivered. Palliative care rehabilitation is not alone in its difficulty in clearly specifying interventions (Wade 2005) but, unlike mainstream rehabilitation, is not even beginning to recognise this as a problem. The example I have given here is fairly

typical of the literature on rehabilitation in palliative care, which is much more concerned with promoting rehabilitation than interrogating the concept or evaluating its effectiveness; as such, the tone of much of it comes close to evangelical.

A brief synopsis of interventions mentioned in a selection of representative papers is provided in Table 2.1 (Cooper 2006; Kealey and McIntyre 2005; College of Occupational Therapists 2004; Doyle *et al.* 2004; Findlay *et al.* 2004; Jolliffe and Bury 2002; NCHSPCS 2000; Robinson 2000). These interventions are recommended to take place against a background of good pain and symptom management, attention to nutritional status, skin and pressure care, and appropriate management of any incontinence.

Table 2.1: Rehabilitation interventions in palliative care

Interventions aimed at improving or maintaining physical function	Exercise, mobility training, bracing and splinting, transfer training (moving between two seated positions – bed to chair, for example), lymphoedema management, non-pharmacological pain management (such as transcutaneous electrical nerve stimulation).
Interventions aimed at improving or maintaining independence in daily activities	Self-care skills training, instruction in compensatory techniques, full review of equipment needs, management of breathlessness and fatigue.
Interventions aimed at enhancing social participation	Support of family and carers, home adaptations to enable patients to remain in their own environment, facilitating creative and leisure activities.
Interventions aimed at improving or maintaining cognitive function	Compensatory strategies for cognitive problems such as poor concentration, memory loss and perceptual difficulties.
Interventions supporting patients' psychological and emotional well-being	Counselling and supportive therapy, relaxation therapy.

2.2.5 Summary

What we appear to have is a collection of components rather lacking in specificity and cohesion. High ideals are expressed for the intended outcomes of rehabilitation, but without sufficient indication of the mechanisms by which these can be achieved. Issues in mainstream rehabilitation are neglected in the palliative care rehabilitation literature. Rehabilitation in palliative care is a relatively new phenomenon. Those who write about it, particularly in the UK, do so from within the hospice establishment, and there is an apparent lack of awareness of the questions that researchers and clinicians in mainstream rehabilitation have been grappling with over a number of decades, such as team working, goal-setting processes and evaluation.

2.3 Partnership and participation

Issues of 'partnership', 'participation' and 'patient-centred care' are at the forefront of the Government's current agenda for National Health Service (NHS) reforms (Department of Health 2004*a*; Department of Health 2004*b*; Department of Health 2003; Department of Health 2001; Department of Health 2000*a*; Department of Health 2000*b*), and have had a consequent influence on palliative care service providers in the UK (Kite and Tate 2005). These terms are used to describe a variety of activities or objectives, from patient participation in strategic decisions about health services (often referred to as 'user involvement'), to the participation of individual patients in making decisions about their own care (Florin and Dixon 2004). It is this second sense of 'participation' that I will be discussing here, with specific reference to patients' involvement in the rehabilitation process.

2.3.1 The imagery of 'helping'

Partnerships between patients and professionals have been promoted in palliative care since its inception (Saunders 1990), and the recognition of their importance predates the current political agenda. The basis of palliative care is said to be a partnership between the caring team and the patient and family. It has been suggested that interactions between patients and health care professionals should be seen as a meeting of experts, with patients as experts in the subjective impact of their illness, and health professionals as experts in diagnosis and management (Twycross 2003). Partnerships are seen as the key to palliative care rehabilitation, which 'centres around the wishes and aspirations of the patient' (NCHSPCS 2000: 3), facilitates patients and their families to 'play an active role in establishing goals' (Santiago-Palma and Payne 2001: 1051), and 'gives patients [...] control, independence [and] choice' (Hockley 1993: 11).

Inevitably, however, given the power differential between health professionals and patients, it is impossible to sustain the language of equal participation, and the notion of partnership is frequently overtaken by a more traditional vocabulary, with the implication that the professional has the more dominant role. David (1995: 60), for example, begins a report on patients' views of rehabilitation by being critical of the notion that rehabilitation is seen as something done *to or for*, rather than *with* the patient, but ends by proposing that 'rehabilitation is all about helping people to maximise their potential. We [staff] give them [patients] the options and facilitate them to make the choice'. The notion of offering help and assistance crops up regularly. There is an emphasis on professionals *helping* patients; for example, rehabilitation involves 'helping a person with cancer to obtain maximum [...] function' (DeLisa 2001: 970), 'helping [...] patients to live with their

disability' (Dietz 1981: 15), and 'helping patients to [...] adapt to the losses they are experiencing' (Bye 1998: 12). The NCHSPCS (2000: 3) offers the following description:

Palliative care rehabilitation

- *helps patients gain opportunity, control, independence and dignity;*
- *responds quickly to help people adapt to their illness;*
- *takes a realistic approach to defined goals;*
- *is continually evolving, taking its pace from the individual.*

It is evident that rehabilitation *helps* patients to gain opportunity ... responds quickly to *help* people adapt ... takes a *realistic* approach to *defined* goals. Professionals are being helpful, and realistic, and taking the initiative. Although the patients are able to set the pace, it is the professionals who are instrumental in defining the goals. The subtext is very much that of active professional, compliant patient.

It is true, of course, that the idea of partnership does not have to exclude the notion of providing help. But the way in which 'help' is referred to in these extracts does not, self-evidently, point towards a strong interpretation of patient involvement, and it is important to be clear about the nature of the partnership that is being proposed. There are two issues that need to be resolved. Firstly, the language used here by professionals to describe palliative care rehabilitation suggests a relationship which is professionally driven. Does this way of talking represent a more realistic appraisal of the potential extent of partnership in palliative care, or is it an unconscious retreat into older habits of thought? Secondly, these accounts imply that patients are deficient in some way – needing to improve or regain function, hope, quality of life – and are in need of the skills of professionals to achieve these things. In view of recent debates about the nature of

disability that question precisely this assumption, we are obliged to ask whether this is a defensible position. In what follows, I will consider each of these issues in turn.

2.3.2 The nature of the partnership in palliative care rehabilitation

As I have already observed, the relationship between patients and professionals in palliative care is suggested, ideally, as a meeting of experts. With an overall objective of achieving the total good of the patient (Randall and Downie 1999), palliative care strives to combine the medical good, derived from perceived physical needs and professional knowledge, with the patient's values, preferences and aspirations. However, while patients might be expert in what constitutes their total good, they will also be presenting to professionals with a range of problems with which they want assistance, not the least of which will be a relentlessly deteriorating illness. The patient, in this situation, is dependent on the professional, and is thus vulnerable. Furthermore, his or her autonomy is compromised by being cared for in a health system where service objectives are set and evaluated by professionals, and driven by economic and policy considerations. Whatever the rhetoric, patients will, in fact, have very limited power to shape or influence the care that is provided.

In general terms, then, we can demonstrate an unequal distribution of power in patient-professional relationships in palliative care. This is not to imply that partnerships are impossible or undesirable, merely to suggest that these ideas should not be applied uncritically. There is a distinct lack of empirical evidence which might help us to understand the realistic extent of patient participation in palliative care. Commonly accepted wisdom is that professionals must act in the best interests of their patients, and must do so in a manner that is neither dictatorial nor paternalistic. In order to achieve this,

it is self-evident that professionals will need to work together with patients to determine the patient's goals and priorities.

Turning specifically now to rehabilitation in palliative care, we can add an additional problem to the already vexed issue of partnership. Patients do not access rehabilitation services themselves, being unaware of both their availability and their effectiveness (Thomson *et al.* 2006; Eva 2001; Söderback *et al.* 2000; Söderback and Paulsson 1997). Patients are referred by other professionals, and referral generally coincides with an exacerbation of illness causing increasing disability. Rehabilitation is likely to be only one of a range of services being offered at this time, and other concerns may be more pressing, such as decisions about further anti-cancer treatment, or the need to communicate altered prognosis to the family (Cheville 2001). Patients may not have the emotional and physical energy to contribute to a process requiring them to participate actively in identifying priorities and setting goals.

2.3.3 Disability as synonymous with deficiency

The image of disability portrayed in the palliative care literature is that of deficiency. Patients are described as highly dependent (Cowap *et al.* 2000). They experience motor and sensory deficits, and the fear of losing their independence engenders feelings of hopelessness and distress (Cheville 2001; Robinson 2000). They require the interventions of professionals to develop coping strategies, and to readapt to society (DeLisa 2001; Hockley 1993). This notion of disability as synonymous with deficiency (often termed the 'Medical' or 'Bio-medical Model') is one which is unanimously rejected by disability theorists. They argue instead that disability 'is not simply an attribute of a person, but a complex collection of conditions, activities and relationships, many of which are created

by the social environment' (Bickenbach *et al.* 1999: 1173). In opposition to the 'Bio-medical Model', then, the 'Social Model of disability' (Oliver 1990a; Oliver 1990b) has become an umbrella term for a range of theories, models and ideas identifying social attitudes, economic circumstances and the built environment as the basis for understanding disability.

In the same way that there is very little overlap between the fields of mainstream rehabilitation and palliative care rehabilitation, there is virtually no communication between palliative care rehabilitation and disability studies. An exception here would be the recent edition of the *Journal of Palliative Care* (2006, Volume 22 No. 3) which discusses the need for palliative care to take note of the Social Model of disability, but the topic is considered from the point of view of a person with a chronic disability being in the position of requiring palliative care, rather than from the perspective of disability arising out of a terminal illness.

The lack of interaction between the rehabilitation / disability literature and palliative care is unfortunate, given the significance of disability for palliative care patients in general and spinal cord compression patients in particular. I would like to explore these ideas further at this point, in order to examine the extent to which the disability literature's conceptualisation of the nature of 'the disability problem' might make a contribution to an understanding of the project of rehabilitation in palliative care, and to the way in which we understand patient participation and partnerships in palliative care rehabilitation.

2.4 The relationship between a life-threatening illness and disability

2.4.1 Definitions of disability

Throughout the discussion so far, I have been using the word disability in the way in which it is commonly and colloquially understood, i.e. as incapacity, or an inability to perform a certain function. However, in order to further the discussion of the relevance of the social model of disability to palliative care rehabilitation, it is necessary to be more precise in defining disability and certain related terms.

In 1980, the World Health Organisation's (WHO) International Classification of Impairments, Disabilities and Handicaps (ICIDH) distinguished impairments from disabilities, defining impairment as any loss or abnormality of psychological, physical or anatomical structure or function, and disability as any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner, or within the range, considered normal for a human being. These definitions were not favourably received by disability scholars and activists, who regarded them as medically focussed, and as portraying disabled people as inadequate and abnormal (Miles 2001). While being happy with the idea of impairments as biological dysfunction, they recast disability as a social inadequacy, rather than a personal one. Disability, in these terms, is seen as the limitation of opportunities – caused by physical and social barriers – preventing people with impairments from taking part in the normal life of the community on an equal level with others (Finkelstein and French 1993). The WHO responded to this critical response by reframing 'impairment, disability and handicap' as 'body functions and structure, activity, and participation' in the updated version of the ICIDH, the ICF – the

International Classification of Functioning, Disability and Health (World Health Organisation 2001).

2.4.2 The Social Model of disability

Finkelstein and French's (1993) conception of disability describes the basis of a Social Model, which argues that a 'medical' ideology of disability, emphasising weakness and dependence, and casting disability as a tragedy for an individual, is implicated in sustaining the social oppression of disabled people (Oliver 1990*b*; Finkelstein 1980). We are said to live in a disability-denying society (Marks 1997), where people who are disabled or chronically ill cause unease. Being neither 'sick' nor 'well', they do not conform to the norms of the sick role by withdrawing from social activity and striving to become well; but neither do they contribute to society in a way considered productive. The argument is that, to avoid confronting this discomfort, society excludes and marginalises disabled people (Murphy *et al.* 1988). It chooses to perceive the causes of disability as located within individuals; and as physical and psychological problems that require professional intervention to 'cure' or 'fix'. In opposition to this line of thinking, a social model of disability proposes that disability is not an individual's problem, but that it is a result of social practices and prejudices that regard disabled people as 'inferior, dependent, and, by implication, of little or no value' (Imrie 1997: 263). Thus, social and political solutions should be sought to remove the environmental and attitudinal barriers which are said to prevent the full participation of disabled people in society. Personalising disability leaves individuals to overcome obstacles, rather than requiring society to take action. A simple example is given (Oliver 1998): the problem with public transport is not

that a person is unable to walk, but rather that buses and trains are not easily accessible to a person using a wheelchair.

In Social Model terms, rehabilitation is at best misguided, and at worst oppressive. The notion that a disabled individual should be returned to as near normal functioning as is possible begs a number of questions – in particular, that there is such a thing as ‘normal’. A rehabilitation ‘industry’ is necessary for professionals as a source of income (Finkelstein 1993). It is of no benefit to disabled people, for whom it reinforces abnormality and inadequacy.

On this account, bringing about changes in society will free disabled people to live their lives as they choose. However, this view has not gone unchallenged (Crow 1996). Williams (1999) argues cogently for a need to ‘bring the body back in’. Similarly, Kelly and Field (1996: 247) state that ‘coping with the physical body has to precede coping with relationships’. Susan Wendell, a disabled feminist academic and writer, suggests that, because it fails to recognise the importance of the experience of ‘the negative body’ (1996: 166), the Social Model cannot achieve its objective. In an autobiographical account of the experience of living with chronic fatigue syndrome, Wendell describes the way in which learning to manage a recalcitrant body was vital to her achievement of an acceptable quality of life. She argues that the acknowledgement of an alternative form of embodiment must accompany the Social Model’s attitudinal change and environmental adaptation in any useful response to disability.

The Social Model, then, has been criticised for excluding ‘impairment’ from the discussion. Shakespeare and Watson (2001) note that as a political slogan, ‘people are

disabled by society, not by their bodies' is a more powerful statement than the somewhat mundane 'people are disabled by society and also by their impairments'. However, what constitutes strong political rhetoric does not add up to a credible model of disability in their view. To ignore the fact that impairment is a central part of daily personal experience for disabled people produces a lopsided theory, which, taken to its logical extreme, would not see impairment as something to avoid, having interesting consequences for road safety campaigns and immunisation programmes.

2.4.3 The implications for rehabilitation in palliative care

The purpose of introducing the social model of disability into the discussion of rehabilitation for patients with metastatic spinal cord compression is to draw attention to the very wide range of existing conceptualisations of disability. While I agree with Shakespeare and Watson (2001: 24) that what is needed is an inclusive approach, theorising disability as 'a complex dialectic of biological, psychological, cultural and socio-political factors which cannot be extricated except with imprecision', it is important to recognise that there are a number of unresolved tensions in the literature.

As I suggested earlier, two distinct – though related – issues are of particular significance. First there is a tension between the enthusiasm for partnership, on the one hand, and a more conservative view of the relationship between patient and professional, on the other. Rehabilitation in palliative care has adopted the 'partnership and participation' language, but it is still not clear how far the patient-driven agenda is, or can be, realised in palliative care settings. This tension is not eased by the fact that, as I have already indicated, the literature on rehabilitation in palliative care is largely oblivious of the debates about goal-setting and evaluation in mainstream rehabilitation (and by the fact that the mainstream

literature has not addressed itself to the particular problems of palliative care). Second, there is the tension between the 'deficiency' model of disability, implying the need for personal adjustment, and the social model, implying that it is society which needs to adjust. Again, the literature on rehabilitation in palliative care includes little reference to the wider debates about the nature of disability; and, equally, the work of the disability theorists takes no account of people whose disability is the result of life-threatening illness.

In both cases, discussion is curtailed by the indifference which writers in one field display towards the concepts, problems and potential solutions in another. And in both cases, too, there is virtually nothing about the patient's point of view – nothing, for example, about whether palliative care patients can identify with the partnership ideal, or about whether the idea of 'adjustment' to disability (let alone the Social Model' understanding of it) even begins to make sense to them. I shall develop this further in the next section where I argue for the need for patients' perspectives on the experience of disability.

Even where there are attempts to present an overview of some kind, these gaps remain. Taylor (1999), for example, offers us the following categories for understanding disability and rehabilitation:

Table 2.2: Conceptual framework for disability and rehabilitation

Social Model	Political activism, changing society, addressing attitudes, influencing social policy.
Independent Living Model	Advocacy, peer support, removal of barriers, professionals as support.
Rehabilitation Model	Focus on activities of daily living (for example, dressing independently), provision of aids and adaptations.
Biophysical Model	Focus on symptoms (for example, interventions to increase range of movement, improve pain tolerance, deal with depression).

Up to a point, this sort of framework is helpful, in that it organises some of the options in a logical way. In practice, we can locate rehabilitation in palliative care firmly in the Biophysical and Rehabilitation models, since there is no acknowledgement in the palliative care literature of disability as anything other than a personal tragedy, and no suggestion that anything more than professional care, help and support might be required to enable patients to achieve a good quality of life. However, from the point of view of the present study, the framework poses far more questions than it answers. Can the Social Model and the Independent Living Model really apply to palliative care patients? On the other hand, are the Rehabilitation Model and Biophysical Model really the best we can offer them? And do people who have a life-threatening illness, *and* a disability, *and* all the emotional consequences of both conditions, really have to fall through holes in models designed to fit other people and other problems? These are the questions which form the basis of this research.

2.5 The need for patients' perspectives on the experience of disability

2.5.1 A brief summary so far

In reaching this point, I have endeavoured to show that metastatic spinal cord compression is a significant cause of disability in cancer care. Optimal outcomes in terms of both mortality and morbidity rely on early diagnosis and appropriate medical management, as emphasised by the bulk of the literature on the subject. The overall prognosis for patients with cord compression is poor, with only one in five surviving a year or more. Despite the fact that disability is recognised as a major issue for these patients, there is only a very small amount of literature discussing rehabilitation, and what little there is fails to be consistent in its approach. Comparisons can be made with the management of traumatic spinal cord injury, as the two conditions have common features; but rehabilitation programmes known to be effective with patients with traumatic spinal injuries cannot be applied wholesale to patients with spinal cord compression secondary to cancer because of the fundamental differences in prognosis.

The palliative care literature offers a number of conceptualisations of rehabilitation, in terms of intended outcomes and the components of its delivery, but clear mechanisms for implementing and evaluating rehabilitation are absent. There are suggestions from a professional perspective about the way in which we might understand palliative care patients' rehabilitation needs; for example, Cheville (2001) comments on disability as only one of a number of serious concerns for palliative care patients, and Randall and Downie (1999) offer an analysis of various models of partnership. However, we lack an indication of the patients' perspective.

2.5.2 The lived experience of disability and life-limiting illness

Up to this point, then, my discussion of disability and rehabilitation in palliative care has focussed almost exclusively on literature from a professional or theoretical perspective. While the rehabilitation literature is somewhat thin on reports of patients' experiences of rehabilitation, there is a wealth of sociological and health-care literature on the lived experience of disability, and a growing body of work on patients' experience of living with life-limiting disease.

The bulk of this literature comprises researcher-mediated accounts of illness and disability, typically using in-depth interviews with patients or disabled people, and reporting on aspects of the lived experience of a particular condition. There is a smaller, but no less significant, corpus which offers theoretically-informed first-person analyses of disability, and to which I shall turn first. Among others, Robillard (1999), Wendell (1996), Toombs (1995) and Murphy (1990) draw on their own academic disciplines (including anthropology, sociology and philosophy) to theorise about the body in relation to self and society. For example, Murphy (1990) considers the consequences of the idealised body in American culture on disabled people with particular reference to Goffman (1963, 1959). He argues that, in their contravention of the values signified by the 'ideal' body (youth, virility, activity, beauty), disabled people betray the 'American Dream': 'The disabled serve as constant, visible reminders to the able-bodied that the society that they live in is shot through with iniquity and suffering, and that they live in a counterfeit paradise, that they too are vulnerable. We represent a fearsome possibility' (Murphy 1990: 117).

In a similar manner, Wendell (1996) takes Addelson's (1983) concept of 'cognitive authority' as the starting point for an examination of the ways in which 'scientific Western

medicine' claims authority over a person's body, 'delegitimising' the patient's own experience of their body. 'For example,' Wendell claims, 'our own phenomenological descriptions are at best treated as weak evidence for the truth of medical or scientific descriptions. They are almost never treated as even weak evidence *against* a medical or scientific description of our bodies' (Wendell 1996: 119, emphasis in original). Seen in these terms, it is the doctor, rather than the disabled person, who directs an individual's perception of his or her body, as well as society's cultural norms with regard to health and disability. As long as scientific medicine strives for health as an ideal, illness and disability must necessarily be regarded as inadequacy and failure. In Wendell's view, this serves to undermine the patient's confidence in the lived experience of his or her own body, and of the lived experience of his or her disability.

In representing the lived experience of disabled people through research, medical sociology has distanced itself from medicine's tendency to 'disregard the patient as anything but the possessor of the body or illness' (Wallach Bologh 1982: 190). Using predominantly qualitative methods to achieve rich and textured descriptions, these accounts emphasise the importance of context and individual biography in understanding the complex and nuanced ways in which illness is experienced. Many illnesses and conditions have been studied, for example paraplegia (Yoshida 1993), rheumatoid arthritis (Rosenfield and Faircloth 2004, Williams 1984, Bury 1982), stroke (Pound *et al.* 1998), HIV (Carricaburu and Pierret 1995) and multiple sclerosis (Driedger *et al.* 2004). Comparative studies across different groups have also been carried out, for example Ville *et al.* (1994), who compared the experiences of three groups of people (those with

paraplegia, those with poliomyelitis, and a third group with no impairment) to show the way in which prevailing cultural norms influence identity in particular groups.

As Lawton (2003) notes, this body of work is distinctive for its use of the narrative accounts of mentally able, verbal and articulate adults. Where cognitively or verbally impaired groups of people have been studied (such as people with dementia), the voices we hear are most commonly those of lay or professional care-givers. This same feature can be seen, to some extent, in research into the lived experience of life-limiting illness, where accounts of carers and health care professionals have been used a proxy for the patients' experience, particularly when reflecting on experiences up to and including the time of death (for example, Young *et al.* 2007). Methodological and ethical sensitivities have a significant impact on patients' participation in research at the end of life, as does the patient's own physical and emotional capacity to take part. However, valuable insights have been gained into (for example) the lived experience of enforced dependence on carers (McPherson *et al.* 2007), quality of life (Cohen and Leis 2002), and the provision of health services (Osse *et al.* 2002), through the use of in-depth interviews with palliative care patients.

In contrast to sociological research, rehabilitation research has remained firmly rooted in a bio-medical framework, with services assessed by reference to provider-established norms (Kramer 1997). The lack of research considering patients' perspectives on illness, impairment, disability and rehabilitation has been noted as a cause for concern (Materson 1997, for example).

The accounts that are available to us concerning the impact of rehabilitation on patients' lived experience of disability are not encouraging. Keith (1997) comments on the highly repetitive nature of assessments on admission to a rehabilitation facility, and the depersonalisation experienced in an institutional setting. Bendz (2000) reports on the differences between patients' and professionals' discourses in a stroke rehabilitation setting, patients being concerned with re-establishing their former social identities, while staff focussed on biomedical details of impairment and dysfunction. In the account perhaps most closely relevant to this thesis, Robert Murphy, a person with a primary tumour of his spinal cord, considers his ambivalence towards rehabilitation services. On the one hand, he felt encouraged by the visible progress he made in occupational therapy and physiotherapy; on the other, some of the rehabilitation processes and activities he was required to engage in did not contribute positively to his self-esteem: 'I was doing well in occupational therapy, although I thought some of the exercises ridiculous. Nonetheless, visitors to our house still scrape their feet on the doormat that I made in O.T. Yolanda is the only person who knows its origins, a sign of the care I have taken to keep secret the indignities visited upon me in my disability' (Murphy 1990: 54).

While there are several studies of patients' experience of cancer and life-limiting illness (Mathieson and Stam 1995), there is a shortage of accounts that deal directly with the lived experience of disability consequent on life-limiting disease. In particular, we do not know how patients with metastatic spinal cord compression construe their disability, or the terms on which rehabilitation would make sense to them. This means that the delivery of rehabilitation can be no more than a professional 'best-guess'. At present, judging from the literature, the professional 'best-guess' has a strong focus on the provision of help and

care, but is this what patients want and need? The following account, given by a patient with spinal cord compression, suggests that the answer to this question is: not necessarily.

2.5.3 Anne's story

As part of an earlier research study into occupational therapy outcomes in palliative care, I interviewed Anne (not her real name), a woman in her early forties diagnosed with metastatic spinal cord compression (Eva 2001). In the course of the interview, Anne spoke at some length about her experiences of rehabilitation. After a two-week stay on an acute oncology ward having radiotherapy treatment, she was transferred to a local hospice to await the allocation of a wheelchair-accessible council property. She remained in the hospice for several months. The following is a précis of the transcription of the original interview, but I have retained her words in telling the story.

At first I wasn't too worried, as the GP had reassured me that I just had a benign fibroid. Things got more serious when I noticed some weakness in my legs, and then one morning, I just couldn't stand up. That was when the cancer was diagnosed, and in the space of a few days I went from being a fit and healthy person with a few tummy problems, to being a paraplegic cancer patient. Looking back, it was a real shock to the system: having a diagnosis of cancer, and being disabled. Prior to the illness, I'd lived in shared accommodation, and I'd worked as an administrator for a firm of accountants. And of course now that I was in a wheelchair, it wasn't possible to return to my home or my job. The actual work involved computers and answering telephones, and would have been quite suitable for a paraplegic, but the office was up a flight of stairs and there was no lift.

They did talk about rehabilitation in the hospice, but nothing ever really happened. It was all just about sorting out the flat. Everything seemed to happen in a big rush at the last minute: all of the things that we needed suddenly arrived and so I had to be discharged. There was nothing that happened at the hospice that prepared me for what life was going to be like as a disabled person. I think some bit of my brain had thought it was going back to life as it knew it before. And of course, it wasn't; I was totally unprepared for it. What would have helped, would have been to have had some counselling before I left the hospice. Not deep intensive therapy, but more to do with things like 'this is what it's like being a disabled person', and 'this is what it might be like to go and live in the outside world'. Eventually, after I'd been discharged, I asked if there was someone I could meet, and a nurse put me in contact with the local young disabled unit. I met up with the receptionist who works there, who is in a wheelchair. It was good to be able to talk to someone in the same boat.

It took a while for it to sink in that I'd got a kind of double whammy. Because even if I felt ever so well, I was still disabled. I mean, you could have a cancer that went onto remission, and you could be your normal self during that remission. But however well I felt, I was still in a wheelchair. So it was like two completely separate things: an illness that might be going to kill me, and a disability. The rehabilitation that I had that helped me was the work I did with the community OT once I got home. She suggested ways of getting out, of getting around my local area. We went out in the wheelchair, down the road to the shops, and to the library. And then we tried the different ways of getting in to town, going in the Ring-A-Ride bus, and we went in the ordinary bus, and we tried taxis, to see which worked best. You need some help getting used to a wheelchair. You need to learn to trust it over humps and bumps. I wouldn't have plucked up the courage to try these things on my own.

Anne describes a focus on her cancer diagnosis, and a relative lack of support and information relating to living with a disability. She spoke further of little co-ordination of services, with the referral to the community occupational therapy service being made only after she had been home for some while, and then only following a chance remark to a district nurse.

Interestingly, Anne's account contrasts markedly with that of the hospice staff, who described making every attempt to engage Anne in the decisions and arrangements that needed to be made about her discharge. In their view, she was unapproachable, procrastinating, and hard to form a relationship with. Opportunities offered – such as becoming involved in the activities of the day hospice – were not taken up. To some extent we can account for this difference in perception by considering the way that Anne's identified needs differed from what was being offered. For Anne, the day hospice did not provide the information on being disabled, and the contact with a supportive peer group of other paraplegic wheelchair-users, that she was looking for. This discrepancy also has methodological implications, and I will consider these in Chapters 3 and 4.

2.6 Conclusion

Anne draws our attention to the unique situation in which people with metastatic spinal cord compression find themselves: coping with implications of advanced cancer and the consequences of disability. As Anne points out, her disability and her cancer each create their own set of problems, but they combine in a way that produces unique challenges for her.

In contrast, the descriptions given of rehabilitation in the literature on metastatic spinal cord compression are limited, with the emphasis falling too strongly on function, independence and patient autonomy on the one hand (in response to disability), and on the provision of care on the other (in response to terminal illness). There is little on how the two conditions interact.

The review of the literature identifies clear empirical gaps in the understanding both of the value of rehabilitation for patients with spinal cord compression, and of potentially successful mechanisms for its implementation. I have identified five areas of concern:

- We lack a comprehensive, consistent account of the way in which rehabilitation could be operationalised in terms of the components of rehabilitation interventions, with existing recommendations being setting-specific and with a division between ‘specialist palliative care’ on the one hand and ‘specialist rehabilitation’ on the other.
- There are tensions around the extent to which mainstream, specialist rehabilitation approaches are appropriate in palliative care, particularly in relation to the patients’ participation in the rehabilitation process.
- We do not have a sufficient understanding of the relationship between a life-threatening illness and disability. As Anne’s story illustrates, patients with spinal cord compression have to cope with a poor prognosis as well as with the day-to-day physical, psychological and social consequences of a disability. The palliative care literature, particularly that which is concerned with rehabilitation, is largely oblivious of the debates in the disability field.

- In all of these areas, the perspective which we find in the literature is entirely a professional one. There is no indication of the way in which patients understand their disability, or the desired outcomes (if any) of rehabilitation interventions.
- We have some indication in the literature of the ways in which approaches to rehabilitation are shaped by local contexts, and there is the suggestion that (at least a subset of) patients could benefit from targeted rehabilitation interventions. Looking at the local situation in one UK Cancer Centre, Anne's story suggests a reactive, rather than a coordinated, approach to rehabilitation.

On the basis of these gaps in our understanding, this study was designed to examine the consequences of disability resulting from metastatic spinal cord compression – with a strong emphasis on patients' own accounts of their experiences – and to determine the conditions under which rehabilitation could be operationalised effectively for this group of patients.

In Part II, I will elaborate on the research questions, design and methods employed to address these issues.

PART II
RESEARCH DESIGN AND METHODOLOGY

Chapter 3

Research aims and design

3.1 Introduction

In this chapter I provide an account of the logic of the research design and the research process, making relatively brief references to the philosophical and epistemological issues.

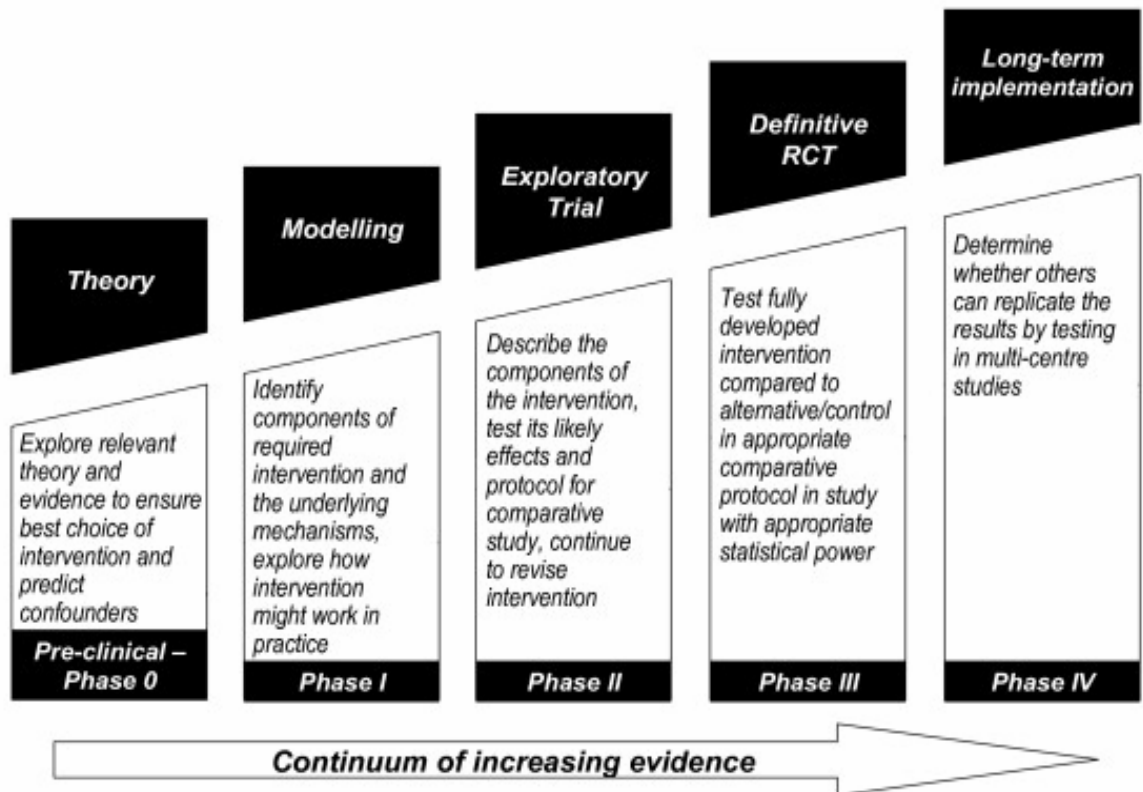
Detailed methodological discussion and analysis will follow in Chapter 4.

3.2 Researching complex interventions

From the concerns raised in the review of the literature, a key question that arises is how we might operationalise and, ultimately, evaluate rehabilitation for patients with spinal cord compression in a way that takes account of patients' experience of living with disability. I have indicated a number of reasons why we are not able to move straight to an experimental study of a rehabilitation intervention: we lack information on the components and structure of such an intervention, and we do not know whether patients' views of desirable outcomes agree with those of professionals.

In general terms, the design and evaluation of complex interventions, such as rehabilitation, is problematic. A large number of diverse factors, which include both behaviours and organisational structures, act and interact with one another to achieve a range of (not always welcome) outcomes. The Medical Research Council provides a useful pragmatic framework for researching complex interventions, setting out four phases in the development and evaluation of such interventions (Campbell *et al.* 2000; Medical Research Council 2000a).

Figure 3.1: The MRC framework for the evaluation of complex interventions



In the first ‘pre-clinical’ phase, the theoretical basis for the intervention achieving its intended outcomes is established. The second phase, the Phase I or modelling phase, develops an understanding of the specific components of an intervention and the mechanisms whereby they are likely to achieve their effects. In the third phase, the Phase II or exploratory trial phase, a feasible protocol is designed to compare the intervention with appropriate alternatives, leading to the fourth Phase III main trial phase, evaluating the intervention and its possible effects through a randomised controlled trial with appropriate statistical power. The final phase examines the long-term viability of the intervention. Since

its publication in 2000, this framework has been internationally influential (Campbell *et al.* 2007), successfully used in a wide variety of treatments, services and interventions, including secondary prevention of coronary heart disease (Byrne *et al.* 2006), intensive care nursing (Blackwood 2006), stroke care (Redfern *et al.* 2006; Robinson *et al.* 2005), palliative care in multiple sclerosis (Higginson *et al.* 2006), and primary care management of psychosis (Lester *et al.* 2005).

My study encompasses the first two stages: (i) the Pre-clinical Phase, and (ii) Phase I, where mechanisms are identified and outcomes are predicted. It is intended that the results of this Phase I research will form a foundation for continuing on to Phase II, namely the design of an exploratory trial which would apply and evaluate the rehabilitation intervention developed, and identify the conditions under which this intervention could be delivered and evaluated across a larger population.

3.3 Research aims and questions

This study, therefore, was intended to achieve the following:

1. To ascertain what might constitute effective rehabilitation interventions for patients with metastatic spinal cord compression.
2. To identify the conditions in which these intervention might be delivered.
3. To ground proposals in spinal cord compression patients' experience of disability.

To fulfil these aims, the following research questions were posed:

1. What are the consequences of disability for patients with metastatic spinal cord compression?

2. What strategies do patients themselves use to manage disability?
3. What do health care staff, particularly rehabilitation professionals, understand to be the consequences of disability for this patient group, and correspondingly, what are their views on the significance and provision of rehabilitation?
4. To what extent is rehabilitation being provided to these patients, and with what effect?
5. Where rehabilitation is not being provided, why is this the case?

3.4 Research design

On the basis of these questions, the parameters for the research design can be outlined. My procedure in this section is to consider each of the research questions in turn, and identify the information required to answer it. Cumulatively, this will build into a research design, which I will summarise formally at the end of the process.

It will be clear from the following discussion that the five questions are interlinked. In taking each one separately, my intention is to provide as clear an account as possible of the logic of the design. The various technical, ethical and philosophical matters arising in this question-by-question process obviously require further elaboration, and will be discussed later in this chapter, and in Chapters 4 and 5.

3.4.1 Question 1: Consequences of disability

To identify the consequences of disability arising out of spinal cord compression, data were required from a number of sources: chiefly, from patients themselves, but also from carers and health care professionals. While there are a number of possible ways of

gathering this data, including formal, standardised measures, or via a self-administered questionnaire, face-to-face interviews offer obvious methodological and ethical advantages. From an ethical standpoint, this is a vulnerable population of patients; particular care is required in ensuring that data gathering takes place at a pace and level with which participants are comfortable. Methodologically, face-to-face interviews provide a good opportunity for generating rich, in-depth data which is at the same time meaningful to the participant and relevant to the interviewer (Robson 2002; Bowling 1997).

While interviews with patients provide important insights into their views and experiences, their accounts are inevitably shaped by their own perspectives and contexts. Since there are a number of 'stakeholders' (Pawson and Tilley 1997; Guba and Lincoln 1989) in the provision of rehabilitation, any account of what might constitute effective rehabilitation interventions would require information from a variety of sources. Carers' and health care professionals' views, relative to the patients', were therefore also important. Taking the patient as the central focus led to a recruitment strategy whereby patients were invited to participate in the first instance, with carers and health care professionals included as appropriate on a case-by-case basis. (For a comparable procedure, adopted in a study designed to assess the need for respite and support services among palliative care patients, see Wiles *et al* 1999. Other examples of health-related research involving interviews with patients and professionals include: Eales *et al* 2006; Goodwin and Happell 2006; Krother and Clendon 2006; McSherry 2006; Ross *et al* 2005; Raine 2003; Avis *et al* 1999; Hart 1999).

Given the illness trajectory of spinal cord compression, it was likely that patients' and carers' perspectives would change as the illness progressed. For this reason, a longitudinal approach to data gathering was taken (Saldana 2003; Mason 2002), with a number of interviews over a period of time. (For examples of longitudinal qualitative studies in health care, see: Graungaard and Skov 2007; Maben *et al* 2007; Woodgate 2005; Edwards *et al* 2004; Sanders and Skevington 2003; Murphy 1999).

The need to collect in-depth interview data from a range of sources and over several interviews inevitably limits the number of participants. What it implies is a small-*n* multiple case-study (Stake 2005; Yin 1994; Ragin 1987) in which patients, their carers and associated health care professionals would provide an account of the consequences of disability arising out of spinal cord compression. I will elaborate on this in section 3.5, but eight to twelve cases were anticipated at the outset.

In emphasising the advantages of face-to-face interviews, I do not mean to dismiss other data collection strategies. Standardised measures, for example, can provide an additional dimension to interview data. In this study, one standardised measure was incorporated into the interview process: the Schedule for the Evaluation of Individual Quality of Life: a Direct Weighting Procedure for Quality of Life Domains (SEIQoL-DW) (O'Boyle *et al.* 1995). The purpose of using SEIQoL was to gauge the consequences of disability in computable 'quality of life' terms, and to see how far this measure corresponded to the patients' spontaneous accounts. I will say more about the method later in the chapter.

3.4.2 Question 2: Patients' strategies for managing disability

Information on strategies for managing disability is, again, required from patients themselves. Having settled on in-depth interviews as a method for gathering data for Question 1, questions related to coping strategies were incorporated into the interview schedule. Carers' perspectives on patients' coping strategies were also sought, recognising that there may well be aspects of which patients were unaware or did not recognise.

3.4.3 Question 3: Health care professionals' views on disability and rehabilitation

The need to interview health care professionals had already been established with Question 1. In addition to information related to a particular case, health care professionals were asked to comment on their general experience of the need for, and the process of, rehabilitation of patients with spinal cord compression.

3.4.4 Question 4: Provision of rehabilitation and effects

I also sought to determine the range of rehabilitation services provided to this group of patients, and to elicit the patients' views on the kinds of intervention that were helpful (or intelligible) at different stages of their illness. The second of these objectives is part of the 'identifying mechanisms' project, with respondents being invited to comment on what it is about a rehabilitation intervention that is effective (or not).

Clearly, participants' views of rehabilitation could be established during interviews. However, a dozen cases (at most) would not provide sufficiently comprehensive data on the range and extent of rehabilitation services being offered, so it was necessary to undertake a wider survey of the population concerned. A retrospective audit (Kogan and Redfern 1995) was carried out of the medical records of all spinal cord compression

patients admitted to the radiotherapy unit during the study's two-year data collection period, gathering both demographic data on patients, and process data on the rehabilitation provided.

The possible strategy of gathering data through observation of rehabilitation interventions (such as physiotherapy treatment sessions or occupational therapy home visits) was also considered. Given that a range of viewpoints was being sought in answer to the research questions, it was likely that there would be discrepancies between individual accounts. Observational data can be a useful complement to interview data in this respect, in recognition of the potential contrast between 'what people say' and 'what people do' (Dihle *et al.* 2006; Adams *et al.* 1999; Paley 1999; Stone *et al.* 1999). However, in this study, the advantages were outweighed by logistical disadvantages: observation is time- and labour-intensive. Spinal cord compression is an oncological emergency and admissions to the unit are unplanned and unpredictable. As a part-time researcher, it was highly likely that I would spend considerable amounts of time in hopeful inactivity.

3.4.5 Question 5: Reasons for non-provision of rehabilitation

While the possibility of limited rehabilitation provision was recognised at the design stage of the study, it was only once the research was under way that the significance of this question became apparent. The almost complete absence of rehabilitation in situations where one would normally anticipate at least some intervention led to careful inspection of the whole data set. In particular, I became interested in another set of mechanisms: not, this time, the mechanisms that might (in context) be responsible for a good patient-centred outcome, but instead the mechanisms that could account for the fact that so little rehabilitation was taking place – despite the good intentions of all relevant staff, and

despite the facilities for providing rehabilitation being in place. This will be the main topic of Chapter 10.

3.4.6 Summary

Drawing all this together, the research design, in outline, consists of:

- i. A detailed, interview-based study of a small number of cases, to achieve an in-depth understanding of the consequences of disability for each patient; to elicit the views of patients, carers and health professionals on the effective management of disability, including (where relevant) rehabilitation; and to identify, where possible, some of the mechanisms responsible for positive rehabilitation outcomes, as well as mechanisms accounting for the fact that (as it turned out) not much rehabilitation was actually taking place.
- ii. An audit of disability and rehabilitation in the wider population of spinal cord compression patients on the radiotherapy unit, to provide an account of patients' 'rehabilitation pathway' – their disability-related problems, the extent to which they were in contact with rehabilitation staff during their stay, the services offered, and the basis upon which these were delivered.

In summary, then, the study combines: (i) a multiple case-study design (George and Bennett 2004; Gomm *et al.* 2000; Yin 1994) with (ii) a retrospective audit of medical notes. As I will explain later, the 'case study' part incorporates the principles of realistic evaluation (Pawson and Tilley 1997) and grounded theory (Glaser and Strauss 1967).

In the rest of this chapter, I will fill in some of the details, considering specifically the advantages of case study design, the Pawson and Tilley framework, the use of SEIQoL,

sampling and recruitment, the data collection strategy, and the strategy for data analysis. In Chapter 4, I will turn to the methodological and epistemological 'matters arising'. In Chapter 5, I will discuss the essential nuts and bolts of the study: funding, recruitment, ethics, project management, logistics and so on.

3.5 Case study

Case studies comprise a detailed examination of an event, or set of events, to develop and test explanations that may be generalisable to other events (Gomm *et al.* 2000; Keen and Packwood 1995; Yin 1994), commonly drawing on multiple sources of evidence (Robson 2002; Yin 1994). While case study research has been sidelined in some methodology texts as a weak alternative to rigorous experimental or survey methods, yielding no more than introductory or complementary data (Robson 1992), it has also been strongly defended as an entirely legitimate alternative (in appropriate circumstances) to statistical methods and formal models (George and Bennett 2004).

Statistical methods, formal models and case study methods share an epistemological logic in their attempt to derive testable models or theories from data, but they differ in aims and methods. Statistical methods are designed to estimate the causal effects of variables in large samples across populations. Formal models are used to formulate hypotheses about causal mechanisms using deductive logic, leading to complete and consistent theories. Case studies seek to make testable claims about (what might turn out to be) processes and mechanisms through in-depth analysis of a small number of cases. Methodologically, they differ in selection of cases and samples, data gathering strategies, and the use of inductive and deductive logic. Arguably, each approach has particular advantages when answering

certain kinds of questions, and there is a trend towards using them in a complementary way (George and Bennett 2004).

3.5.1 Strengths of case study methods

Case study methods have a number of specific advantages:

First, by limiting the sample to a relatively small number of cases (sometimes just one), case study research can achieve in-depth understanding of social processes, analysing a range of data in order to produce a robustly evidenced understanding of what has led to what. Data will usually be collected in a wide variety of ways, including interviews, observation, analysis of official records, and any other sources which may be helpful in achieving this understanding. Multiple case study designs permit between-case comparisons, as well as within-case analysis.

Second, and of particular relevance to this study is the idea that case study work can provide a 'close up' of social mechanisms, which can be examined directly, in real life situations, rather than indirectly through statistical methods. George and Bennett (2004), for example, describe the method of 'process tracing', a systematic approach to tracing the links between possible causes and observed outcomes. In terms of health-related research, this will be a potentially valuable method if it can help to identify the 'underlying mechanisms' referred to by the MRC's framework for the evaluation of complex interventions (Medical Research Council 2000*a*). In theoretical terms, it suggests an obvious link with the context-mechanism-outcome framework of Pawson and Tilley (1997), to be discussed at greater length below, and more generally the rapidly growing

literature on 'social mechanisms' (Elster 2007; Hedstrom and Swedberg 1998a) to which I will return in Chapters 4 and 10.

Third, case studies have high conceptual validity (George and Bennett 2004), enabling the researcher to consider contextual factors in detail. Many of the concepts of interest to health services researchers, and particularly those in palliative care – for example, rehabilitation, need, quality of life, dignity, fatigue, social participation, and a 'good death' – are notoriously difficult to operationalise in quantitative terms, creating considerable problems with measurement. In particular, what counts as a 'need', or 'participation', tends to vary from one context to another. Case studies permit detailed examination of context in a way that is usually difficult in statistical designs.

Finally, case study methods have been used to complement quantitative studies in at least two distinct ways. On the one hand, they can be used to examine statistically identified 'deviant' cases (outliers) more closely, with a view to determining why they are deviant. On the other, they can be used heuristically to generate new hypotheses for testing by surveys or experimental designs.

3.5.2 Limitations of case study methods

As is the case in any research method which concentrates on a relatively small number of instances, researchers undertaking case study research must take into account the problem of case selection, as well as the trade-off between high internal validity and the ability to make generalisations which apply to larger populations.

- Selection bias can occur when the cases selected are skewed towards having, or not having, a particular characteristic; for example, a set of patients with spinal cord compression who share a common primary diagnosis.
- Case studies have limited ability to estimate the causal weight of variables across a range of cases. While they have excellent capability in assessing the relationship of the variable to the outcome (whether and how it mattered), they are not strong on assessing how much it mattered.
- Case studies, it is generally – but not universally – agreed (Hammersley and Gomm 2000), cannot be representative of populations. However, some case study researchers argue that they do not aspire to findings which are applicable to diverse populations. The value of case studies lies rather in their ability to ‘uncover or refine a theory about a particular causal mechanism [...]. Case study researchers are more interested in finding the conditions under which specified outcomes occur, and the mechanisms through which they occur, than uncovering the frequency with which those conditions and their outcomes arise’ (George and Bennett 2004: 31).

3.5.3 Case study ‘trade-offs’

Like all research methods, then, case study research has certain advantages and drawbacks. Suggesting that these are more appropriately seen as trade-offs than as methodological and epistemological dichotomies, Gerring (2004) lists several dimensions along which design trade-offs occur: the type of inference under consideration (descriptive – causal); the scope of the proposition (breadth – depth); the extent to which

the sample is representative of a population; the causal insights derived (causal effect – causal mechanism); and the strategy of the research (theory generation – theory testing). Case study research represents a specific trade-off profile: it has a ‘methodological affinity’ for descriptive, in-depth, theory generating studies which are able to suggest, but which cannot confirm, causal mechanisms. In the choice ‘between knowing more about less and knowing less about more’ (Gerring 2004: 348), it is positioned towards the ‘knowing more about less’ end of the spectrum.

I will briefly consider two of Gerring’s trade-off categories in order to elaborate on this point. A demonstration of *causal effect* will rely on evidence of the regularity of co-occurrence (of X and Y, say) in a sufficiently large number of instances, and will therefore require a much larger sample than is typical of case studies. However, this demonstration presupposes the identification of a *causal mechanism*: ‘X must be connected with Y in a plausible fashion; otherwise it is unclear whether a pattern of covariation is truly causal in nature’ (Gerring 2004: 348). It is this task, the identification of causal mechanisms (or at least persuasive candidates for causal mechanisms), that case study research is particularly well suited to, since delineating the mechanism (tracing the links between possible causes and observed outcomes) requires detailed examination of social processes in (what will inevitably be) a small number of cases. A causal link between X and Y having been plausibly identified, it can then be tested in larger sample designs, whether cross-sectional or experimental.

This first trade-off already implicates a second, that between exploratory and confirmatory research: the candidate causal mechanism is identified through a study designed precisely to yield a hypothesis about what the mechanism is, and only

subsequently is this hypothesis subject to a test capable of confirming or disconfirming it – the ‘generative moment’ followed by the ‘skeptical moment’ (Gerring 2004: 349), the conjecture followed by the refutation (Popper 1969). Case study research usually represents the ‘conjectural’ moment, providing a set of ‘in depth’ data which is far more conducive to the generation of plausible hypotheses than the ‘broad-but-shallow’ data of large-sample studies (compare Sayer’s 1999 account of ‘intensive’ and ‘extensive’ research; the long-standing philosophical distinction between the ‘context of discovery’ and the ‘context of justification’, about which I will say more later; and the distinction between the ‘modelling’ phase and the ‘definitive RCT’ phase in the MRC framework for the evaluation of complex interventions, discussed at the beginning of this chapter).

However, as Gerring points out, the boundary separating ‘generating’ from ‘testing’ is not hard and fast: the exploratory phase is subject to the kind of discipline that involves testing hypotheses ‘in a rough-and-ready way’. The point of a case study is to hold the hypothesis accountable to evidence, an alternative to inventing it, or deriving it from grand theory; hence the various procedures that have been suggested to ensure this sort of rigour. For example, Odell (2001), following Campbell’s (1975) multiple implications technique, recommends the explicit introduction of alternative hypotheses, comparing one’s newly derived expectations with the facts of the case. This involves asking questions such as: ‘If this theory is valid, what else should one expect to see?’ In this context, the conjecture/refutation distinction becomes, to a certain extent, one of degree: ‘Even if such a study supports the hypothesis more rigorously than any previous work has done... all case methods are still at a disadvantage, relative to the large-n statistical method, in providing support for the more ambitious claim to have tested theory’ (Odell 2001: 172).

As will become clear later in this chapter and the next, I have tried to adopt such procedures myself. For example, as outlined in section 3.5.5, I draw on Pawson and Tilley's (1997) idea of the 'teacher-learner' process, a procedure in which research participants are invited to consider and comment on emerging hypotheses – in effect, taking Odell's suggestion a step further.

The virtues of case study design have been recognised in health-related research (Keen and Packwood 1995, for example), and it has subsequently been employed in several clinical contexts, including palliative care (Lynn *et al.* 2002; McGrath and Joske 2002; Lee 2002; Grocott and Cowley 2001), cancer care (Singer *et al.* 2000), rehabilitation (Roelofsen *et al.* 2002), and user involvement in decision making (Walker and Dewar 2001).

3.5.4 Case study research and complex interventions

I have noted that the understanding and evaluation of rehabilitation, as a complex intervention, can pose significant challenges. Systematic, rigorous testing of complex rehabilitation interventions has proved challenging (Wade 2005), and so the evidence base for such interventions is small in comparison with medical interventions. Common pitfalls in researching complex interventions include pragmatically defined, poorly specified interventions lacking a theoretical basis, as well as inadequate descriptions of implementation. Both problems limit our understanding of the reasons for local success or lack of it (Campbell *et al.* 2007; Campbell *et al.* 2000). A complex intervention, by definition, will not work in the same way with each patient. The mechanisms in operation vary according to individual contexts: patients' co-morbidity, psychological coping mechanisms, motivation and social support systems, among other things. However, recent work in stroke rehabilitation, cardiac rehabilitation and dementia care and chronic

fatigue (for example) has demonstrated the potential for developing robust studies, leading to multi-centre trials (White *et al.* 2007; Chambers *et al.* 2006; Graff *et al.* 2006; Sackley *et al.* 2006; Forster and Young 2005; Bradley *et al.* 1999). It is noteworthy that, in these studies, attention has been paid to the processes by which outcomes are achieved. Since this is a particular virtue of case study research – its emphasis on identifying processes and mechanisms – it is an approach that is likely to be valuable at an early stage in researching complex interventions.

3.5.5 Identifying contexts, mechanisms and outcomes

I have situated this research in the first two phases of the Medical Research Council's framework for evaluation complex interventions (Medical Research Council 2000a), aiming to identify processes and mechanisms with desirable outcomes. In a recent review of the framework (seven years after it was first published), Campbell and colleagues (2007) note the international influence it has had in health services research, and re-emphasise the importance (particularly in work before definitive randomised controlled trials) both of achieving a clear understanding of context, and of clarifying the mechanisms by which the intervention being developed might achieve its aims. Contexts are seen as including 'the wider socio-economic background, health services systems, the characteristics of the population, the prevalence or severity of the condition studies, and how these factors change over time' (Campbell *et al.* 2007: 455). An explicit account of the cause of a particular problem, whether it is amenable to change, and the specific mechanisms by which an intervention might achieve a result, are integral to the explanatory power and generalisability of any future experimental testing (Campbell *et al.* 2007; Oakley *et al.* 2007).

The project of identifying mechanisms, contexts and outcomes, which Campbell *et al.* (2007) regard as a necessary precursor to conducting trials on complex interventions, echoes the framework adopted by Pawson and Tilley (1997). These authors propose a context-mechanism-outcome (CMO) configuration for developing and testing hypotheses about effective interventions, a CMO hypothesis being a proposition which states what it is about an intervention that works, for whom, and in what circumstances. The idea, which can be generalised from evaluative research (the primary concern of Pawson and Tilley) to any study of social processes, is that causal mechanisms do not work in a 'blanket', universal way; rather, they operate – produce certain outcomes – only in very specific contexts, which the researcher must be able to identify.

In a health service context, programmes (such as smoking cessation campaigns) and interventions (such as rehabilitation for patients with spinal cord compression) cannot be theoretically developed and delivered in ideal conditions, guaranteeing specified outcomes. Causation is not simply external: intervention x does not straightforwardly, or consistently, produce outcome y . Rather, outcomes are the result of interactions between stakeholders, interventions, environments, and so on. According to Pawson and Tilley (1997: 34), 'cause describes the transformative *potential* of phenomena. One happening may well trigger another, but only if it is in the right condition in the right circumstances.' A desired outcome can only be attained in conducive circumstances. These circumstances, being the complex interplay of a number of factors, are generally not superficially observable. Account needs to be taken of 'attitudinal, individual, institutional and societal processes' (1997: 216).

This suggests that one way of identifying strongly-evidenced CMO configurations for rehabilitation with spinal cord compression patients is to test a range of possibilities explicitly, by inviting the participants (whether patients, carers or practitioners) to comment on actual or potential intervention strategies and, if they feel it necessary, to suggest amendments. Pawson and Tilley refer to this as the learner-teacher process, where a researcher engages in a reciprocal relationship with participants, 'learning the stakeholder's theories, formalising them, teaching them back to the informant, who is then in a position to comment upon, clarify and further refine key ideas' (1997: 218). As I will explain later, this was in fact a feature of the interviewing strategy adopted in the present study.

It is worth noting, at this point, one consequence of adopting a 'mechanisms' approach to case studies, a consequence which is quite explicit in Pawson and Tilley's account. It implies a strong form of realism. There are, on this view, mechanisms out there waiting to be discovered – objective reasons why things happen, in context, or why they do not – and the hypotheses we frame about them can be true or false, or at least more or less accurate. There is a continuity 'between natural science explanation and social science explanation and program evaluation explanation' (Pawson and Tilley 1997: 71). Not all advocates of case study work take this view (Donmoyer 2000; Stake 2000), and quite a few slot case studies into the 'naturalistic inquiry' paradigm (Guba and Lincoln 1989). But the position I take here is unequivocally realist, and I accept the corollary: that the conclusions I draw may not be articulated, accepted, or even recognised, by the study participants. However, I will defer a more detailed discussion until the next chapter.

3.6 Quality of life data

A relatively minor, but still significant, part of the study involved the use of a quality of life measure, the Schedule for the Evaluation of Individual Quality of Life – Direct Weighting (SEIQoL-DW), during the interviews with patients. Initially, this was intended to complement the more open-ended interviewing methods, the idea being that it would be useful, for triangulation purposes, to have a standardised method of gauging the consequences of disability in quality-of-life terms. For example, it might help to assess, more objectively, the extent to which quality of life deteriorated with the progression of the disease, and the consequences of disability became gradually more difficult to deal with. At the same time, however, the selection of an individualised measure such as SEIQoL-DW would (I originally thought) bring with it additional advantages.

SEIQoL-DW is a brief quality of life measure which is derived from the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (O'Boyle *et al.* 1993). The measure allows respondents to nominate the areas of life which are most important to them, rate their level of functioning or satisfaction with each, and indicate the relative importance of each to their overall quality of life. It has been shown to have high levels of consistency and validity with cancer and palliative care patients, and has been found to be acceptable and practical to use with these patient populations (Clarke *et al.* 2001; Campbell and Whyte 1999; Waldron *et al.* 1999; O'Boyle and Waldron 1997; Hickey *et al.* 1996).

The individualised nature of SEIQoL-DW, the way in which it permits respondents to nominate the areas of life that are most important to them, seemed to offer (potentially, at least) one way of specifying 'context' in Pawson and Tilley's CMO configuration. It could help to identify personal differences between patients, differences which might turn out

to be factors relevant to the success, or otherwise, of rehabilitation initiatives. If, for example, a patient considered spending time with her/his family to be most important, that would have implications for the kind of rehabilitation programme that could usefully be offered. If, however, s/he considered the future financial security of the family to be most important, that would have somewhat different implications. The idea that SEIQoL-DW might possibly be useful as an assessment tool in the devising of suitable programmes of rehabilitation was an attractive one.

In the event, SEIQoL-DW did prove to be of value, but not in the way I had anticipated. As I will explain in more detail later, the unexpected finding was that, according to the SEIQoL-DW measure, the patients' quality of life was relatively unimpaired (a result confirmed in a survey by Levack 2004). Indeed, the quality of life of these patients, as scored by SEIQoL-DW, was often higher than that of healthy patients of a similar age. This may, of course, be an artifact of the measure, and of the circumstances in which it was used. But there is an alternative explanation, and my interpretation is that this apparently odd result is in fact telling us something interesting about the psychological coping devices used by these patients. However, further discussion of this topic will have to be deferred until Chapters 7 and 12.

3.7 Sampling

All patients with metastatic spinal cord compression referred for treatment at the Oxford Cancer centre in a two-year period (July 2003 and June 2005), were eligible for recruitment to the study, subject to two conditions: that they were deemed well enough to participate by medical and nursing staff, and that they consented to do so. Theoretical sampling, in Glaser and Strauss' (1967) terms, where data collection is driven by emerging theory, was

not a possibility, given the sensitivities of carrying out research with people who are dying. It was essential that patients' well-being was prioritised over the needs of the study. However, as far as possible, I selected cases in such a way as to achieve a spread across gender, diagnosis and age. To a considerable degree, this was successful, and there is generally a good fit between the characteristics of the patients on whom the case studies are based, and the demographics of the patient population as a whole, as is evidenced by a comparison between Table 5.2, and Tables 8.1 and 8.3. On the basis of hospital records, informal conversations with staff, and a pragmatic decision about the amount of data it would be possible to manage within the study's resources, I planned to recruit between eight and twelve cases. In the event, I recruited nine.

Once the patient had been recruited, her/his permission to approach the carer was also sought. Seven of the nine recruited patients granted this permission. Of the two exceptions, one patient (Ben) lived alone and did not have local 'carers', his close family and friends living abroad; the other (Gill) asked that I did not approach her husband, saying that he was not comfortable talking to health care professionals. In addition to carers, significant health care professionals were invited to participate on a case-by-case basis. Once it became apparent that there were relatively few health care professionals who were significant in providing rehabilitation, key ward-based therapy, nursing and management staff, as well as therapy management staff, were also approached and invited to participate, on a purposive sampling basis.

A further discussion of recruitment procedures will be found in Chapter 5.

3.8 Interviewing strategy

In this section, I will outline the methodological considerations involved in designing an interviewing strategy. The more practical aspects – identifying a suitable place and time, recording, the pacing of interviews, and so on – will be discussed in Chapter 5.

Broadly speaking, the interviews could be described as semi-structured, though I do not find labels such as this particularly helpful. On each occasion, I made a list prior to the interview of what I wanted to know from that respondent. For the initial interview with each patient, this list varied hardly at all; but differences appeared in succeeding interviews, with changes being introduced depending on what I had been told at the first interview. The checklist for the first interview for each patient is set out in Table 3.1. Checklists for subsequent interviews with patients, interviews with carers, and interviews with health care staff can be found in Appendix I.

My original intention was to interview patients and their carers separately, as I wanted to elicit their perspectives independently. Part of the reason for this was that I thought the patient might be inhibited by the carer's presence, not wishing to say anything that might cause the carer distress (and vice versa). However, the issue of whether to interview singly or in pairs proved to be a more pragmatic question than I had anticipated; and on three occasions, joint interviews were undertaken. In two instances, this was at the patient's request and, as it turned out, the carer's presence was invaluable: in one case, the carer was able to prompt the patient helpfully; in the other, the patient's daughter was able to fill gaps in her memory (there was a three-month period about which the patient was amnesiac). In the third case, the carer joined the interview and the patient during the interview preliminaries, and then declined to leave.

Table 3.1: Interview schedule: patients - first interview

1.	Description of events leading to the time of the interview, from onset of spinal cord compression symptoms.
2.	What do you understand about what has happened to you? What have you been told about your illness?
3.	What do you expect will be happening to you in the next few weeks ... months?
4.	Tell me about how much you are able to do (for yourself / work / leisure / important activities) at the moment. Are there things that you cannot do as a result of the SCC?
5.	I'm interested in the rehabilitation you have had – the contact you have had, for example, with OTs and physios – interventions that have helped you to manage your everyday activities ... could you tell me a bit about that? How it was introduced to you? What did you feel you needed? What was your understanding of what rehabilitation was aiming to achieve? Were you ever asked what your goals / hopes were?
6.	<i>Will by now have got a sense of perceptions of being disabled. Phrasing of question will depend on what's come up so far.</i> You talk about what it's like living with a disability. Can you tell me how that has changed things for you? (How do you feel about yourself / about life?)
7.	In your experience of spinal cord compression, what are the things that have been important to you / that have helped you / have not helped?
8.	Is there anything that I haven't asked about that you think is important, that you would like to tell me about?
9.	SEIQoL

3.8.1 Realism versus phenomenology

I have already noted that, for each interview, I prepared a checklist of things I wanted to know. One consequence of this is that the interviews were perhaps somewhat more directed than is sometimes the case in relatively unstructured qualitative interviewing. In phenomenological studies, for example, the interviewer is discouraged from asking questions that are overly specific, the point being to elicit accounts of whatever the respondent thinks is important, sticking to his/her own words, and without probing on specific issues. For example, Thomas (2005: 69) concedes that 'anger cannot be understood without a grasp of both its relational and cultural contexts'. But she adds: 'It is important

to note, however, that the researcher does not use a structured interview protocol to probe for these contexts; instead, the angry person is asked, "What aspects of the experience stand out to you?". In Thomas's view, then, although anger cannot be understood independently of context, context is not something the researcher can ask about explicitly, on pain of 'contaminating the data'. (The nursing literature contains numerous examples of this kind of thinking: see, for example, discussions in Secret *et al.* 2005; del Barrio *et al.* 2004; Wimpenny and Gass 2000; Chambers 1998; and many more.)

This line of thought is clearly at variance with the Pawson and Tilley (1997) strategy of explicitly testing out hypotheses with interview respondents. The discrepancy can be at least partly accounted for by the very different philosophical positions represented by Pawson and Tilley, on the one hand, and the phenomenologists, on the other. While Pawson and Tilley believe that it is possible to identify causal mechanisms, writers of the phenomenological persuasion believe that 'reality consists of the meanings in a person's lived experience' (Omery and Mack 1995: 141), and that researchers consequently strive to 'understand experience rather than provide causal explanation' (van der Zalm and Bergum 2000: 212). As a result of this difference, Pawson and Tilley recommend a hypothesis-testing approach to interviewing, while phenomenologists claim to adopt a strategy that avoids 'contaminating' (Chambers 1998) or 'polluting' the respondent's 'meanings'. In this study, I find myself very much on Pawson and Tilley's side; further justification of this position will be found in Chapter 4.

I would not, however, want to overstate the extent to which the interviews were driven by my own agenda. In common with most qualitative researchers, I tried to maintain a certain flexibility, as far as possible enabling respondents to find their own route through

the material, rather than taking them through a sequence of prepared questions step by step. I also remained alert to the introduction of any unexpected claims, themes and concepts, as well as to the expression of apparent inconsistencies. The main difference between my approach and that of some qualitative researchers – certainly phenomenological writers – is that I was not reluctant to raise specific issues with the respondents, or to seek their opinions on some of the theories and assumptions that had emerged either from the literature or from previous interviews.

3.8.2 Flexible design

This is probably the point at which I should confirm something which has up to now remained implicit in the discussion: that the interviewing strategy evolved during the period of data collection, reflecting what Robson (2002) has called ‘flexible design’. The questions I asked during the later stages were partly determined by the original checklists (see Appendix I); but they were also shaped by two contingencies. First, when interviewing a patient for the second or third time, there were always topics, events and situations – mentioned on earlier occasions – to which I wanted to return. Second, there were frequently ideas – ‘hypotheses’ seems slightly too grand a word – which had surfaced during my reflections on the data collected so far, and which I wanted to test out with the next suitable respondent. A simple example is the view expressed by most of the rehabilitation staff that direct contact with a consultant was something ‘you didn’t do’. I wondered whether the consultants took the same view, and whether they were likely to discourage rehabilitation staff from engaging in face-to-face contact. Accordingly, during subsequent interviews with consultants, I put the point to them directly, and learned that

not only did they not discourage face-to-face contact with rehabilitation staff, but that they would actively welcome it.

3.8.3 A note on narrative

One further observation, to which I will return at various points in this thesis, is that a significant portion of the interview material generated by patients and carers took the form of 'narrative'. These respondents would often narrate events that had happened to them, creating (in effect) short stories about aspects of their lives. This is, of course, a common experience among qualitative researchers, and there is now a substantial literature on narrative approaches to interviewing and qualitative analysis, especially in health-related research. Here I am simply noting the fact that my interviews elicited 'narratives', and that I began to take an interest in what (if anything) makes them different from other types of qualitative data, and how they should be analysed. I will say more about narrative later in this chapter (3.9.3), and in Chapters 4 and 11.

3.9 Analytical strategy

In designing the research, I naturally gave considerable thought to the strategy I would adopt for analysing the case study data. Two questions were of particular importance: how I would analyse 'within-case' material, and how I would make 'between-case' comparisons. I will begin the discussion with the question of 'within-case' analysis, and in particular the idea of process tracing.

3.9.1 Process tracing

Process tracing is a method outlined by George and Bennett (2004) in their book on case study. The idea is not new, even if the terminology is unfamiliar. Tilly (1997: 48), for example, suggests that theoretical propositions should be based on 'relevant, verifiable

causal stories resting in differing chains of cause-effect relations', and Goldstone (1991: 60) suggests that it is necessary to determine '*which* aspects of the initial conditions observed, in conjunction with *which simple principles* of the many that may be at work, would have to be *combined* to generate the observed sequence of events' (emphasis in original). Before I add further comment, it is worth noting the extent to which this formulation reflects the CMO framework of Pawson and Tilley (1997), 'principles' standing in for mechanisms, 'initial conditions' for context, and 'sequence of events' for outcome.

According to George and Bennett, the process tracing method attempts to identify the causal process responsible for a particular outcome. It sets a stringent standard. If we consider a hypothesis capable of explaining a certain sequence of events, then '*all* the intervening steps in a case must be predicted by the hypothesis, or else that hypothesis must be amended' (2004: 207). In other words, one is aiming at a step-by-step analysis that persuasively shows how, starting at A, B and C, the sequence eventually arrives at X, Y and Z. In a sense, this is not so much a method as a goal. It demands that we be able to fill in each stage of the process being described, and show how each step arises as the result of the previous ones. It is not enough to say: this happened, then this happened; rather, it must be possible to show that this happened because that happened.

In terms of data collection, process tracing is (and must be) eclectic, drawing on any source that may provide clues to the causal sequence. Each step in the chain must, in some way, be documented, some form of data providing evidence that the transition from F to G, say, is explicable. The implication is that the researcher undertaking case study work with process tracing in mind is constantly looking for gaps in the sequence, relative to each case. Why did *L* happen rather than *M*? How can *P* be consistent with *Q*? What

connection is there, exactly, between *R* and *T*? What accounts for *W* if not *V*? Many of these questions can be answered by interviewing the people concerned, and inquiring about their reasons. However, as with any realist approach to research, we should not assume that interview respondents necessarily understand the connections between one step and another. The account we finally arrive at, while it is accountable to the evidence, does not have to be accountable to 'what the respondent agrees with'.

The most obvious example of process tracing in this study is the attempt to find a convincing explanation for why (as it turned out) so little rehabilitation was taking place. As I shall explain at greater length in Chapter 10, there are a number of 'off-the-peg' explanations for this outcome, explanations which refer to deficiencies of some kind: not enough time, not enough money, not enough professional knowledge and skills, not enough good communication, and so on. None of these explanations fill in the details of the causal sequence through which a patient with a metastatic spinal cord compression diagnosis spends time in a hospital ward, is seen by various members of the rehabilitation staff, and is discharged home with the recommendation that further rehabilitation be undertaken in the community... but still never gets any rehabilitation.

As George and Bennett observe, the 'process-technique must be adapted to the nature of the causal process thought to characterize the phenomenon being investigated', and they refer to (among other types of causal sequence) 'complex interaction effects' and 'path-dependent processes' (2004: 212). In Chapters 7 to 9, I will present the evidence to support a hypothesis, developed at length in Chapter 10, that the outcome I describe as 'not much rehabilitation' can be explained in terms of a complex adaptive system (CAS), which involves both complex interactions and path-dependency. The CAS explanation *does* fill in

the causal-sequence details, in a way that other explanations fail to, as I shall try to show. However, further discussion is deferred till then.

3.9.2 The constant comparative method

I will now turn to the question of 'between-case' analysis. I am not convinced, in the end, that the explanation presented in Chapter 10 could have been arrived at simply by studying individual cases on their own terms. An essential part of the analysis, I think, was the comparison between cases that was taking place throughout. In this respect, as far as I can see, I was practising something very like the constant comparative method, as described by Glaser and Strauss (1967). A brief discussion of this method might be useful at this point.

Glaser and Strauss do not describe the constant comparative method very precisely, but the basic idea is reasonably clear, and involves a comparison of similar events or circumstances in the sites being studied. When, for example, two events (in different locations) appear relevantly similar, a category is devised to refer to them both – even if this terminology is not used by the people being studied. The authors' own example is 'social loss'. 'The category of "social loss" of dying patients emerged quickly from comparisons of nurses' responses to potential deaths of their patients' (1967: 105). In other words, the researchers noticed something similar about nurses' response to their dying patients in a number of different wards. This 'something similar' is an appraisal of how great a loss this patient will be to her friends, family or society as a whole.

What is apparent, then, is that categories are applied to 'things witnessed' (or 'things uttered') on the basis of a perceived similarity. In Glaser and Strauss's example, the first

level of category is *nurses' responses to potential deaths*, introduced (presumably) on the grounds that this is a regularly observable feature of the anticipation of the death of a patient. Once this category is established, it refers to a class of situations that can be studied and compared. In this case, when various members of the class are examined by the researcher, it turns out that they have another feature in common: the tendency of nurses to say things like: 'He was to be a doctor', 'She had a full life', and 'What will the children and her husband do without her?' According to Glaser and Strauss, such comments can be classified as the evaluation of the 'social loss' represented by the patient's death; and the shorthand *social loss* therefore becomes a further category, defining another class of events.

On further examination of the members of this class, it transpires that the evaluation of social loss is associated with the amount, or quality, of care afforded to the patient. Glaser and Strauss do not refer to *patient care* as a category itself; but clearly it must be one, and clearly it must have been retrieved from the data in the same way as 'nurses' responses to potential deaths' and 'social loss'. At this point, however, the authors refer to 'properties': the idea that patient care varies with the degree of social loss is described as a 'property' of the category 'social loss'. It would appear, then, that when one category is observed to be associated – contingently – with another category, Glaser and Strauss talk of the 'properties' of the category; but as this is never spelled out, the discussion can be rather confusing.

However, we can see how theoretical accounts will 'emerge' from constant comparison. Similarities between situations lead to categories which represent that similarity; and additional categories will be identified when further similarities are recognised. When it is

noticed that two categories are regularly associated, a 'property' is identified, and the basis of a (causal) theory is established. Further iterations of this process result in the gradual 'emergence' of a 'substantive theory'.

This is, in essence, the procedure followed for 'between-case' analysis in the current study. For example, a category which emerges from the patient interview data is 'psychological responses to disability'. Comparing the various things patients say about their disability, I recognised a common psychological manoeuvre occurring which involved a lowering of expectations, a relaxing of the criteria for what constitutes an acceptable mode of life. On the basis of this observation, I formulated the concept 'revising downwards' (much as Glaser and Strauss formulated the concept 'social loss' by comparing nurses' responses to potential deaths of patients). This, then, is a theoretical category, rooted in the data.

'Resisting the disabled identity' also emerged from a comparison of the patients' various references to their disability. But, in this case, I also noticed that, in other contexts ('exploring boundaries', a further category), patients implicitly acknowledge disability. This in turn led to the category 'double tracking', the idea that patients both resist and recognize their disability, depending on context. These categories are obviously related to 'revising downwards'; and the whole concept cluster played a significant role in subsequent causal accounts.

The constant comparative method, then, played a crucial role in the analysis of the data collected in this study. However, in other respects the research strategy adopted does not closely resemble grounded theory. How far it is legitimate to borrow this method from

grounded theory while failing to comply with the requirements of (for example) theoretical sampling is a question I will take up in the next chapter.

3.9.3 Narrative

As noted in 3.8.3, some of the interview data collected in this study takes a narrative form. Patients told stories about their recent experiences, or about their lives (carers and health care professionals told stories, too, but I will here focus on the patients). This raises interesting questions, as there has been a great deal of discussion about the place of narrative in both health care (Greenhalgh and Hurwitz 1998*a*, for example) and social research (Elliott 2005; Riessman 1993; Polkinghorne 1988; Mishler 1986). Given the vital role that the analysis of narrative played in this study, there is more to be said about it (in Chapters 4 and 11). Here, I will make only a brief comment about the link between narrative and the constant comparative method in the analytical strategy.

The analysis of narrative can take a number of different forms (see Elliott 2005 for a comprehensive review). For example, a framework proposed by Labov and Waletzky (1967), which involves identifying the phases of a narrative – abstract, orientation, complicating action, evaluation, resolution, coda – has been popular (for example, Riessman 1993; Cortazzi 1991). There are clearly studies in which this is a useful analytical strategy, but it does not suit the purpose of my study, where I am concerned with how patients narrate the story, and how (in doing so) they portray themselves and others in a particular way, producing a certain type of response in the audience. In other words, I am interested in how the patient-narrator deploys a range of narrative devices in order to create a particular effect. To this end, as I will explain more fully in Chapter 11, I draw on a range of literary techniques (Abbott 2002; Manlove 1989).

This approach to narrative analysis dovetails nicely with the constant comparative method, because comparisons can be made between the way in which different patients, as narrators, represent themselves; which in turn permits further new concepts to emerge. If I can expand the example from the previous section, most of the patients in the study told stories in which they represented themselves as resourceful, resilient, problem-solving, and able to cope with situations that might have defeated others. In the same way, then, that the concept of 'social loss' emerged in the main Glaser and Strauss (1967, 1965) example, the concept of 'representing the self as resourceful' emerged here; and, not surprisingly, it was associated with several other categories, such as 'resisting the disabled identity' and 'not needing rehabilitation'. In this way, then, narrative analysis fed the constant comparative method, helping to build concept clusters which were subsequently incorporated into the evolving theory.

From this point of view, then, the analysis of patients' narratives generated further categories and, to that degree, there is no methodologically significant difference between the narrative data and the rest of the interview material. However, as I will show later, narrative plays an additional role in this study. The stories patients told – and, in particular, the way they told them – elicited a certain kind of response from the health professionals; and this link between the story and the response turns out to be one of the key mechanisms accounting for the 'not much rehabilitation' outcome. How this mechanism works is the subject of Chapter 11.

3.10 The audit

Routine medical records and notes are not usually a reliable source from which to try and extract research data: they tend to be incomplete, inconsistent and inaccurate. I was

fortunate, however, in that the radiotherapy unit where I conducted the audit had, starting in 1999, rationalised the process of record keeping. A new multi-professional system of notes had been instituted, with all the participating disciplines contributing to a single, centralised record for the unit; and the system was still being audited at six-monthly intervals when I undertook my own study between July 2003 and June 2005. Moreover, in 2002, a senior house officer, Martin Scott-Brown, had conducted a six month audit of metastatic spinal cord compression patients, extracting data from this system, and had effectively shown it to be reliable. It seemed reasonable to suppose, then, that relevant data could be extracted successfully from the unit notes; and this proved to be the case.

As I shall explain in more detail in Chapter 8, during the two-year period studied, 82 patients were admitted to the unit with a diagnosis of metastatic cord compression. Of these, six were subsequently found not to have the condition, and three records were untraceable. The remaining 73 cases are the basis for the audit.

A data sheet (which can be found at Appendix II) was prepared, and used to extract information from the multi-professional system. It includes data on length of stay, the extent to which patients were in contact with rehabilitation staff, degree of mobility on admission and at discharge, place to which discharged, services offered, and the basis on which these were delivered. The statistical analysis of this data (Chapters 8 and 9) provides a general overview of the care pathway for metastatic spinal cord compression patients during this period, and makes it possible to operationalise 'rehabilitation' in terms of contact with physiotherapists and occupational therapists, as well as equipment and services provided.

I made use of the multi-professional notes in one further way. It was occasionally helpful to check the records on individual patients, in order to determine whether the ideas I was developing were consistent with the detailed, day-by-day entries made by doctors, nurses, and rehabilitation staff. Nothing seemed to disconfirm the theories I was considering, and a number of cases illustrated them rather well. I have included one of these in Chapter 8.

3.11 Summary

In summary, then, the research consisted of a series of interview-based case studies, combined with a retrospective audit of medical notes, with a view to identifying both the consequences of metastatic cord compression for the patient and the mechanisms by which effective rehabilitation can be delivered (or, as it turned out, the mechanisms responsible for the fact that not much rehabilitation is being provided). The study was conceived as an example of Phase I in the MRC framework, and Pawson and Tilley's (1997) Context-Mechanism-Outcome configuration was adopted as a conceptual basis for data collection. Within-case analysis was informed by George and Bennett's (2004) account of process tracing, and between-case analysis was modelled on the constant comparative method of Glaser and Strauss (1967), with analysis of narrative as a variation on that theme.

During this chapter, I have acknowledged the realist implications of the 'mechanism' concept, along with one important consequence: that my conclusions might not match the 'naïve' accounts of interview respondents. This is not, perhaps, the most common understanding of qualitative research, especially accounts of it which lean towards an interpretivist view, or which claim that the researcher's conclusions represent just one

construction, not necessarily 'privileged', among others. So widespread are these latter views of qualitative methods that, in the next chapter, I will briefly defend the position adopted here.

Chapter 4

Philosophical considerations

4.1 Introduction

The previous chapter concentrated on the technical aspects of the research design, and put a number of theoretical and philosophical questions on hold. However, I recognise the need to clarify and explain the position I have implicitly adopted in formulating the design, and I will do so in this chapter. I will deal with four topics, which I will outline briefly before going on to discuss them in greater depth:

4.1.1 Realism and antirealism

The research design is explicitly realist in orientation, and cuts across the many antirealist currents in social theory, as well as a significant body of methodological writing, especially in qualitative research: phenomenology, constructivism, naturalism, hermeneutics, and other postmodernist approaches. My position is that we can aspire to accounts of an ontologically independent world which are at least approximately true, and that these approximately true accounts, proposed by the researcher, need not correspond to the accounts offered by people who participate in the study. I need to justify this position, if only briefly.

4.1.2 Borrowing from grounded theory

The data analysis strategy adopts the constant comparative method of grounded theory, but the study does not (partly because it cannot) comply with other grounded theory requirements, particularly that of theoretical sampling. I need to justify this rather eclectic attitude – an attitude which some authors (Baker *et al.* 1992) describe as ‘method slurring’ – and to explain why borrowing from grounded theory is consistent with realism.

4.1.3 Realism and narrative

As I have noted, some of the data elicited in the interviews took the form of narrative, a concept which, during the last decade or so, has become the focus of considerable interest in social research. However, there are numerous ambiguities about the role of narrative in research studies, and narrative-based research is not usually associated with the kind of realism I adopt here. I need to explain my approach to narrative, and explain why it fits the realist orientation of the study.

4.1.4 Causal claims and mechanisms

In the social sciences, the idea of a 'mechanism' is inevitably associated with realism, and a realist approach to research and evaluation. However, the concept has only recently been borrowed from the philosophy of science, and is not yet widely used in health services research. Crucially, any description of a mechanism will imply some sort of causation; and causal processes are in fact referred to in the investigation's research questions ('What are the *effects* of rehabilitation, when it is provided?', 'When rehabilitation is not provided, what *accounts for* this?'). Qualitative research tends to steer clear of the idea of causality, and most constructivist methodological writing actively rejects it. Moreover, there are very reasonable philosophical grounds for arguing that the only way properly to identify causal relations is through statistical analysis. I need to show that I have some prospect of identifying causal relations in a qualitative study.

It will be evident from this brief summary that these topics are all linked. Causality and mechanisms intrinsically belong to a realist framework, and (I would argue) grounded theory is most naturally understood as a realist approach to social research, despite attempts, by some writers, classify it as 'interpretivist'. Narrative, which is connected to

grounded theory in this study, has not been widely discussed in a realist context – I know of only one significant exception – but I will suggest that an interest in narrative is not inconsistent with realism. I will try to bring out other links between these topics as I proceed.

4.2 Realism and antirealism

It is sometimes argued that qualitative research presupposes antirealism. Here are two examples: ‘qualitative research is based upon the belief that there is no one singular universal truth, the social world is multi-faceted, it is an outcome of the interaction of human agents, a world that has no unequivocal reality’ (Cutcliffe and McKenna 1999). ‘The qualitative paradigm does not conceive of the world as an external force, objectively identifiable and independent of man. Rather, there are multiple realities’ (Filstead 1979: 35). On other occasions, an antirealist perspective is adopted independently of the view that there is something called the ‘qualitative paradigm’ that presupposes it: ‘It does not make sense to speak of a division between a ‘subjective’ mind and the ‘objective’ world’ (Omery and Mack 1995: 141). ‘There is no such thing as an objectively ‘true’ account of ‘things in themselves’ [and] there is no technical procedure for ‘validating’ that an account corresponds to this timeless, objective ‘truth’ (Leonard 1999: 60). ‘Objectivity is a chimera: a mythological creature that never existed’ (Lincoln and Guba 2003: 279). ‘There exist multiple, socially constructed realities’ (Koch 1999: 25). For all of these writers, the notion that there might be an objective account of independent ‘things in the world’ is illusory. In response, I would like to offer four observations.

First, despite the pervasiveness of the antirealist position, particularly in qualitative nursing and allied health research (for example, Aranda 2006; Foster *et al* 2006; Rolfe 2006;

Speziale and Carpenter 2006; Stevenson 2005; Hammell and Carpenter 2003), it does not represent a consensus. In offering an alternative position, I draw on a tradition within sociology and social theory which stretches back nearly a century, and arguably back to J.S. Mill (1806 – 1873). It includes writers who describe their work as ‘analytic induction’ (Cressey 1953; Robinson 1951; Lindesmith 1947; Znaniecki 1934); connects to some classic methodological writing of the 1950s and 1960s (Glaser and Strauss 1967; Becker 1958); surfaces in the context of qualitative comparative analysis (Ragin 1992) and British ethnography (Hammersley 1991; Hammersley and Atkinson 1983); and leads to recent discussions of social mechanisms (Hedström and Swedberg 1998*a*; Pawson and Tilley 1997; Elster 1989). In a somewhat different form, it also links to critical realism (Bhaskar 1998; Bhaskar *et al.* 1998). By appealing to this tradition, for every reference to ‘multiple realities’ or the ‘chimera of objectivity’, one can respond with a reference to ‘moderate realism’ (Hammersley 1991), ‘fallibilism’ (Seale 1999), or ‘approximate truth’ (Miller 1988).

Second, a realist position implies that it is possible for one person to be closer to the truth, or to portray it in more accurate and persuasive terms, than another. The postmodernists may claim otherwise, and Guba and Lincoln (1989: 45) may suggest that ‘data derived from constructivist inquiry have neither special status nor legitimation; they represent simply another construction to be taken into account’, but the fact remains that the researcher is in a position of epistemological privilege. The main point, I would argue, is this: in any investigation, each participant has only one case – his or her own experience – on the basis of which to make sense of things. The researcher, by contrast, has a much wider range of cases (that is, all the people interviewed) to draw on. This is not merely a matter of sample size. Even more significantly, the researcher is in a position to spot

connections between the different cases that no individual respondent can possibly see, and is therefore able to formulate ideas and concepts not available to participants. It is this kind of epistemological privilege – and the ability to make ‘constant comparisons’ – that grounded theory takes advantage of.

Third, the argument that qualitative research is inescapably wedded to a particular view of the universe – that there is no ‘single, objective reality’ – or that it presupposes this view, seems flawed. It is not so much argued, as stated. Why should the use of certain research tools commit the researcher to an ontological position? Why, for that matter, should the use of quantitative tools be deemed ‘reductionist’? Taking someone’s temperature, or calculating their body mass index, does not commit us to the view that everything can be reduced to numbers (Eva and Paley 2004), any more than using a spoon to eat a bowl of cereal commits us to the view that the universe consists of fluids and small particles. Quantitative and qualitative research tools are on different scales. Maps provide a helpful analogy here: the use of an Ordnance Survey map does not ‘presuppose’ a belief in the existence of footpaths which a motorway map denies. In the same way, the use of quantitative research instruments does not ‘presuppose’ a realist view of the universe, while the use of qualitative research instruments ‘presupposes’ an antirealist view. Tools, including research tools, do not have ontological beliefs built in (Paley 2000). Researchers will no doubt have their preferred ontology, but it is a mistake to suppose that using certain kind of tool somehow *commits* you to a particular view of the universe.

Finally, there is a pragmatic consideration. An antirealist position may be feasible in certain kinds of sociological or anthropological study, which are not intended to have

directly practical consequences. In health services research, however, the position is somewhat different. Consider a research study in which a patient claims one thing (perhaps that rehabilitation was not offered) but health care professionals claim something else (that it was, but the patient showed no interest). This is the situation implied by 'Anne's story' in Chapter 2. If we are to understand how rehabilitation services can be designed and then delivered, in a way that the patient can both recognise and understand, then the answer to the question 'What actually happened?', as a chunk of history, is vitally important. Two scenarios suggest themselves in this case. The health professionals did not, in fact, offer rehabilitation; or they did offer it, but the patient was not in a fit emotional state to recognise this fact (and the health professionals failed to recognise *that*). The practical implications of these two scenarios are completely different. Being able, on empirical grounds, to discriminate between them is therefore essential. A postmodernist stance of undecidability would not contribute to the practical task of developing a service to patients.

4.3 Borrowing from grounded theory

4.3.1 Grounded theory and realism

Despite frequent claims that grounded theory belongs to the antirealist 'interpretivist paradigm' (see, for example MacDonald and Schrieber 2001; Charmaz 2000; Annells 1996), I would argue that it is entirely consistent with realism, at least as far as the original text, *The Discovery of Grounded Theory* (Glaser and Strauss 1967), is concerned. It is true that Strauss and Corbin (1998) tend to encourage the interpretivist view, but Glaser (2001) has repudiated it; and although *The Discovery of Grounded Theory* focuses on the generation of theory, Glaser and Strauss do not reject the project of verification (1967: 12-18), they

merely wish to redress the balance in methodological writing. Moreover, with regard to qualitative and quantitative methods, they insist that *'each form of data is useful for both verification and generation of theory'* (1967: 17-18, emphasis in original).

Consistent with my view about the inevitability of the researcher's epistemological privilege, the categories, properties and theories which 'emerge' from the constant comparative method need not reflect the concepts spontaneously used by study participants. This is certainly true of the study on which Glaser and Strauss draw to illustrate their ideas. 'Social loss' is a researcher's concept, generalising over comments such as 'He was so young, 'He was to be a doctor', 'She had a full life', and so on (1967: 106). And there is no suggestion that the theoretical account, 'patient care tends to vary positively with degree of social loss' (1967: 106), is one the health professionals would recognise, let alone accept. It is also worth noting that this is, by implication, a causal claim: it is the assessment of social loss that determines the amount, or quality, of patient care.

In all these respects, Glaser's and Strauss' book is clearly consistent with realism (Dey 1999). In saying this, I want to distance myself from writers, such as Charmaz (2000), who have described it (and Glaser's subsequent writings) as 'positivist'. This claim is based on the widespread assumption that positivism is a realist doctrine; but it has been persuasively argued (Paley 2001; Hacking 1983; Halfpenny 1982) that most positivists were – and, in some cases, still are – antirealists. To the extent that this is true, Glaser and Strauss cannot be placed in the positivist camp. In the discussion which follows, then, I will take *The Discovery of Grounded Theory* to be a text consistent with realism – if not

expressly a realist text – and that this claim conveys an approximate truth, in correspondence with the facts.

4.3.2 Grounded theory: three key ideas

At the core of grounded theory, as represented by Glaser and Strauss (1967), are three ideas. First is the emphasis on theory generation, as opposed to theory verification. Grounded theory is a way of arriving at concepts and theories through an analysis of data; attempts at verification may follow later, but they are not grounded theory's primary concern. Second is the principle of theoretical sampling, which is designed to ensure that a sufficiently diverse set of data is examined. The idea here is that, in theory generation, diversity in sampling is more important than statistical representativeness, which is more appropriate to theory verification. Third is a method of generating theoretical concepts, the constant comparative method. By analysing the data in a certain way, and by identifying various 'categories' and 'properties', new concepts – obviously well suited to making sense of the data – can be formulated.

There are a number of other features associated with grounded theory, such as Glaser and Strauss's approach to (not) reading the literature before commencing fieldwork. However, these features are not emphasised to the same degree in the text, and they do not seem to define grounded theory in quite the same way (Atkinson *et al.* 2003). So I will limit myself to commenting briefly on these three fundamentals.

The concept of theory generation is congenial from my point of view, given that the present research is conceived, in part, as a Phase I Modelling study in MRC terms. Theory verification would be closer to an exploratory trial or the definitive randomised controlled

trial. Similarly, as I have explained in Chapter 3, the constant comparative method reflects the way in which theoretical concepts were formulated during data analysis. I would argue, then, that this study incorporates two of the three fundamental ideas of grounded theory.

The principle of theoretical sampling, however, is not something I was able to comply with fully. As with the constant comparative method, Glaser and Strauss's account of theoretical sampling tends to lack precision; but the outline is clear: 'the basic question in theoretical sampling... is: *what* groups or subgroups does one turn to *next* in data collection?' (1967: 47, emphasis in original). Sampling is driven by the progressive development of theoretical concepts, not by any requirement that the achieved sample be representative: 'our criteria are those of *theoretical purpose and relevance* – not of structural circumstance' (1967: 48, emphasis in original). This involves decisions about what to observe, or who to interview, being made during the course of the research, rather than at the outset (as would be the case with a survey, for example). This was not really feasible in the present study, given that my cases – and therefore my interview respondents – were significantly determined by 'structural circumstance': admissions to one radiotherapy unit over a certain period of time, and limited to patients deemed by staff to be physically and emotionally robust enough to participate in the research. While it was my intention to achieve maximum variety sampling, I was not sufficiently in a position to make decisions about 'what groups to turn to next' on the basis of an emerging theory.

However, if Glaser and Strauss's idea is slightly reinterpreted – if, for example, we argue that it is the data collection strategy *in general* that is governed by theoretical considerations, rather than sampling *specifically* – then even the present study can be said

to comply with that principle. I can make this claim on the grounds that, in the later phases of the study, decisions about which individuals to interview, and what questions to ask, were indeed led by the theoretical account that was gradually emerging. While one could equally frame this as a hypothesis-testing strategy, of the kind recommended by Pawson and Tilley (1997), it is not clear that these two descriptions – theoretical sampling and hypothesis testing – are referring to different activities. As Seale (1999) has argued, theoretical sampling can plausibly be regarded as a testing procedure, even if Glaser and Strauss do not themselves depict it in those terms. The more general version of the ‘theory-driven’ principle – that the data collection strategy as a whole is partly governed by the ongoing development of theory – underlies the concept of a ‘flexible design’ (Robson 2002) which explicitly includes grounded theory in its rubric, and which I referred to in Chapter 3.

In summary, then, the study borrows two of the three key ideas in Glaser and Strauss (1967). The one significant exception, theoretical sampling, could not be adopted for practical (and ethical) reasons. However, in a more general sense, the study was still theory-driven, given that the data collection strategy was, in its later stages, partly governed by the gradual development of a theoretical account. Moreover, grounded theory is entirely consistent with the realist orientation, a fact which is suggested by some of Glaser and Strauss’s own examples.

4.4 Realism and narrative

I noted in the previous chapter that some of the interview data in this study took a narrative form, and observed that there has been a great deal of discussion about the place of narrative social research (for example: Elliott 2005; Riessman 1993; Polkinghorne 1988;

Mishler 1986). In much of this literature, narrative is associated with constructivism (Foster *et al.* 2006; Mills *et al.* 2006; Bailey 1997; Gubrium and Holstein 1997), hermeneutics (Barton 2004; Wiklund *et al.* 2002; Frid *et al.* 2000; Ezzy 1998), and other antirealist approaches. To what extent, then, is the recognition of narrative as an analytical concept consistent with realism?

One way of dealing with this question is to cite the connection, in this study, between narrative analysis and the constant comparative method, as described in Chapter 3. Showing how narrative elements are used, by patients, to portray themselves in a certain way leads to the formulation of concepts and categories that can be used in the process of building a theory about how patient-narrators respond to disability. As with other theoretical claims in grounded theory, these researcher-accounts will not necessarily coincide with the explanations offered by the respondents, and are intended to describe a pattern of events and circumstances which (as I argued earlier in this chapter) individual respondents may not be in a position to recognise. In this context, therefore, realism does not involve taking the patient's story as an accurate rehearsal of what took place; it means using the story as evidence on which to base a theory, aspiring to accuracy, of the patients' reactions to disability and the malignant spinal cord compression diagnosis.

This line of thought shares with constructivism the view that patients use narrative to 'construct the self'. Admittedly, I would prefer to say that they use narrative to *portray* the self (to themselves, as well as to others) in a particular way, and I would take a non-committal view of whether this 'construct' really *is* the self, or whether it is just a representation (which may, or may not, be accurate). But the constructivists and I agree

that people use narrative to construct and communicate significant ideas about themselves.

However, in placing narrative analysis in the context of Glaser and Strauss's version of the constant comparative method, I am taking an important further step. This step is to use between-case analysis to generate new categories from the narrative data, and to formulate explanatory hypotheses. It is to say, of a certain group of patients, that they 'construct the self' in a similar way, and with similar consequences. In fact, I will suggest (in Chapter 11) that some of these consequences affect, not merely the patient, but the health care professionals who listen to, and interpret, the narratives they hear. This further step achieves two things in particular: it implicitly generalises to a population, and it makes a causal claim (that the patient's construction of the self has a specific effect). This is, perhaps, the point at which the constructivist and I part company.

Without going into the details prematurely, Chapter 11 will argue that the way in which health care professionals 'process' the patients' narratives, the way in which they unreflectively make sense of the stories they hear, leads them to make various assumptions, which in turn lead to various decisions. The 'processing' of narrative is an important part of this account, and the idea is that this 'processing' is based on the cues which the narrative itself provides. It follows that a careful examination of these cues – the range of narrative features and devices that stories employ – is essential to an understanding of the causal link between story and response. If we can trace how these features of a story – plot, characterisation, narration – encourage the 'audience' to 'read' it in a particular way, we can understand why the audience then reacts as it does. As I have already suggested, the explanation that emerges, citing a number of psychological

mechanisms, will not necessarily match the respondents' accounts of what is going on. This is the ultimate hallmark of realism: the researcher proposes the existence of a mechanism which does not reflect the respondents' constructs.

This use of narrative analysis in the context of grounded theory converges with some recent developments in 'psychonarratology', the empirical study of literary response (Bortolussi and Dixon 2003) and, more generally, interdisciplinary work on narrative theory and the cognitive sciences (Herman 2003). As Bortolussi and Dixon observe, a great deal of theory in literary criticism is untested, while 'readers' are 'understood as universal, aggregate, hypothetical entities responding in unison' (2003: 6). Outlining a systematic programme of empirical research on readers' responses to narrative, they point out that a first requirement is to be able to define 'textual features' objectively. These features include the distinctions made in classical studies of narratology, such as narration styles, plot structure, techniques for marking discourse and story time, and aspects of characterization. They are represented by '*text variables*', while reader responses are represented by '*construction variables*' (2003: 47). The goal is to examine the causal relation between the two.

Bortolussi and Dixon have literary narratives primarily in mind, and their research interests are largely experimental. In contrast, I am dealing with 'natural' narratives, and the present study is qualitative. However, the cognitive approach to narrative includes 'narrative experiences' (Gerrig and Egidi 2003) other than literary ones, and the theory of 'natural narratology' says that 'the framework of natural narrative can be applied to *all* narrative' (Fludernik 2003: 244, emphasis in original), an idea which Jahn (2003) extends to the 'internal' narratives of recollection, dream and imagination. Moreover, in some

instances the cognitive approach has involved the study of health and illness (Klein 2003: 56, for example, claims that 'narrative accounts of traumatic events aid the healing process'). As for the second contrast, the main question is whether causal claims about the relation between textual features and reader responses can be made on the basis of qualitative studies; and this, in its generalised form (whether causal claims of any kind can be made by qualitative researchers) is a topic that I will deal with in the next section.

In summary, then, the use of narrative analysis is consistent with a realist orientation, and my interest in the causal link between the narrative devices used by patients and the response of health care professionals reflects the trend towards interdisciplinary studies of the causal link between 'textual' and 'construction' variables. The question still outstanding concerns the capacity of qualitative research, rather than experimental studies, to identify these causal links, and it is to this that I now turn.

4.5 Causal claims and mechanisms

To what extent, and by what means, can a qualitative study identify causal relations? The question is not answered in the MRC framework for the evaluation of complex interventions, even though the rubric for Phase 1 includes the instruction: 'Identify [...] the underlying mechanisms', and notes that this might be achieved by 'qualitative testing through focus groups, preliminary surveys, case studies, or small observational studies' (Medical Research Council 2000a: 4). Nor is it explicitly discussed in (for example) Glaser and Strauss (1967), even though many of their theoretical statements are implicitly causal ('patient care tends to vary positively with degree of social loss'). They refer only to the observation of an association between categories, leading to the identification of a category's 'properties' (discussed in the previous chapter). On the other hand, as I have

noted, a great deal of writing about qualitative research rejects the very idea of causation, and there is a philosophical and sociological tradition which suggests that causes can only be identified statistically. Perhaps this is the best place to start.

4.5.1 Statistical and Boolean methods

Arguably, the most common approach to identifying causal relations in sociology is through statistics. This is often traced back to Hume's account of causation, which is that it consists of no more than regularities: to say that A causes B is merely to say that all (or most) instance of A are followed by instances of B. In philosophy, this idea became the standard view during the middle years of the 20th century (Salmon 1989), the period dominated by logical positivism, and was codified by Hempel and Oppenheim (1948) in the 'deductive-nomological' theory of explanation, or the 'covering law' model. Although the covering law model was originally intended as an account of explanation in the natural sciences, Hempel (1942, 1962) also applied it to social science, subject to the qualification that universal laws (*all* instances of A are followed by instances of B) are very unlikely in this context, so social scientific laws must be probabilistic (it is probable, to some specifiable degree, that instances of A will be followed by instances of B). In practice, this view translates into familiar statistical procedures such as regression, which is designed to weight independent variables, treating them as causal factors.

There is, however, a current of thought in sociology which represents, in effect, a qualitative variation on this statistical theme. It is associated with the term 'analytic induction', and in its most recent version it is based on Boolean logic.

4.5.2 Analytic induction and qualitative comparative analysis

Analytic induction was originally associated with Znaniecki (1934), though its best known codification is by Cressey (1953: 16). The procedure Cressey describes has several steps. First, a rough definition of the phenomenon to be explained is formulated. Next, a hypothetical explanation of this phenomenon is constructed. Third, a single case of the phenomenon is studied, to determine whether the hypothesis fits the facts. Fourth, if the hypothesis does not fit the facts, either the hypothesis is reformulated, or the phenomenon is redefined in such a way as to exclude the case. Fifth, further cases are examined, in the same way, until what Cressey calls 'practical certainty' is attained, and (sixth) a universal relationship is thereby established.

The procedure bears some resemblance to Mill's Method of Agreement (Halfpenny 1982: 94). Take several cases of the phenomenon, *X*, and examine its antecedents on each occasion. Suppose that, for two such cases, the antecedents are: ABC and ADE. Then, according to the Method of Agreement, we may hypothesise that A, the common factor in these antecedent clusters, is the cause of *X*. If a further case is now examined, in which the antecedents are AFG, the hypothesis continues to 'fit the facts'. If, on the other hand, the antecedents of the new case are BFG, the hypothesis will have to be revised (for example, the reformulated hypothesis might suggest that the cause of *X* is either A or B separately, or both of them working together).

There are obviously some severe limitations to this procedure, in both the Mill and Cressey versions. It is, for one thing, very vulnerable to counter-examples. We would have a problem if the antecedents of the fourth case to be examined are CDF. There is no obvious way of reformulating the hypothesis in a way that makes sense of all four cases,

and it is by no means clear whether a somewhat bigger sample will make matters worse or better. Moreover, the most that this procedure can achieve is to identify the necessary conditions of X (as only cases of X are examined). There is, with this method, no way of determining the phenomenon's sufficient conditions. For even if A were constantly present among all the examined cases of X, we would have no way of knowing whether *all* As are followed by X. The only method of determining this is to examine at least some relevant cases of $\sim X$, to see whether any of them have A as an antecedent. This is the main point made by Robinson (1951) in the best known critique of analytic induction.

Following Robinson's critique, only partially ameliorated by Turner (1953), analytic induction fell out of favour. However, it has been rehabilitated, at least to some extent, in more recent writing (Goldenberg 1991; Manning 1991). The main change is the introduction of the comparative dimension, in which the researcher examines different types of case, including 'those marked by negative as well as positive outcomes' (Hicks 1994: 92); in other words, cases of $\sim X$ as well as X. This new version is, in effect, the one that is presented by Denzin (1989) and Hammersley and Atkinson (1983), and is designed to circumvent the second problem outlined in the previous paragraph. It does so by adding the Method of Difference to the Method of Agreement (Halfpenny 1982), although it is still doubtful that it can attain a 'universal solution' of the kind envisaged by Cressey.

One particular problem, even in the revised form of analytic induction, is that it makes no provision for hypotheses of any complexity, or for joint effects of multiple causal conditions (Lieberson 1991; Glaser and Strauss 1967). For example, consider three 'positive' cases and three 'negative' cases:

X ABC, ACE, BCD

~X ADE, BDE, CDE

Here, it is impossible to identify a single factor as either a necessary or sufficient condition of X. All five factors appear in both X and ~X cases. However, further inspection of these cases does suggest a possible hypothesis: that a necessary (and conceivably sufficient) condition for X is the presence of any *two* of A, B, and C. This hypothesis would no doubt have to be tested against additional cases; but it at least discriminates between the six cases we do have. A further development of analytic induction, therefore, would usefully include a system for identifying more complex conditions than those that are associated with a single factor.

The Boolean logic incorporated into qualitative comparative analysis offers a solution. Introduced by Ragin (1987), qualitative comparative analysis involves the study of a relatively small number of cases, some of which are 'positive' and some of which are 'negative', and the use of Boolean logic to identify complex sets of necessary and sufficient conditions. In the example above, Ragin would use the formalism $[X = AB + BC + AC]$ to express the 'solution' to the set of six cases. However, larger data sets, and more complicated solutions, are also feasible with the aid of the appropriate software package. Ragin (1987) discusses Mill's methods, along with analytic induction, in his review of 'case-oriented comparative methods', and it is clear (as Hicks 1994 also notes) that qualitative comparative analysis is designed to build on that tradition.

There is, however, a further limitation in analytic induction (and, correspondingly, in qualitative comparative analysis). This limitation is that, in common with statistical methods, analytic induction identifies relations between variables. Where statistical

procedures represent the connection between independent and dependent variables through regression equations, say, analytic induction and qualitative comparative analysis represent it through necessary and sufficient conditions or Boolean logic. In both cases, the causal connection is depicted as an association between the variables concerned. This is a limitation because, in an association, there is frequently a sense of 'missing information'. For instance, Ragin (1987) undertakes a reanalysis of a study by Rokkan (1970) in which the dependent variable is 'whether a major split in the working class movement was provoked by the Russian Revolution' in a number of European countries. The independent variables included: 'whether the state established a national church or remained allied with the Roman Catholic Church', and 'whether the state formed early or late'. A Boolean solution to the truth table for this study can be derived – for example, one condition associated with a split in the working class movement, after the Russian Revolution, is a national church in a late-forming state – but there is nothing in this solution which 'shows the working'; it remains unclear, in other words, exactly how this condition causes the working class movement to split. All we have is a 'black box', with the independent variable as input, and the dependent variable as output. What is missing, arguably, is something that recent writers have called a 'causal mechanism' or a 'social mechanism'.

This brings us full circle, and prompts some further comments on the idea of a causal mechanism.

4.5.3 Mechanisms again

There are several ways of defining 'mechanism' in this context (Mahoney 2000). One of them treats causal mechanisms as synonymous with independent variables associated

with outcome. For example, Boudon (1998: 172) defines a social mechanism as 'the well-articulated set of causes responsible for a given social phenomenon'. This does not help us to get beyond relationships between variables. An alternative approach is to define a mechanism as an event or process which 'intervenes' between the independent and the dependent variable. For example, Hedström and Swedberg (1998b: 13) describe mechanisms as 'analytical constructs that provide hypothetical links between observable events'; and Kiser and Hechter (1991: 5) say that a mechanism 'describes the process by which one variable influences the other, in other words, how it is that X produces Y'. This is an improvement, but is still somewhat ambiguous, as it leaves open the possibility that the 'mechanism' is yet another independent variable mediating the association between X and Y. If the idea of a mechanism is to have theoretical value, it will have to be something more than another name for an additional independent variable.

A third alternative is explicitly associated with realism, and defines causal mechanisms as 'ultimately unobservable physical, social or psychological processes through which agents with causal capacities operate, but only in specific contexts or conditions, to transfer energy, information, or matter to other entities' (George and Bennett 2004: 137). Similarly, Mahoney (2001: 575) defines a causal mechanism as 'an unobservable entity that – when activated – generates an outcome of interest'. Additionally, of course, there is Pawson and Tilley, who make a point of distinguishing between a mechanism and a variable: 'A mechanism is thus not a variable but an *account* of the make-up, behaviour and interrelationships of those processes which are responsible for the regularity' (1997: 68).

While this line of thought owes something to Merton (1967), the reference to unobservability in some definitions indicates the influence of Bhaskar (1998). But it is not

immediately obvious why a causal mechanism, in the social sciences, *has* to be unobservable (Bhaskar's ideas were originally worked out in the context of natural science). One reason that has been offered (for example, by Mahoney 2003) is that, if the mechanism were observable, it would no longer be the 'final mover', but would itself be in need of explanation; in other words, a causal mechanism that becomes observable loses its mechanism 'status', and reverts to being just another variable. I do not find this particularly convincing. To use an analogy: removing the back of a clock, and examining the arrangement of components inside, does not change the status of the mechanism that makes it work, although it is true that further explanations may now be necessary to explain how this or that component functions. But the fact that causal explanations occur in 'hierarchies' is not necessarily related to the question of observability: one may explain how X works by referring to mechanisms A, B and C, and then launch into an explanation of how C works by referring to 'sub-mechanisms' P, Q and R, and still have everything (X, A, B, C, P, Q, R) in full view.

In this study, as Chapter 3 has made clear, I adopt the idea of a mechanism as a process of some kind, a process which can in principle be described, step by step, as an intelligible sequence (with no 'gaps', as it were), but not one that is necessarily unobservable. This is the reason for my interest in what George and Bennett (2004) call 'process tracing'. In adopting this idea, I select from a range of 'nuts and bolts', as described by Elster (1989) with particular emphasis on various psychological states, along with some more sociologically oriented concepts. As Hedström and Swedberg (1998b: 21) note, 'explanations of most concrete social events or states require resort to several elementary mechanisms; one is not enough'. This observation reflects my own experience, in that I

arrived at what seems to be a persuasive causal explanation of the way in which rehabilitation services are delivered (or, often, not delivered) to patients with metastatic spinal cord compression by collating these mechanisms into a specific, and detailed, account.

In doing so, I explored the connection between the idea of a mechanism and the idea of a system. The earlier reference to hierarchies of explanation is reminiscent of the systems theory literature (Skyttner 2001; Pattee 1973*a*; Boulding 1956), in which systems are represented as being organised hierarchically (systems, sub-systems, and so on). To this extent, it may be worth examining the extent to which some mechanisms, or some combinations of mechanisms, are the equivalent of certain types of system. It will turn out (in Chapter 10) that the causal process I describe is best construed as a very particular type of system – a complex adaptive system (Johnson 2001; Stacey *et al.* 2000; Flake 1998; Holland 1995). I will postpone a fuller discussion of this idea until then.

4.5.4 The context of discovery and the context of justification

I began section 4.5 with the following question: to what extent, and by what means, can a qualitative study identify causal relations? An initial response to this question was to suggest that analytic induction, perhaps in its most recent version, qualitative comparative analysis, might be regarded as the qualitative equivalent to statistical analysis, relating independent and dependent variables through Boolean logic rather than through regression weightings or odds ratios. But there are problems with this approach, because (like statistics) it puts a ‘black box’ where one would expect some account of the ‘cogs and wheels’ (Hernes 1998: 74). This returned the discussion to mechanisms and to

the idea that, in some cases at least, the relevant mechanisms might be observable (although the clock example is only analogical).

There were times in this study when I did have the impression that I was doing the equivalent of inspecting the inside of the clock: 'but if you think that, then it follows that you will do this; and then the consequences will clearly be...'. Certainly, I tried to put the material together in a 'cogs and wheels' sort of way. In the final analysis, however, I think this impression is illusory. I agree with Hume that we do not in fact *observe* causation, even though it often feels like that. What we do instead is observe things that suggest – sometimes powerfully – that a causal mechanism is operating. But this observation, and the thoughts that spring from it, take place in the 'context of discovery' (Giere 1999), which refers to whatever it is that prompts people to formulate hypotheses about the world, whether it involves inspection of the data, a sudden hunch, a series of conversations, or even a dream. Such experiences can lead to firm convictions, and a sense of 'knowing'. But being convinced is not the same as demonstrating, or providing strong evidence; and the testing of the hypotheses that have been formulated takes place in the context of justification. In the social sciences, this inevitably involves a more systematic enquiry and statistical testing.

The question as to whether qualitative research can *identify* causal relations is, I will suggest, ambiguous. While it can serve as a context of discovery, a method of grounding hypotheses in data (as I think Glaser and Strauss intended), it cannot serve as the context of justification, a method of confirming those hypotheses. The MRC document on complex interventions succumbs to this ambiguity, at least in terms of the language it uses: 'identify [...] the underlying mechanisms' (2000a: 6). But what it means is: 'on the

basis of case studies, focus groups, or observation studies, identify things that look as if they might be underlying mechanisms'. In other words, formulate hypotheses about what the mechanisms are; subsequently, test those hypotheses in a Phase II exploratory trial and a Phase III definitive RCT (the context of justification).

So we come full circle again, with a result that might seem disappointing. Qualitative studies can be richly suggestive, but they cannot confirm or disconfirm. Was that not known already? Certainly; but the point of the discussion has been to show that the methods adopted in this study are consistent with its realist orientation, and that 'seeking causal mechanisms' is something that a qualitative study can legitimately do, even if it cannot finally demonstrate that those mechanisms really do exist.

This discussion secures the philosophical underpinnings of the study, as a basis for the presentation and discussion of the results in Parts II and III.

Chapter 5

Procedures and patients

In this chapter I will describe the practical and procedural aspects of the study (for example, the ethical considerations, recruitment, interview procedures), and briefly introduce to the patients on whom the nine case studies are based.

5.1 Ethical considerations

Patients with metastatic spinal cord compression comprise a vulnerable group. For many, the onset of spinal cord compression is an indication of advancing cancer, and the days, weeks and months following diagnosis are likely to be anxious and uncertain. Over the last decade, there have been debates about the ethical acceptability of any kind of research with dying patients (Hopkinson *et al.* 2005; Jubb 2002; Casarett and Karlawish 2000; Mount *et al.* 1995; de Raeve 1994), with the argument that ‘dying’ in itself should exclude people from research, being countered by the position that research will strengthen the evidence base thereby leading to better care. The volume of research reported in palliative care journals would seem to indicate that the latter view predominates, but research ethics committees are known to be cautious in approving studies seeking to recruit dying patients (Ewing *et al.* 2004; Lee and Kristjanson 2003; Stevens *et al.* 2003).

In this study, careful consideration was given to the general ethical principles of integrity, justification, justice, beneficence, respect and honesty (Medical Research Council 2000*b*).

In particular, attention was paid to the following aspects:

- A clear justification for the study, and its potential to contribute to actual improvements in patient care.

- My own skills and abilities as a sufficiently competent and sensitive researcher.
- The availability of support for participants, should they need it, and for myself.
- Research governance in the form of academic supervision through Stirling University and through the regular (bi-annual) meeting of a Research Advisory Group which included two patients and a carer (see Appendix III).
- A carefully designed recruitment protocol (see Appendix IV), recognising the importance of patients not being coerced into participating.
- The availability of clear written information for all participant groups – patients, carers and health care professionals. (These are included in Appendices V, VI and VII.)
- Written consent was obtained from every participant (an example of the consent form is included at Appendix VIII). In addition, a method of process consent was used (Beaver *et al.* 1999), whereby continuing participation in the study was negotiated at every contact with patients, carers and health care professionals.
- A clearly thought-through strategy for intervening in situations where concerns arose relating to safety or poor practice. (In the event, there were no significant incidents.)

The study received approval from the Oxfordshire Applied and Qualitative Research Ethics Committee (date of application: 7 April 2003; date of approval: 8 May 2003; AQREC Study No.: A03.003) and from Stirling University Department Research Ethics Committee (date of application: 12 May 2003; date of approval 17 July 2003). (See Appendix IX.)

5.2 Funding

This study was funded by a local health services research fund, the Oxfordshire Health Services Research Committee, with the specific intention that results would improve local services. A grant of £53,421 was provided to cover staff costs (mine as researcher and secretarial support for transcribing the audio taped interviews) and associated research costs. A Gantt chart of research activity over the three year funded period is provided in Appendix X. I was funded for two days a week for three years to carry out the research. For the remaining three days a week, I was employed by the Oxford Radcliffe Hospitals Trust as the manager of the Hospital and Community Palliative Care (Macmillan nurse) teams.

5.3 Recruitment of participants

Patients with metastatic spinal cord compression who were referred for treatment at the Oxford Cancer Centre in the two year period between July 2003 and June 2005, and who were deemed by medical and nursing staff to be well enough to be interviewed, were eligible for participation in the study. Written permission was obtained from all relevant consultants for their patients to be approached. Patients were recruited from the Frank Ellis radiotherapy unit, from the hospice (Sir Michael Sobell House) and through the oncology out-patient clinic. (I describe the geographical context of the study in more detail in Chapter 6.) All patients recruited had received radiotherapy on the Frank Ellis Unit.

5.3.1 Method of recruitment

In the first instance, patients were approached by a member of staff known to them, usually a ward nurse or doctor, or a consultant. A structured and clear recruitment

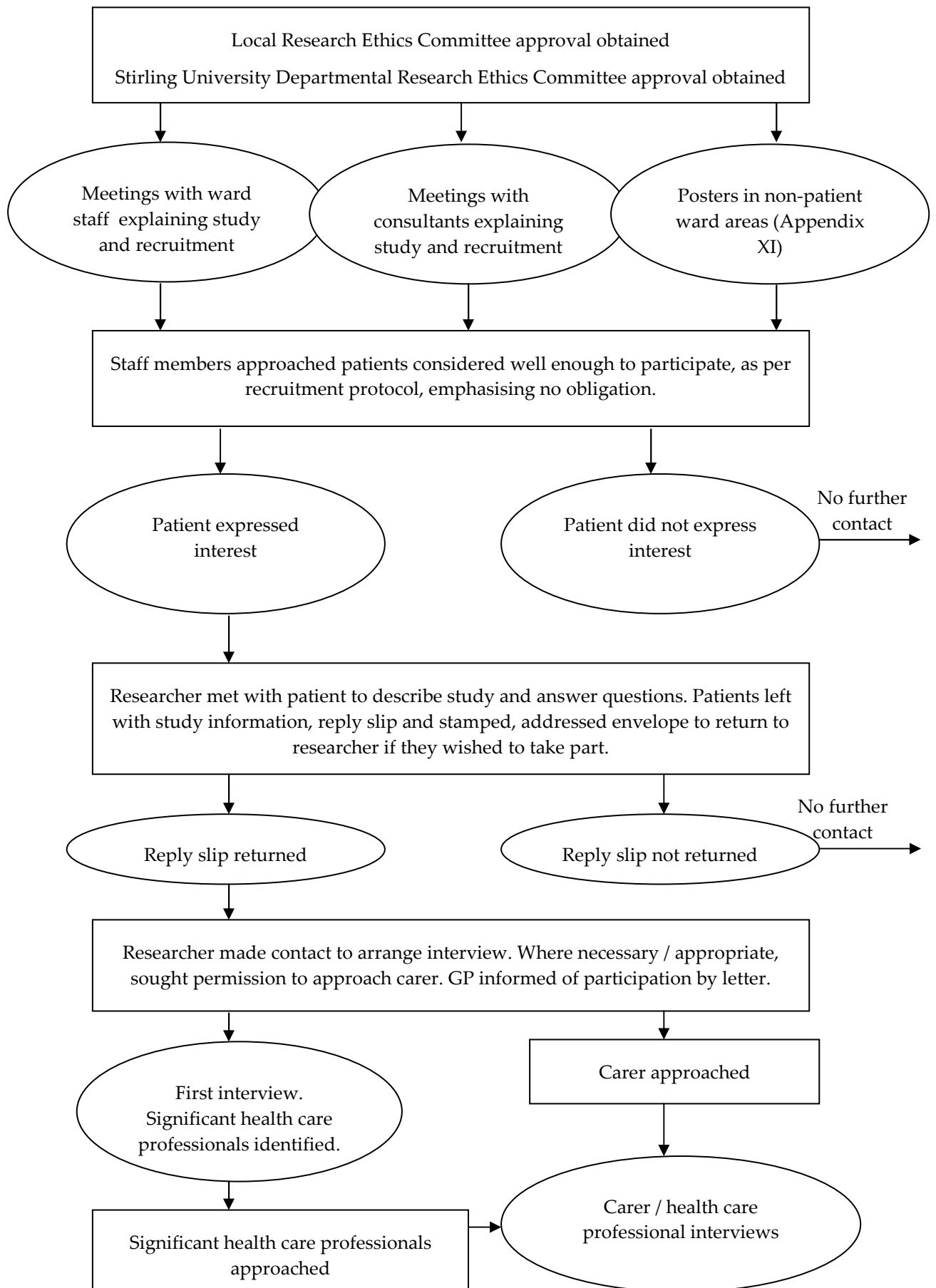
protocol was provided to all staff. The flow diagram in Figure 5.1 outlines the methods and procedures of recruitment.

Twenty five of the 76 patients with a confirmed diagnosis of metastatic spinal cord compression admitted to the Frank Ellis Unit between July 2003 and June 2005 were approached by staff to consider participation. Eight agreed to discuss the study further with me. All returned reply slips confirming their willingness to take part. One was unable to be interviewed as he moved to a distant part of the country after discharge from hospital. One other withdrew very shortly before the scheduled interview owing to a family bereavement.

Data are not available for the total number of patients with spinal cord compression admitted to the hospice during the recruitment period. Two patients were approached by staff, and both agreed to participate. One further patient was recruited through oncology out-patients at the time of a recurrence of spinal cord compression.

Each case study was centered on one patient. As described above, a total of nine patients agreed to participate. Carers were approached once the patient had agreed to participate in the study. Permission to approach the patient's carer was sought from the patient, and the most appropriate way of approaching the carer was negotiated. Significant health care professionals were invited to participate on a case-by-case basis. Once it became apparent that there were relatively few health care professionals who were significant in providing rehabilitation, key ward therapy, nursing and management staff, as well as therapy management staff, were approached and invited to participate.

Figure 5.1: Methods and procedures of recruitment



5.4 Data collection

As discussed in Chapter 3, the following data-collection strategies were employed:

- In-depth, semi-structured interviews were undertaken with patients at least once, and where possible at intervals throughout their illness (see Table 5.1). The exact length of the interval between interviews varied between cases, and depended on the patient's circumstances and health. In the intervening period I kept in touch with patients directly where they had invited me to do so, or sought guidance from staff who were in regular contact with the patient as to the timing of further contact.
- SEIQoL-DW (O'Boyle *et al.* 1995) was carried out with patients at each interview, where possible. There were occasions when patients were too tired at the end of the interview to participate in further assessment.
- An audit of the medical records of all patients admitted to the Frank Ellis Unit with metastatic spinal cord compression over the two year data-collection period.

5.5 Negotiating the study

The rehabilitation of patients with spinal cord compression had been a longstanding issue of concern to the nursing on the Frank Ellis Unit. From the initial stages of developing the ideas for the study, through its implementation, to feeding back preliminary and then final results, I kept an on-going, open dialogue with the ward staff. Staff were welcoming of my presence on the ward, and supportive of the research, but even so, it took concentrated and determined effort to keep the profile of the study sufficiently high to ensure their collaboration in recruiting patients.

5.6 Interview data

A total of 53 interviews were carried out with 44 individuals (see Table 5.1). Interviews were tape recorded and transcribed verbatim, with one exception. When I interviewed Gill (Patient VII) for the second time, she requested that the interview not be recorded, explaining that there were things she wanted to say that she did not want kept on tape. She spoke during the interview of her distress about the loss of a sexual relationship with her husband. She was happy for me to keep notes during the interview, to which I added immediately after the interview was finished. Interviews took place at a time and place convenient for participants, either in participants homes or at various venues around the hospital or hospice. The quality of sound on two interviews (Ben, Patient II, for the third interview; and Case IV, Palliative Care Occupational Therapist) was too poor to provide a useful transcription. Having been worried about the sound in both interviews, I had kept more detailed notes than normal during these interviews.

5.7 Audit data

The following data were collected (data collection pro-forma in Appendix II):

- Demographic details such as age, gender, diagnosis, level of lesion.
- Admission details such as length of stay, destination of discharge.
- Functional details such as mobility on admission, discharge and follow-up, and functional problems identified during admission.
- Mortality.
- Rehabilitation information such as rehabilitation referrals made during admission, interventions offered, and rehabilitation follow-up arranged.

Table 5.1: Interview matrix

First diagnosis SCC - RIP	Patients			Carers		Health Care Professionals				FEU Staff	Managers and Specialists
06.06.03 – 18.04.04 (10m12d)	Alf <i>Patient I</i> 05.07.03	Alf <i>Patient I</i> 21.11.03		Alice <i>Carer I</i> 05.07.03	Alice <i>Carer I</i> 21.11.03	Maeve <i>Pal. Care CNS</i> 17.08.04				Meera <i>FEU Nurse</i> 07.07.05	Vivien <i>ORH OT Services Manager</i> 01.08.05
26.01.04 – 10.10.04 (8m15d)	Ben <i>Patient II</i> 12.02.04	Ben <i>Patient II</i> 01.07.04	Ben <i>Patient II</i> 22.07.04			Maggie <i>FEU Nurse</i> 04.03.04	Jacqui <i>Hospital OT</i> 13.07.04	Trevor <i>Oncology Consultant</i> 27.07.05	Pat <i>FEU Physio</i> 03.08.05	Melissa <i>FEU Nurse</i> 08.07.05	Theresa <i>PCT Therapy Services Manager</i> 01.08.05
05.05.02 – 29.06.04 (2y1m22d)	Celia <i>Patient III</i> 31.03.04			Carolyn <i>Carer III</i> 31.03.04		Janet <i>Pal. Care OT</i> 24.04.04	Janine <i>Social Services OT</i> 20.08.04			Nancy <i>FEU Nurse</i> 08.07.05	Ursula <i>Oncology Head Nurse</i> 03.08.05
14.01.04 – 04.07.04 (5m20d)	Derek <i>Patient IV</i> 01.04.04	Derek <i>Patient IV</i> 14.06.04				Sally <i>Pal. Care Social Worker</i> 27.05.04	Jane <i>Pal. Care OT</i> 01.06.04			Norma <i>FEU HCA</i> 11.07.05	
24.05.04 – 09.07.04 (1m15d)	Eddie <i>Patient V</i> 02.06.04			Erica <i>Carer V</i> 02.06.04		Jenny <i>FEU OT</i> 23.06.04				Muriel <i>FEU Nurse</i> 11.07.05	Maggie <i>FEU SCC 'Link' Nurse</i> 07.07.05
16.01.03 – 03.07.05 (2y5m12d)	Frank <i>Patient VI</i> 22.06.04	Frank <i>Patient VI</i> 12.08.04		Felicity <i>Carer VI</i> 22.06.04		Mandy <i>Pal. Care CNS</i> 17.08.04	Janet <i>Pal. Care OT</i> 19.08.04	Pam <i>Pal. Care Physio</i> 08.09.04		Penny <i>FEU Physio</i> 25.07.05	Verity <i>FEU Ward Manager</i> 13.07.05
10.10.03 – 05.10.05 (1y11m25d)	Gill <i>Patient VII</i> 18.11.04	Gill <i>Patient VII</i> 18.04.05	Gill <i>Patient VII</i> 14.06.05			Sally <i>Pal. Care Social Worker</i> 28.04.05	Janet <i>Pal. Care OT</i> 30.06.05	Victoria <i>Pal. Care Consultant</i> 20.07.05	Mandy <i>Pal. Care CNS</i> 03.08.05	Natalie <i>FEU Nurse</i> 05.09.05	Joy <i>Pal. Care OT</i> 04.08.05
02.02.05 – 03.06.05 (4m1d)	Hugh <i>Patient VIII</i> 22.04.05			Hilary <i>Carer VIII</i> 22.04.05		Joy <i>Pal. Care OT</i> 01.07.05	Paula <i>FEU Physio</i> 08.07.05	Julie <i>FEU OT</i> 08.07.05			Marilyn <i>Pal. Care CNS</i> 13.09.05
09.05.05 – 24.05.05 (15d)	Ian <i>Patient IX</i> 16.05.05			Irene <i>Carer IX</i> 22.07.05		William <i>Oncology Consultant</i> 01.07.05					

5.8 Data analysis

As noted above, in the majority of cases interviews were tape recorded and transcribed verbatim. Data were initially coded and analysed manually (see Chapters 3, 10 and 11 for an in-depth account of this.) NVivo software was then used to manage, revise and further develop the coding structure, confirm categories and explore connections between categories. The software assisted in systematic searching of the text and organisation of categories and themes.

The validity of the data analysis was tested in a number of ways:

- All transcribed interviews were carefully checked for accuracy and intonation against the original tape recording following transcription.
- Two researchers independently performed a preliminary analysis and the results were compared. A selection of interview transcripts and coding were checked by a third researcher and by advisory group members.
- Where possible, I endeavoured to secure participant feedback. Participants were invited to check transcripts. All of the patients and carers declined, but the health care professionals were happy for me to return their transcripts to them for review. Minor mistakes in transcription were noted, but no revisions of content were requested. In addition, I attended staff meetings at intervals to both formally and informally feed back on interim findings, and to provide staff with the opportunity to raise any questions or issues of concern.

The audit data were entered into an SPSS data file. Simple descriptive statistics were used to characterise the sample in terms of demographic and clinical variables, and to examine differences between sub-samples.

5.9 Confidentiality

The following measures were taken to protect patients' confidentiality:

- Participants were assured of anonymity in the material written up for the study. All participants were assigned pseudonyms.
- All materials bearing any identifying data (such as audio tape recordings and consent forms) were kept in a secure filing cabinet in a locked office.

5.10 The nine cases

In the second half of this chapter, I will offer a brief pen portrait of each of the nine patients involved in the case studies. Table 5.2 provides a summary.

Table 5.2: Cases

Name	Age (at onset of SCC)	Gender	Primary cancer	Survival post diagnosis
Alf	70s	Male	Prostate	10m12d
Ben	40s	Male	Thymus	8m15d
Celia	50s	Female	Myeloma	2y1m22d
Derek	70s	Male	Prostate	5m20d
Eddie	80s	Male	Prostate	1m15d
Frank	60s	Male	Kidney	2y5m12d
Gill	40s	Female	Breast	1y11m25d
Hugh	80s	Male	Prostate	4m1d
Ian	60s	Male	Bladder	15d

5.10.1 Alf

I met Alf on the Frank Ellis Unit. He had been admitted two weeks previously, in pain and immobile. Radiotherapy had caused – by his account – a ‘miraculous’ recovery; not only could he now walk, he could also manage stairs, making his return home to his second floor flat feasible. He lived with his disabled wife, Alice, both of them in their seventies, and enjoyed a close relationship with family who lived nearby. Alf and Alice liked to be active. They went on outings together most days – to the park, to the local garden centre for tea, to nearby restaurants for lunch. Alf described himself as ‘a Joe Blunt person’, valuing plain-speaking and having a pragmatic approach to life:

I’m a fatalist, you’ve got to put up with it: it’s life. Why worry about it? Doesn’t do you any good, do it? I could make myself miserable as sin quite easily, but what good would it do? None whatsoever. You might as well look on the bright side, and do what you can, when you can. I’ve made up my mind and so has Alice, we’re going to enjoy every day we possibly can now while I’m able to enjoy it. That’s what we’re doing. We’re living day by day, and if we can do it, we will do it. We’ll thoroughly enjoy ourselves as much as humanly possible.

Alf (Patient 1: Interview 1)

Alf enjoyed about six months of relative independence, until a second episode of cord compression caused deteriorating health and function. He and Alice spent the last two months of his life together in a nursing facility, Alice coincidentally needing assistance for her own health problems.

5.10.2 Ben

Ben had been diagnosed with cancer a year before the onset of his spinal cord compression. He declared himself delighted to take part in my study: as a supervisor of post-graduate

students himself, he felt he would enjoy being 'on the other side' of the research process. He lived alone, and, while he had an active social life with a large group of friends, he valued his privacy and independence. He had chosen not to tell his local friends that he had cancer:

I am quite a solitary sort of guy. [...] None of my friends in [...] know [about the diagnosis] and that's allowed me to have this really nice life, you know, a genuine life with my friends. [...] It's a decision I made and I think it'd been a very good one. Because all my relationships here are very genuine. It hasn't been necessary to tell people. Anyway, why should I?

Ben (Patient 2: Interview 1)

For Ben, this new development in his illness – the onset of spinal cord compression – was unwelcome, visible evidence of his illness:

The significant thing about the cord compression is I can't continue living that kind of, I'd call it a double life, because now it is very obvious, it's like badge on my chest. That there's something wrong and I can choose to explain it to people any way I want, I can say I fell down stairs or I can say I'm very seriously ill with a cord compression. [...] I guess the crutch will, uh ... I haven't really thought about that. I don't know the answer.

Ben (Patient 2: Interview 1)

Ben died at home nine months after his cord compression was diagnosed. Friends and family – once told – rallied, and he remained relatively active and optimistic about his life.

So maybe as things change, your ability to cope with it changes. It's just a wonderful package about life, isn't it? When you're living it there's no option, and you find a grace in it, and an ability to cope.

Ben (Patient 2: Interview 2)

5.10.3 Celia

Celia was an African-Caribbean woman in her fifties. Up until her hospitalisation with spinal cord compression, she had worked as a carer. She was an active member of her local church, taking part in missions, and enjoying her church's participatory style of worship. She had an intense faith in God, and was disappointed that none of her children shared her beliefs. She lived alone, although as her illness progressed, her children took it in turns to support her live-in carer to assist her with her daily activities.

She spent several months in hospital following her diagnosis of spinal cord compression for problems unrelated to her cancer. On her discharge, she was offered, and declined, a place at the local specialist rehabilitation centre, opting instead for a day a week at Sobell House day hospice. She was a self-contained woman, who spoke very little. Hospice staff remarked on their difficulty in understanding wishes and priorities. This, however, was not a barrier to her receiving a great deal of input from hospice and community rehabilitation services. Her home was extensively adapted to accommodate her limited mobility, including the provision of a stair lift and a level-access shower room.

Celia survived for two years following her diagnosis of cord compression.

5.10.4 Derek

Following radiotherapy, Derek was discharged to a community hospital as an interim measure prior to going home. However, while discharge home was being planned, he fell and fractured his femur, and, once this had been plated and pinned at the John Radcliffe, he was admitted to Sobell House, where he had previously been a regular at the day hospice.

Initially, attempts were made to discharge him home, but these gradually ceased and he remained in the hospice for the four months until he died.

Derek's mobility was curtailed by refractory neuropathic pain. He was very cautious about moving: his fall had knocked his confidence, and he believed that his spine was unstable:

The cancer has got in to the spinal column and that has collapsed. Or it's on the point of collapse, so if I put too much weight on my spine I'm going to get this complete collapse, and if that happens I could be paralysed.

Derek (Patient 4: Interview 1)

While this did not concur with medical opinion, it kept Derek increasingly bed-bound. Both physiotherapy treatment and the ward staff's encouragement to attend the day hospice became less and less frequent. Derek acknowledged that his progress had been 'knocked on the head', but found many things to enjoy in hospice routine:

Wash and brush up. That takes about half an hour. Usually a nurse visits, blood, somebody came and took my blood this morning. By the time they found it, that took about half an hour, to find a vein. [Laughs]. Oh, all sorts of things happen... it's surprising really, you know, visits, like yours, which break up the morning. Lots of little things, stupid things, but they help to, you know, break up my day.

Derek (Patient 4: Interview 2)

5.10.5 Eddie

Eddie was a talkative man in his eighties. He had lived an eventful life, and was eager to tell me about it: his childhood in a mining village, his wartime experiences, his subsequent naval career, his marriage, and the death of his son in a road accident.

He was impatient with his family's and the ward staff's concerns about his ability to continue to cope on his own at home. His daughter, Erica, took leave from her job as a

project manager to be with her father while he was having radiotherapy. She arranged twice-daily physiotherapy for him, and several occupational therapy home assessment visits. Eddie was resistant to – as he saw it – all the fuss.

He declined community services after he was discharged, and struggled at home for a fortnight before being admitted to the John Radcliffe, where he died a few weeks later.

5.10.6 Frank

Frank, a retired financial advisor in his late sixties, had been extremely unwell during and after his radiotherapy with a difficult to diagnose neurological condition. After several readmissions to hospital and unsuccessful attempts at treatment, he was admitted to Sobell House in-patient unit, unresponsive and with a very poor prognosis. However, contrary to expectations, he stabilised, though he remained confused and disorientated. The ward staff began to propose discharge. Frank's wife, Felicity, recalled:

That [...] frightened me. [...] He wasn't following the pattern that they'd expected, which had been initially [a prognosis of] two to three weeks, then it was several weeks, and then it was, 'Well, we're looking at several months now, we don't know. But he's taking up a bed space, and he needs very little care from us. We need to think about him moving on.'

Felicity (Carer 6: Interview 1)

Discharge planning proceeded slowly, as Frank and Felicity needed considerable support at home. After more than five months in the hospice, Frank's condition suddenly – and unexpectedly – improved.

Just like that. One Friday afternoon I'd taken visitors in. I mean, he'd had better periods and then he'd go down again. Plateau out. [...] On this particular day, very old long standing friends of ours [...] visited. She was talking to Frank and he asked her a relevant question about something she'd said. And

I thought, 'Oh! He's on the ball today! That's good.' And a bit later on he asked her something off his own bat, and I thought, 'Wow!' you know. And I thought, 'It won't last!' [...] But, two weeks later and he's still as clear as a bell. And it's never slipped.

Felicity (Carer 6: Interview 1)

Frank returned home, still bed-bound, but determined to continue making progress. He died at home a year later.

5.10.7 Gill

Gill was a successful career woman. She described herself as a meticulous, organised perfectionist, who enjoyed being fit, smart and attractive.

Before I went ill I [...] had never ever looked so good, I really looked after myself. I had a stressful job. When I came home in the evening I would undress and go straight to the gym, just to release some of the tension of the day, and come home and shower and then do tea, you know, and that was, that was working out really, really well.

Gill (Patient 7: Interview 1)

She attributed her early symptoms of back pain and fatigue to a busy, hard-working lifestyle, and reached a point of near-collapse before seeking treatment. By the time her primary breast cancer was confirmed, her disease was widespread. Her consultant explained that she would not be considered for a mastectomy:

'But why?' I said, 'Why can't I have a mastectomy, so I can get on with my life?' And then he said, 'Well it's gone too far, it's gone to secondary bone cancer.' [...] I said, 'How do I get over this now, what do I need and how do I need to fight it?' and he just said to me, 'I'm sorry, my dear,' he said, 'it's

treatable where the pain's concerned, but it's ... not curable...' And I thought, you know, what do I do now?

Gill (Patient 7: Interview 1)

With characteristic pragmatism, Gill organised her life and her family to accommodate her slowly advancing illness and disability. She had a stair-lift installed, arranged carers, moved into the wheelchair-accessible spare bedroom, organised her funeral. She talked openly about her sadness at many losses: her independence, the body she had been proud of, closeness and intimacy in her relationship with her husband. She died, as she had wished to, in Sobell House hospice.

5.10.8 Hugh

Hugh was a retired academic, internationally respected in his field. His passions were reading, writing and walking, and he was keen to adapt his environment and his lifestyle to be able to continue with these activities as much as possible. His awareness of people with disabilities who lived active lives was an encouragement to him:

[I've had to] rethink my participation in committees. You ought to have access for wheelchairs everywhere and particularly with old buildings [...], it can become quite tiresome sometimes. [...] I would say a year ago, eighteen months ago, I regarded myself as unusually fit for [my age] and I could do plenty of things, a lot of walking and an active kind of life. But the suddenness of the cancer is a shock. I think I've seen enough people, colleagues at work and high profile people on television who have obviously done such positive things in wheelchairs. Of course I realise more now what they were accomplishing, but it also makes me believe it can be done.

Hugh (Patient 8: Interview 1)

Hugh had two episodes of cord compression, recovering reasonably well from the first. However, he deteriorated after his second course of radiotherapy, and died at home less than a month later.

5.10.9 Ian

Ian described himself as 'a bit of an inventor'. He ran his own business, designing and manufacturing engineering equipment. He was nearing retirement, and worried about the effect of his illness on the financial security of the company. He was frustrated by the doctors' seeming unwillingness to provide him with clear information on the likely course of his disease – both his primary cancer and the spinal cord compression. He had a great deal of pain, but was uneasy about the treatment options that were offered, interpreting the PRN morphine written up on his drug chart as an indication of something sinister:

[It] leads one to think, although I've been trying not too hard to think about it, that I am not going to leave here [the radiotherapy in-patient unit], I will leave in a box. I've been told I can have liquid morphine on demand, when I want it I can have it. [...] That's an indication that perhaps, I don't know, that's the problem, I don't know. But there may be no future for me.

Ian (Patient 9: Interview 1)

Ian's anticipated discharge home was cancelled at the last minute, due to the ward staff's increasing concerns about his ability to manage safely. He was discharged to his local community hospital, where he deteriorated rapidly and unexpectedly, and died within a week.

PART III
RESULTS

Chapter 6

Introduction and background to the results

6.1 Introduction

In Part III, I will show that disability is a significant problem for patients with spinal cord compression, and for their families. Participants describe a number of ways in which disability – or the threat of it – causes concern and limits their daily activities and social participation. Furthermore, patients and their families receive little support in managing disability. In Chapters 7, 8 and 9, I will present evidence to support these claims, and I will also consider the obvious question that presents itself: why is the support patients receive so cursory? I will preface my presentation of the results with some background on local service provision, to provide a context for the data.

6.2 Response to disability and provision of rehabilitation

Why are patients receiving inadequate advice or help with their disability? Why is little that counts as rehabilitation being provided? The answer to this question is less obvious than one might initially suspect, and involves a number of related factors. These can be summarised under three broad headings, as follows:

6.2.1 Patients' orientation towards disability

Chapter 7 focuses on patients' response to the diagnosis, their consequent state of mind, and their orientation to the idea that they have a disability. In effect, it discusses the psychology of the patients, relative to the fact that they are dealing with both disability and terminal illness. It suggests that patients, families, and staff are generally hopeful that mobility will

improve with treatment. The extent to which one can make future plans in the light of a great deal of uncertainty is limited. Patients adopt a range of strategies for managing disability.

6.2.2 The inpatient experience of rehabilitation

Chapter 8 turns to the way in which the patient's orientation to disability interacts with events and processes on the ward, and looks particularly at the experience of inpatient rehabilitation. The acute hospital environment does not, and cannot, support an extended process of physical and psychological 'adjustment' to disability. The ward-based rehabilitation effort is therefore restricted to interventions aimed at ensuring safe discharge. Further, and partly as a consequence of this, patients' experience of rehabilitation on the inpatient unit does not inspire confidence in its value, and therefore does not lead them to seek follow-up services once they have left hospital. This is not because of poor performance or a lack of dedication on the part of the occupational therapy, physiotherapy and other rehabilitation staff. It is rather the result of the way in which the patients' psychological orientation towards disability interacts with a number of organisational factors and constraints.

6.2.3 Coordination between hospital and follow-on rehabilitation services

Chapter 9 follows the patients beyond discharge from hospital. It is generally assumed by staff that disability-related needs will be identified and met once patients have left the acute hospital, but specific referrals for follow-up rehabilitation are very seldom made. This, combined with the patients' lack of incentive for seeking them out, contributes to very little being provided.

The sources of data vary across the three chapters. Chapter 7 is based on the accounts of patients in the first instance, which I then compare and contrast with the accounts of

professionals. We will see that the patients construe what is happening to them in various ways, and that the professionals have their own interpretation of how the patients do this. As we shall also see, the two perspectives do not always coincide. Chapter 8 likewise contrasts the professionals' account with the patients', but also introduces audit data, in order to indicate typical events, processes and procedures on the ward. It deals, for example, with the contacts between patients and rehabilitation staff, and with the relationships between rehabilitation staff and medical and nursing staff. Chapter 9 also combines audit data with interview material from both patients and professionals, in order to depict the experience of patients post-discharge.

However, before moving on to patients' accounts of their experiences of disability and rehabilitation, I will give a brief account of the cancer, palliative care and rehabilitation services in the geographical location in which the study took place, to provide a context for the results.

6.3 Oxfordshire cancer and palliative care services

6.3.1 The Oxford Cancer Centre

The research was based at the Oxford Cancer Centre, one of two regional cancer centres in the Thames Valley Cancer Network. The Oxford Cancer Centre normally admits patients from Oxfordshire and two adjacent counties, Buckinghamshire and Wiltshire. Occasionally patients from further afield (Hertfordshire, Berkshire, Northamptonshire) are admitted. Patients are admitted either from home (or their usual place of residence) or from other hospitals. Three local district general hospitals routinely refer patients: Wycombe General Hospital (High Wycombe, Buckinghamshire), Stoke Mandeville Hospital (Aylesbury, Buckinghamshire) and the Great Western Hospital (Swindon, Wiltshire).

The Oxford Cancer Centre is part of the Oxford Radcliffe Hospitals NHS Trust, a large (1500 bed) teaching hospital spread over three sites in Oxford and Banbury. At the time the research was carried out, the Cancer Centre had three in-patient treatment units: Ward 5E, Blenheim Ward, and the Frank Ellis Unit (FEU). (The three are due to merge when the new Cancer Centre opens in 2008.) There is also a palliative care unit, Sir Michael Sobell House, situated on the same hospital site (the Churchill Hospital in Oxford) as FEU. The research was predominantly centred around patients admitted to FEU.

6.3.2 The Frank Ellis Unit

The Frank Ellis Unit is a 22 bed acute in-patient oncology ward, providing a range of chemotherapy, radiotherapy, radioactive treatments and palliative care. The ward admits cancer patients for planned treatment as well as taking emergency admissions.

The majority of patients admitted for treatment of metastatic spinal cord compression are admitted to FEU for radiotherapy, which is given in five fractions (doses), usually delivered once daily over five days. Patients are routinely mobilised unless there is specific evidence on a magnetic resonance imaging (MRI) scan of spinal instability. Nursing staff follow a set care plan with spinal cord compression patients, which includes discussing spinal cord compression and the anticipated treatment with the patient, monitoring any change in condition, providing appropriate bowel and pressure care, and making referrals to appropriate members of the multi-professional team.

Occupational therapy and physiotherapy services on FEU are provided by therapy staff who are based in the main therapy departments. Provision varies according to staffing needs across the Churchill Hospital site, but is typically around 0.4 whole-time equivalent (WTE)

for both occupational therapy and physiotherapy. During the period of this research, physiotherapy staff were Senior II Grade, and occupational therapists were either Basic Grade or Senior II Grade. Therapy staffing on the oncology wards is not stable: staff are moved around according to pressures on services across the Trust. The therapists working in oncology do not have specialist training or qualifications in cancer or palliative care, relying on experience 'on the job' to build up their skills.

A small minority of patients with metastatic spinal cord compression are admitted to other wards or units in the hospital, for example to neurosurgery if surgery is felt to be an option, or to one of the general wards if beds on FEU are in short supply. Patients are then managed according to local protocols which do not include care plans specific to spinal cord compression.

6.3.3 Sir Michael Sobell House

Sir Michael Sobell House is a specialist palliative care unit comprising an 18 bed in-patient unit, a day hospice, a hospital palliative care team, a community palliative care team, a lymphoedema service and a bereavement service. There are occasions when a patient with spinal cord compression is admitted directly to Sobell House for radiotherapy treatment; but more often, cord compression patients are referred for palliative care follow-up after their acute treatment has been completed.

Sobell House has two full-time senior occupational therapy posts, and one half-time senior physiotherapy post; during the research period, there were several periods when posts were vacant. Therapy staff are based at Sobell House and are integral members of all of the specialist palliative care teams, although they are funded and managed by the Trust's

therapy services department. The Sobell House therapists work across teams, including the hospital palliative care team, and are able to follow patients from hospice or hospital into the community. Patients are normally referred to the occupational therapists and physiotherapists by other hospice staff, for example, by the in-patient unit nurses, the medical consultants or the community Macmillan nurses.

6.4 Oxfordshire rehabilitation services

At the time of this study, rehabilitation services for adults with physical disabilities were delivered through three providers in Oxfordshire:

- The acute NHS trusts, of which there are two: the ORH Trust and the Nuffield Orthopaedic Centre NHS Trust.
- The Primary Care Trusts (PCTs), which provide the Community Rehabilitation Service (CRS).
- Oxfordshire Social Services.

There is a specialist rehabilitation centre in Oxfordshire, the Oxford Centre for Enablement (part of the Nuffield Orthopaedic Centre NHS Trust), predominantly providing services for patients with neurological problems. In neighbouring Buckinghamshire, there is a specialist spinal injuries unit at Stoke Mandeville Hospital.

The interrelationships between these providers are complex, and a great deal of detail is not necessary here. I will instead offer a simple example of service provision as a context for the results presented in Chapters 8 and 9.

6.4.1 An example of a rehabilitation pathway

A spinal cord compression patient, admitted to hospital, who was identified to have rehabilitation needs would be seen by the hospital occupational therapists and physiotherapists. Hospital staff do not provide follow-up into the community. Ongoing rehabilitation needs would be referred on to the CRS for further intervention. Patients requiring major environmental adaptations (such as a ramp for a wheelchair or a level-access shower) would be referred to Oxfordshire Social Service occupational therapy teams. Interventions from both CRS and Social Services are intended to support sustained functional improvement and independence. The services do not have a remit to provide for palliative care patients, although where these patients are referred, staff will do their best to be accommodating.

Where a patient requests or requires (and agrees to) referral to the palliative care services, ongoing rehabilitation would be provided by the hospice occupational therapists and physiotherapist, either in addition to, or instead of, CRS or social services input.

It is extremely rare for a patient to be referred for specialist rehabilitation at a centre like the Oxford Centre for Enablement or similar (as I shall show in Chapter 9).

6.4.2 Discharge planning

'Discharge planning' comprises a significant part of the rehabilitation staff's workload on FEU. Patients are discharged home, or to community hospitals or hospices, or – as is common practice for patients from other counties – back to their referring hospitals. Given the difficulty staff experience in negotiating community services for patients outside of Oxfordshire (as described in Chapter 9), there is strong incentive to return patients requiring care packages to hospitals closer to their homes, for discharges to be arranged locally.

6.5 Service specifications for cancer and palliative care rehabilitation

As previously discussed, the NICE Guidance on Cancer Services (NICE 2004) advises that rehabilitation be made available to cancer and palliative care patients, and provides a number of recommendations for service delivery, including:

- The assessment of rehabilitation needs at key points in the patient pathway, using an assessment tool agreed across the cancer network.
- The availability of a defined referral pathway to rehabilitation services, including self-referral routes for patients.
- The development of evidence-based rehabilitation guidelines against which care can be audited.
- The establishment of referral and treatment criteria to ensure that needs are met at the appropriate level of expertise: these should include guidance on needs which can be met by generalist rehabilitation staff, and those requiring specialist attention.
- Identifying target times for access to rehabilitation services and equipment.
- Agreeing education and training programmes for rehabilitation staff to meet the levels of rehabilitation interventions required.

The NICE Guidance proposes a four-level model as a mechanism for achieving this:

Table 6.1: NICE Guidance 4-level model for rehabilitation provision

Level 1	Recognising palliative care needs as part of a general assessment and knowing how these needs can be met. Providing straight-forward advice on managing common functional problems and conditions such as fatigue.
Level 2	Providing interventions which are slightly more specialist, but which are in response to routine, predictable situations, for example, post-operative physiotherapy following breast surgery.
Level 3	Interventions which require knowledge and experience of cancer and palliative care pathology and treatment, and a deeper understanding of the impact of life-threatening illness on patients and families.
Level 4	Highly specialist interventions for patients who have complex, often unpredictable, specialist needs. Interventions would be provided by allied health professionals with higher-level training in cancer rehabilitation.

Patients with spinal cord compression are categorised in the NICE Guidance as Level 4. If one was following the Guidance, the physiotherapists and occupational therapists on FEU should be operating at Level 3, and expertise at Level 4 should be available at Sobell House. As will be clear in presenting the results in Chapter 8, this is not consistently the case.

6.5.1 Cancer and palliative care rehabilitation

Currently, there are no benchmarks for determining adequate rehabilitation staffing levels in cancer and palliative care. Of course, in any discipline, criteria for generalised adequacy in staffing are problematic (Reiner *et al.* 2005; Finlay 2001); but whereas some indicators exist for medicine and nursing (such as the Minimum Data Set returns collected annually by the National Council for Palliative Care), these are not available for rehabilitation services, as the data are simply not collected. While the NICE Guidance suggests figures for occupational therapy and physiotherapy staffing as an aid to Cancer Networks in costing their services, these can be no more than 'best guess' estimations. Furthermore, the categories used by

NICE – ‘cancer centre’, ‘cancer unit’, and ‘home care’ – make it difficult to compare their estimates with local provision, as the ‘home care’ category does not match up to the local model which comprises a rather more comprehensive specialist palliative care service. A relatively recent rehabilitation staffing audit (of dedicated, specialist filled posts) across the Thames Valley Cancer Network (TVCN) provides the following comparisons (Thames Valley Cancer Network 2005):

Table 6.2: TVCN / NICE rehabilitation staffing comparison

	Locality	Cancer Centre	Cancer Unit	Home Care	Hospice
Physiotherapy	Milton Keynes	-	0	0	0
	Mid & South Bucks	-	0	0	0.6
	Oxfordshire	0.76	-	0	1.1
	East Berkshire	-	0	0	1.0
	West Berkshire	0	-	1.2	1.6
	Total	0.76	0	1.2	4.3
NICE recommendation		4.4	4.0	3.3	
Occupational Therapy	Milton Keynes	-	0	0	0
	Mid & South Bucks	-	0	0	0.66
	Oxfordshire	0.8	-	0	2
	East Berkshire	-	0.47	0.47	0.47
	West Berkshire	1.0		0.3	0.9
	Total	1.8	0.47	0.77	4.03
NICE recommendation		4.4	4.0	3.3	

There are two points I would like to highlight here. Firstly, rehabilitation staffing levels in specialist palliative care (home care and hospice) are slightly higher than the NICE recommendation, whereas in cancer centres and cancer units they are substantially lower. This is a reflection of the fact that, in this region, very little provision is made for cancer patients in cancer centres requiring rehabilitation at Levels 3 and 4 of the NICE model. Cancer rehabilitation is provided by non-specialist therapists as part of generic rehabilitation services. This leads to the second point, which relates to the NICE Guidance

recommendation that staff providing rehabilitation at Levels 3 and 4 should be ‘advanced practitioners’ who have ‘a deeper understanding of the impact of life-threatening illness on patients and families’, having ‘received higher-level training in the rehabilitation needs of patients with cancer’ (NICE 2004: 141). This is a worthwhile aspiration, but not something that is currently deliverable, as I shall explain in the next section.

6.5.2 ‘Advanced practitioners’ in palliative care rehabilitation

The distinction between a ‘specialist’ and a ‘generalist’, in terms of knowledge, skills and qualifications, is much less clear-cut for occupational therapists and physiotherapists than it is for doctors and nurses in cancer and palliative care. (Eva *et al.* 2007). Doctors have a clearly defined career pathway, and the same is increasingly true for nurses, where a degree-level qualification is becoming a requirement for specialist posts. For occupational therapists and physiotherapists working in cancer or palliative care, the differentiation between working at NICE Levels 1 and 2, and at Levels 3 and 4, is more tenuous, tending to reflect local service needs and recruitment and retention issues, as well as local service needs, with grading at local managers’ discretion. In both professions, ‘specialist’ posts are recognised by the professional bodies, with the College of Occupational Therapists and the Chartered Society for Physiotherapy having produced briefing papers and guidance on the development of clinical specialist posts for occupational therapists and physiotherapists (College of Occupational Therapists 2003, Chartered Society of Physiotherapists 2002).

However, although there is recognition of the benefits of a career structure for practitioners with specialist skills, these developments are in their infancy, and the external drivers to gain specialist qualifications that exist for doctors and nurses in palliative care (posts being dependent on qualifications) do not exist for occupational therapists and physiotherapists.

While it is a matter of some debate whether such a requirement would be desirable for these professions, there is arguably less incentive – because qualifications are not mandatory – to make available appropriate training programmes and funding, or to employ sufficient numbers of staff to enable post-holders to undertake specialist post-qualifying education, while at the same time fulfilling their clinical or practice remit. The practical implication of this is that the therapy staff working with cancer patients tend not to have any formal training or specialist skills in cancer rehabilitation.

6.6 Summary

In this chapter, I have presented the context for the results which follow in Chapters 7, 8 and 9.

Oxford is a regional cancer centre, with patients being admitted from Oxfordshire and surrounding counties. The majority of patients with spinal cord compression requiring treatment in the Trust are admitted to the Frank Ellis Unit, where staff have a written care plan for managing these patients. Patients from outside of Oxfordshire may be returned to their referring hospitals because of the complexities of arranging out-of-county discharges to home. There is a high turnover of rehabilitation staff working on the oncology wards, with the maintenance of adequate staffing levels across the Trust as a whole taking priority over the provision of specialist staff to specialist units.

The NICE Guidance on Cancer Services, published in 2004, sets out the recommended service standards for rehabilitation in cancer and palliative care. Due in large part to the lack of infrastructure for training and employing specialist rehabilitation staff, standards in the Thames Valley Cancer Network fall well short of the NICE recommendations.

There are differences between the provision of rehabilitation on the oncology wards and in the specialist palliative care service; therapists in the latter work more closely with multi-disciplinary colleagues, and can be more flexible in working across hospital and community boundaries.

It is against this backdrop that I shall now move on to presenting the results.

Chapter 7

Patients' orientation towards disability

7.1 The context of diagnosis

When invited to tell their story, the majority of patients either began with, or very quickly referred back to, the anchor-point of learning their diagnosis. For some patients, leg weakness or back pain was the first indication of illness of any kind, with cancer being diagnosed subsequent to cord compression. For others, cord compression followed an already established cancer diagnosis. Some understanding of patients' circumstances leading up to diagnosis is helpful, as it provides a context for their frame of mind at the time of their arrival on FEU. The transcript excerpts which follow contrast two participants' responses to their symptoms: Alf's certainty – over an extended period of time – that something was seriously amiss compared with Ben's more rapid deterioration and his unwillingness to acknowledge that there was a problem.

I got up one day, and I had terrific pains in my back. And I do mean terrific pains. I'm not on about backache, I'm on about agony, agony. [The GP said] 'Oh, you've just strained your back, forget about it. It'll go, just walk about. [...]' Well it got worse and worse, until I couldn't even move. And we called [the GP] out here and he gave me another examination, and he said, '[...] I think the trouble is a pulled muscle, do some exercises.' [...] Off he went. [...] It got worse and worse, and I said to my wife, 'It's no good, I can't have this, I shall die!' So I phoned up [my oncologist's] secretary and [...] we got an urgent appointment with [him]. He says at the appointment, 'What do you think is wrong?' I said, 'Bone cancer.' He said, 'Quite right, you're in hospital today'. And I was in the same day. [I did say to my GP] when he was here, 'You realise I've got prostate cancer?' I can't tell him really how to do his

damn job, but if I had a patient in front of me with prostate cancer who suddenly had terrific backache, the first thing I'd think of is bone cancer.

Alf (Patient 1: Interview 1)

It's been two weeks actually [...] since I first noticed the first symptom. [...] So it's been very, very quick. [...] It's been very difficult to assimilate exactly what's happening to you given that certain things are happening faster than your ability to keep up with it. The first symptoms were just, like, numbness in my legs. Obviously with some pain [...] in the back. But I was attributing that to something else. [I didn't realise] the seriousness of it. [...] It was nearly time for my next outpatients' appointment so I was just trying to ignore it. [By the day of the appointment] it was then absolutely acute. [...] I didn't know that I couldn't walk until I left the house. I was walking in the house okay because I had things to hold on to. [...] It was really when I hit the front garden that I realised that without support I was just – whoa! [...] [I drove to hospital and] the doctor thought I must have been mental. Halfway round the ring road I thought, this is crazy, because I couldn't really co-ordinate my legs. [...] But I can only explain it as I couldn't catch up with my own thoughts. By then I really needed to get to hospital so I [just kept] going. They gave me a fifty-fifty chance of maybe walking again so it was really quite shocking. And the attitude of the medical staff was also quite shocking, but very reassuring because they were so concerned and the consultant was buzzing me around the hospital and they were keeping the radiotherapists in late to do the interventions. [...] [The consultant] showed [the MRI scan] to me and it just looked awful. He was rushing and he didn't have time to explain it, just all a big blur really, of bad news, in a sense.

Ben (Patient 2: Interview 1)

In the initial stages following diagnosis, and during admission for radiotherapy, patients have a great deal to contend with in terms of assimilating recent events and adjusting to significant bad news. Participants described feelings of shock, concerns for loved ones, thoughts about life expectancy, and the re-evaluation of relationships:

[The diagnosis of spinal cord compression] was a big shock. [...] It happened very suddenly that I couldn't use my legs anymore. I can't really remember much about anything. All I know is the shock.

Celia (Patient 3: Interview 1)

To be honest with you, I was much more worried about what's going to happen to my wife than me ... [tearful] ... To me, I've had a good time, I'm 77 next month. It's fair enough. My wife as you can see is disabled herself. And she's limited in the amount she can do, and that was very much more worrying.

Alf (Patient 1: Interview 1)

I had the scan [...] done on the Friday. On the Monday I didn't actually see [my consultant], I saw her understudy, Timothy. He seemed very much, doom and gloom if you want the honest truth. I had things in my mind over that weekend, thinking about, well, if I'm going to die from this how ... if the spinal cord is cut that won't kill me, that will just paralyse me, so what and how will I die. [...] So when I saw Tim [...] I was very open with him and asked him the question. I'd asked him, you know, something I've never asked before. I asked him about the life span that this was going to give me. I've never asked that from the moment I was diagnosed. [...] I didn't want to know [before].

Gill (Patient 7: Interview 1)

[It] helps sort priorities, to a certain extent. My first one is to [...] change the way in which I react with Irene [wife]. See it more from her point of view, less from mine. [...] We've been married for nearly forty years [...] Personality wise, I believe, looking back, I may have been a bit authoritative. [...] Since this [spinal cord compression] has happened, I've told her how I feel about this and what I want to do for me, for me to help to see things more from her point of view.

Ian (Patient 9: Interview 1)

Around the time of diagnosis, participants' willingness to engage with the consequences of disability varied, and it is tempting to divide them into groups on the basis of whether they did so or not. For example, one might say that, for some patients (Celia, Derek and Frank),

emotional shock and very poor physical health greatly limited their engagement with others and with their surroundings; that others (Ben, for instance) showed a disinclination to anticipate future problems, preferring to 'wait and see how things turn out'; and that the remainder of the participants directed considerable time and energy towards thinking about how they would manage. And in this latter category, we could contrast Alf's practical approach with Ian's apparently more tenuous hold on reality:

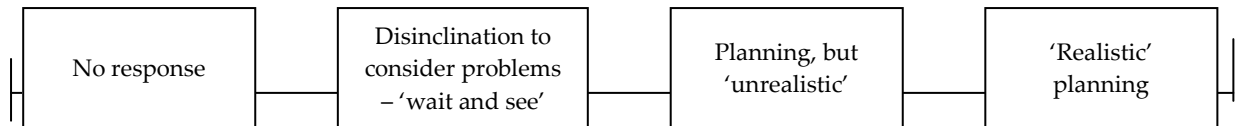
Fortunately, it turned out that I could do the stairs, so getting home [a second floor flat] was possible. [Longer term] we're still going to move anyway because [...] neither my wife, as you can obviously see, nor myself really can take all these stairs. We can do it for a little while. But it's definitely something we're going to start looking at to find somewhere. It's got to be on the ground floor, or where there's a lift. [...] We can't stay indefinitely here [...] with these stairs anymore.

Alf (Patient 1: Interview 1)

[I've recently] bought a camper van because Irene and I wanted go for weekends [...]. I've got some [...] modifications coming for it, to make it a bit easier [...]. Trying to locate power steering at the moment, which I've got a couple of people looking through the second hand market to see if they can find one which can be refurbished, and then that, armed with a knob on the steering wheel, like the old truck drivers used to have, should make that accessible. I've got enough movement in my feet, that I believe I can operate with the feet, the clutch, and it's got power brakes and a clutch. Don't know till I try.

Ian (Patient 9: Interview 1)

One could even plot the patients' responses on a sort of continuum, with 'no response to the disabling consequences of spinal cord compression' at one end, and 'capacity to organise and plan realistically for the future' at the other:

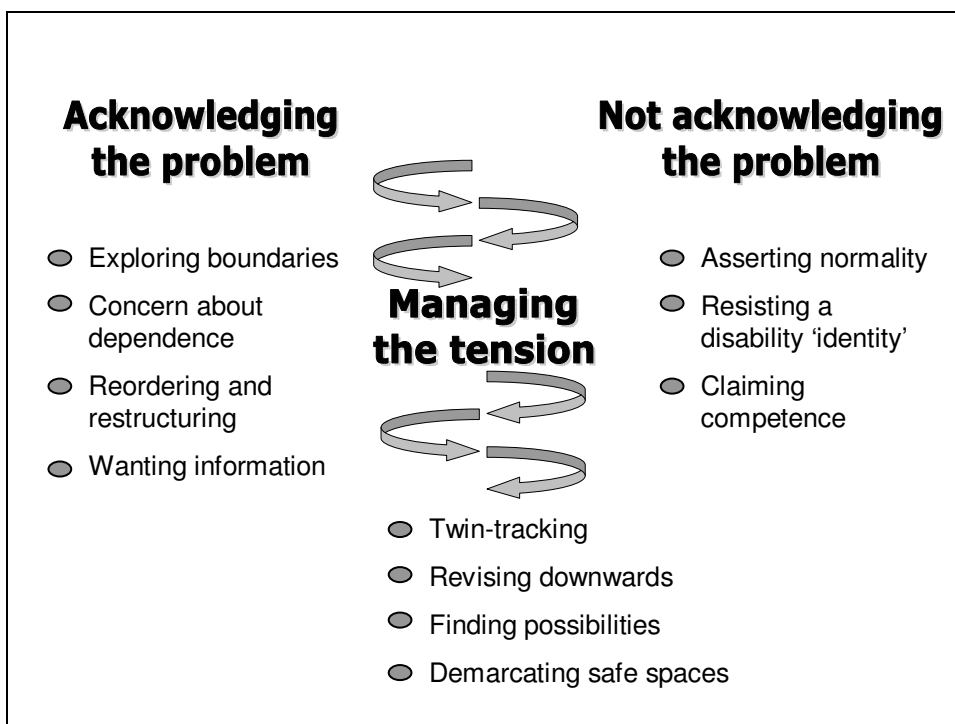


It is very tempting, then, to classify the patients in these terms. Indeed, as we shall see in section 7.3, health professionals do exactly that. But this would be a mistake. At most, the classification reflects an emphasis in any individual case; most of the patients have the full range of responses at different times. They respond and don't respond, they are realistic and unrealistic, they plan and don't plan. So this is a typology of responses, not a typology of patients, a point which I will develop further in this chapter.

7.2 Patients' orientation: three dimensions

There are three dimensions to patients' orientation to disability. On the one hand, they acknowledge that their situation has changed, and that future plans will need to accommodate altered circumstances. On the other hand, they resist the idea of themselves as disabled, wanting to maintain normality, and retain an image of themselves as resourceful and resilient. There is a contradiction – or at least a tension – between these two positions. In an attempt to manage this tension, patients employ a number of devices. I will now consider each of these dimensions in turn. A representation of patients' orientation to disability is provided in Figure 7.1.

Figure 7.1 Representation of patients' response to disability



7.2.1 Acknowledging the problem

7.2.1.1 Exploring the boundaries

Whether the disability that arose out of metastatic spinal cord compression had a sudden or an insidious onset, patients had to adapt to an unfamiliar and, at times, unpredictable body. Previously taken-for-granted motor and perceptual abilities such as sitting, standing, walking or knowing where a limb is without looking at it, were no longer straightforward. Participants described a process of discovering their capabilities and limitations. In some cases, this was explicit: 'What can I do?', 'What can't I do?', 'What will happen if I try to walk to the toilet on the ward rather than calling the nurse for a commode?'

[I'm] seeing what I can and can't do [and] I'm realising that there are [...] limits now. I mean I can't just walk up to town. I just can't do it. It's a tough thing to bear. But you know when you sit in the house you feel okay, and then you go out and maybe after a hundred metres you just feel very weak. [...]

The frightening thing is losing control when you're far away from home: I can't just sit down in the

street. [...] I walked up to the doctors and I had to keep stopping, and I realised I just, I couldn't do that anymore. [...] That's an awful thing to have to surrender yourself to, I think. You can't get around. You're just not as mobile as you were. [...] I'm just kind of working out boundaries, seeing what I can and can't do. And I think I'm quite disappointed at what I can't do.

Ben (Patient 3: Interview 1)

Following on from his description of his plans for modifying a camper van (p113), Ian explained:

[I want to] take Irene away for a weekend, and see if we can cope, on our own. And that will be an acid test for me, regarding independence. [I'm in a] state of very fast learning.

Ian (Patient 9: Interview 1)

7.2.1.2 Concern about dependence on others

Patients were concerned about the extent to which they were dependent on others. There were a number of aspects to this. The first was a wish to be independent and self-reliant:

[The furniture for the new flat comes] flat-packed, got to be assembled, and Angus [son] is going to assemble them because I [...] haven't got the strength to do it anymore. I should have liked to. [...] You want to know the most frustrating thing since my health's gone? Is having to get people to do things for me. I'm so used to having to do it myself, and doing it for other people, and now I just can't do it. [...] I was sat this morning with Angus and he was wiring it up and I thought, Christ, normally I would never get anybody to wire anything up for me! Christ, I'd do it myself, you know, but I knew I couldn't do it. If I'd got down on the floor I couldn't have got up again. [...] I'm so frustrated with what I can't do. [...] I hate people doing things for me, to be truthful about it. [...] I mean if I could do it myself and you'd done it once or twice, that'd be different. But now I can't do it, it's totally different altogether. When you don't do a thing it's all right, but when you can't do it it's all got a different meaning.

Alf (Patient 1: Interview 2)

The second was a desire not to be a burden. While Alf expressed his frustration at his inability to perform tasks at which he was previously adept, Derek had concerns about being an imposition on his family:

No possibility of me going home, at this moment. [...] I'd have to go to my daughter's. Young family. They all love granddad, I mean, you know, we all get on very well, good laugh together. But, I can see myself... my daughter's not going to... it won't be fair, it won't be fair to them. So, going home, no.

Derek (Patient 4: Interview 2)

Thirdly, patients were concerned for the well-being of family carers and were aware of the actual and potential impact of caring on others' lives. Frank, for example, regretted the consequences of his illness on his wife:

Felicity [wife] had a very full life, I mean, she was a school governor and things like that. [...] And for me she's more or less had to forgo most of it, you know. Particularly the school governor, because I mean she was going to meetings twice a week. [...] She couldn't manage to do that, she said. [She's] one of these people who, if you don't do it properly, you don't do it at all. [...] I feel sorry for Felicity, because of, you know, it's changed her life completely.[...] So, I'm grateful that [...] she's prepared to have me home and that's it. But there you are, that's life.

Frank (Patient 6: Interview 2)

Finally, there was the disruption to private and family life caused by the visits of professional carers and home care services, where these were needed.

[The OT from the hospice] came with [...] the physio, and her second year student. We've had a [...] community physio, and a person, an OT came with her first when they were getting me out of bed into the chair, to help me balance. We've had our GP, had three nurses from the surgery practice, they come

to put the suppositories and that in my bowels, because I can't go to the toilet properly. And then we've had carers in pairs, four times a day, so that [...] adds up to about thirty odd people altogether.

Frank (Patient 6: Interview 2)

7.2.1.3 Reordering and restructuring

Patients acknowledged the need to reorder daily life and restructure their activities, and they took practical steps towards achieving this.

Well I'm a fairly philosophical sort of person I think by temperament. I had foreseen it perhaps in terms of a few years and now I see it quite likely in terms of – a bit less. I think I, walking is my main hobby other than writing, so for that, walking is a serious, not only just practical deprivation, it's my main pleasure and activity, so I realise it's a lot to get used to. At the moment I'm just preoccupied with making my home somewhere where I can cope, achieve as many of the normal things which will, in my case, involve my being able to get out, using a car to get out, both to see friends and perhaps to get to the flat places where I can walk or go, be pushed in a wheelchair to scenic country.

Hugh (Patient 8: Interview 1)

In this example, Hugh was making clear plans to adapt his lifestyle to accommodate reduced mobility. There were other, less visible constraints; in particular, managing incontinence and fatigue.

Incontinence was a major issue for patients, particularly when they returned home. On the ward, it was something that staff tended to manage on the patients' behalf, rather than teaching patients to manage it for themselves. To a degree, patients were able to work out their own solutions, as Ben and Alf describe here; but it remained a problem that limited patients' participation in social and community life.

Well, no one's really addressed it with me. I guess there's some things, hey, you've just got to think about yourself. [...] I was very lucky, in the hospital, that I met an eighty year old man with a prostate problem, he told me the best solution's a Comfort bottle, which we sort of laughed at, but it is literally a Comfort, a fabric conditioner bottle, and he says it's the perfect size, it's got a litre and a half capacity. [...] I don't know whether it's something I'm going to be literally stuck with forever, but it does actually worry me in terms of, like when Bob [brother-in-law] was here we could've went to the pub, but I was thinking, 'Hang on a minute,' or could've went to a restaurant and I'm thinking, 'Shit, what would I do when I wee?' I am quite [...] happy to be wheelchaired into a restaurant, or a pub [...] but how do you cope with [incontinence]? I really don't know, I presume you wouldn't have thought it was acceptable to carry a Comfort bottle into a restaurant!

Ben (Patient 2: Interview 2)

Alf believed that his incontinence was inevitable and unsolvable, and planned his excursions carefully. However, his unpredictable bowels were a source of significant embarrassment:

I have queried it, and they reckon [...] the nerves in the bowel [...] are not working right. Not a lot to be done. But it is a very aggravating thing. Whenever I go out, you might laugh at me but I do it, I think where are the toilets. Everywhere. [...] My life is ruled by where the next toilet is really, you know. I've claimed the one in Sainsbury's, that's mine. It's got my name at the top of it! [...] [But] this has happened about three times actually. I went with Alice to go down the bank [...] and I was perfectly all right, wasn't I, Alice? Perfectly all right. I climbed out of the car, and without any warning whatsoever I pooped myself. It was absolutely everywhere. On the floor, on the pavement, in the car, have you any idea. I can't think of anything worse than that. I had to come back up here, holding my trousers as best I could, get a complete bath and change and all the rest of it.

Alf (Patient 1: Interview 2)

It is worth noting, at this point, that neither Ben's consultant nor Alf's Macmillan nurse was aware of the extent of these problems:

Interviewer: Continence issues were problematic for Ben.

Trevor: It's very interesting you raise that because I wasn't aware [of that]. I wasn't aware that he'd said that was a problem for him. So I'm not sure that he ever raised that with me. That's interesting in itself.

Trevor (Oncology Consultant)

[I was aware that] his bowel habit was something that was troublesome to him [...]. Finding it difficult to establish a sort of a regular[...] pattern if you like, that was [...] predictable and manageable, when he was out. And at that time he was having, sort of functional, physically, difficulties, sort of getting on and off the toilet. So I think there was some equipment that was provided then from the district nurse that made him feel safer and able to manage that more quickly, if you like, in response to the need.

Maeve (Health Care Professional – Community Macmillan Nurse)

A further aspect of self-management is learning to deal with fatigue, and adjusting to the necessary changes in their daily timetable. Once again, however, patients did not feel that they had been offered much help or advice in this respect.

It would have been helpful to have simple things explained. Stuff that maybe seems obvious to [the ward staff]. Simple things like the balance between rest and activity for me hasn't been fully explained. So I've just decided to go for it. I've made up my own little exercises and I try to do at least a half mile walk everyday. You know, I really don't know whether that's sensible or not. Maybe it's partly my fault that I didn't find that out before I left [hospital] but you know, you don't know the right questions. That concerns me a little bit, but I mean I don't really feel I can just phone up and ask that, or who would I ask, I don't know. It feels like I'm demanding stuff and I don't want to occupy too much of their time.

Ben (Patient 2: Interview 1)

7.2.1.4 Having information on spinal cord compression

In the preceding section, patients have drawn attention to a lack of helpful information. This is a problem to which other patients also referred. Some of the questions that patients asked have relatively straightforward answers, for example: 'I can understand why my legs don't work, but why this should have gone to my waterworks is a mystery to me.' In general, however, understanding the anatomy and physiology of cord compression was less of a priority for patients than having some indication of what the future might hold. And this is often difficult to predict.

There is the added factor that patients' attitude to information on spinal cord compression was ambivalent. Some patients were reluctant to ask questions, anticipating that the answers they received might be painful to hear.

Derek: You just don't know [what the future will hold]. Nobody can tell me.

Interviewer: Have you asked?

Derek: No, not really. [...] [The doctor has] been very straightforward. What he's told me, he is very straightforward. But I haven't sort of cornered him, if you know what I mean. I mean, will he just wag his finger at me and say, 'Well you are never getting out of here, Elmes!'

Derek (Patient 4: Interview 1)

Those who did want to ask questions were not always sure which member of staff would be appropriate, or when the opportunity might arise.

One thing I'm not quite sure about is who is the natural person to raise things with. Is it the senior nurse looking after me? I don't see the duty ward doctor, the specialists are too high up to be dealing with this [...]. At this stage I'm not sure who I should talk to. [...] My individual nurse has also been the team leader nurse [...] I haven't seen her [much] since I came in. She's obviously been busy. I have

found her very sympathetic and feel confident and feel she has the wider problem and view though, and probably she is the person, it's just I am never sure whether she is on [duty] or not.

Hugh (Patient 8: Interview 1)

7.2.2 Not acknowledging the problem

So far, we have been looking at the ways in which patients acknowledge the problems consequent on disability, and worry about how they are going to deal with them. As I suggested earlier, however, there is another side to this. In some respects and contexts, patients do acknowledge that their lives have changed radically. But in other respects, they contrive not to acknowledge that fact. There are countervailing tendencies which emphasise normality, insist on their resilience and resourcefulness, and resist the very idea that they might be disabled. This tendency is so prominent that, as we shall see in the second half of this chapter, some health care staff talk about patients being 'unrealistic' and 'in denial'. Whether this a plausible interpretation is a question I will take up later. In the meantime, I will examine what the patients have to say.

7.2.2.1 Asserting normality

Participants described the importance of being able to maintain an image of themselves as normal, where 'normal' is shorthand for 'the person I am accustomed to being, unencumbered by illness'.

They gave accounts of themselves that incorporated life's accomplishments: a career in the merchant navy spanning 25 years, internationally recognised academic achievement, prominence in the local community, children and grandchildren, a soon-to-be-celebrated fiftieth wedding anniversary. They feared that common perceptions of cancer (carrying, as they do, the threat of deterioration and, ultimately, death) and disability (connoting

dependence on others and provoking pity) would have an effect on the way they were treated both by family and friends, and by the strangers that they encountered.

It has changed the perception of me, undoubtedly, but it's not something you really notice, it's just everyone's very supportive and kind and stuff. But obviously implicit in that, there's no one treats you like just a mate any more. Everybody knows about cancer and there is a stigma attached to it. [...] And that's what I wanted to [...] avoid for as long as possible. I think what I wanted to preserve was the absolute preciousness of normality.

Ben (Patient 3: Interview 2)

7.2.2.2 Resisting a disability 'identity'

The effort to maintain a sense of normality has a number of interesting ramifications. For example, while being prepared, on the whole, to make adjustments to their daily routines to both compensate for and take account of illness and their reduced independence, patients actively resisted an image of themselves as 'disabled'. In some cases, this was quite explicit. At the time that I first discussed participation in the study with Ben, he was happy to agree but expressed the doubt that he would be of much interest as a research subject, because 'I'm not disabled' – despite, at that stage, having some significant difficulty walking.

Most of the time, however, this rejection of a disability identity was implicit in the way that patients described themselves, and in their orientation to future events. Alf, for example, acknowledged the ways in which life had changed as a result of disability – his frustration at needing his son's help with DIY, his embarrassment at his incontinence – but the way he described these events implied that they were absurd contingencies. He saw himself not as subject to intrinsic limitations, but as the occasional victim of circumstance. In referring to a recent meal out with Alice, he described an unexpected incident:

They've got a board up there and Alice said to me, 'Lets see what they've got up for specials.' And I was feeling perfectly alright, nothing wrong with me, perfectly okay. So Alice went in front of me to look at this board and I stayed behind to looking at the board. And I can't remember nothing else. I come to laying flat on the floor, and she was right beside me trying to help me up. I had no knowledge of it whatsoever, I just went.

Alf (Patient 1: Interview 2)

The point of his presentation of this event was not to draw attention to 'what I have to put up with', but to express surprise at its peculiarity.

7.2.2.3 Claiming competence

Linked to the importance of 'being normal' was patients' wish to retain an image of themselves as resourceful, problem-solving and resilient. Patients struggled with both the visible and invisible social effects of cord compression, and wished to present themselves as competent and capable, and to be treated as such. This is another sense in which they resisted the idea that they were 'disabled'.

In practical terms, this often included finding their own solutions to disability-related problems. Ian spent a considerable amount of time in hospital using his engineering interests and skills to design a knee-brace that he felt the physiotherapist could use with both himself and other patients. Having ready access to a catalogue of knee braces, the physiotherapist was polite but understandably lukewarm in responding to her patient's enthusiasm regarding marketing opportunities.

Eddie, a keen DIYer with a well-equipped workshop, had his own thoughts about managing household activities when anticipating discharge from hospital:

I always wonder how I'm going to get the rice pudding from the kitchen to my table. Now I've got the problem solved. You know the tea trolley, [...] that's got four castors on, take back two castors off, build it up, get ordinary piece of wood on the bottom, so that it doesn't slide. I'm sure there's plenty timber down the shed. Make a couple of handles that screw onto the side of the trolley and I can hold on and walk around with the tea trolley. Make it low enough, with the wheels at the front and solid rubber at the back, push stop, push, stop. Like so. [...] Three o'clock in the morning, wide awake and my head's going round just thinking back at the old place and what I'm going to do. How I'm going to get the rice pudding back from the kitchen.

Eddie (Patient 5: Interview 1)

He was dismissive of the occupational therapist's concerns for his safety, and her offer of a trolley from the disability equipment supplier.

7.2.3 Managing the tension

I have suggested that, in different contexts, the patients both acknowledge and contrive *not* to acknowledge the fact that disability has brought permanent change to their lives. On the one hand, they test out new physical boundaries, worry about being a burden, and accept that they have no choice but to deal with incontinence and fatigue, among other problems. On the other hand, they constantly emphasise normality, present themselves as competent and resourceful, and actively resist the idea that they are now 'someone with a disability'. There is clearly a tension between these two pictures – 'things are not okay', and 'things actually are okay' – although of course it is rarely articulated in this way. Instead, the patients adopt one or more of a series of psychological devices which seem designed to reduce the dissonance between these two self-images. They will, for example, overtly 'twin-track' apparently contradictory conceptions of themselves, 'revise downwards' their criteria for what counts as an acceptable way of life, constantly 'evoke future possibilities' as things

to look forward, and 'demarcate safe spaces', mixing together both 'realistic' and 'unrealistic' aspirations. Below, I consider each of these devices at greater length.

7.2.3.1 Twin-tracking

Patients' goals could appear contradictory. They would make practical plans to compensate for reduced ability and at the same time plan, with equal earnestness, to do things they were clearly incapable of doing. These future plans were not contingent on recovery or improvement: they were simply statements of intent. Sometimes inconsistent plans were described almost simultaneously. For example, here is Ian's account of having to give up one activity on the grounds of poor balance, but showing a determination to succeed in another for which exceptionally good balance is required:

*I've already given up my allotment. [Which makes me feel] sad. That was one of my breaks from work and everything else, go down there, amuse yourself for two or three hours, [...] like winter digging, that sort of thing, that's hard work. [...] [But now] I can't stand alone and move alone, currently, without an aid [walking frame]. Okay, a fork is an aid, but I argue it's not going to be the same thing. [But I have] two, three ambitions, which I **will** achieve. Not a question of wanting to, I **am going** to achieve them. And the first one, which may sound stupid, it is the essence of being independent and standing alone, is I want to go and hit a golf ball. Proper swing, unaided. Followed by a hole.*

Ian (Patient 9: Interview 1)

To make this work, to resolve the contradiction, patients 'twin-track' these inconsistent lines of thought, running them in parallel, rather than examining the relationship between them. In effect, they contrive to create a dissociation between the two ideas.

7.2.3.2 Revising downwards

In the same way that participants tended to resist the 'disability' identity in the interests of maintaining normality, they tended to adjust their conception of what counts as a tolerable mode of life in the face of a gradual deterioration in function. In effect, this was to 'revise downwards' their expectations, their sense of what was bearable. It is, perhaps, a form of cognitive dissonance: since deterioration is inescapable, it is necessary to change one's views about what level of function is consistent with a reasonable quality of life.

This was evident in the comparison in content and tone between first and subsequent interviews; it was also evident, where patients had been interviewed only once, in their reflections on their present situation in the light of previous aspirations.

Patients used expressions such as 'I am still able to...' or 'As long as I can...' to describe ways in which life remained enjoyable. 'As long as I can do x, y or z, everything will be fine, and I'll have nothing to complain about.'

I'd be most unhappy if we couldn't get out to meals and that together, but that's our sole enjoyment in life, really, you know. We sit down and we sometime spend an hour and a half. We sit down, have a drink, chat, all the rest of it, you know. [...] Life is okay at the moment. Put it this way, if it doesn't get any worse than it is now, it's liveable with. I can put up with it as it is now.

Alf (Patient 1: Interview 1)

Four and a half months later, when I interviewed Alf for a second time, things had indeed 'got worse'. He was having increasing problems with incontinence and fatigue, both of which were limiting his and Alice's ability to go out for meals, and walk about town. To deal with this, he revises downward his criteria for what counts as 'liveable with':

Well, the bowels are playing up something horrible, and I feel completely fatigued, I'll be honest with you. I have to fight against it. If I give in I am finished. [...] But there you are, let's be truthful about it, things are a lot better than they could have been. I don't think I have anything to complain about whatsoever. [...] Well, if I couldn't get out, I think I'd be as miserable as sin. [...] If I wasn't able to drive then we would be in trouble, wouldn't we? [...] Even if we just go and see the grandchildren.

Alf (Patient 1: Interview 2)

Celia had looked forward to walking again, and had (briefly) managed this. When I interviewed her at home three months before she died, her pain and deteriorating mobility meant that she was increasingly confined to her bedroom. She continued to hope that she would walk, but found daily enjoyment in

... reading my bible, or listening to the radio, and watching TV. I'm having Sky put in [in her bedroom] now so I can watch some of the church programmes. And my family come to visit.

Celia (Patient 3: Interview 1)

Another striking description of 'revising downwards' was given by Ben. At the time of the first interview, it would not be an overstatement to say that Ben was appalled by the thought of paralysis:

Since I've been able to be walking, it's been alright. I mean, if I had to be in a wheelchair, it would just be terrible.

Ben (Patient 2: Interview 1)

Five months later, he said this:

Because see, getting out in the wheelchair, if we discussed this last November I would have been in tears. [Now] it's an absolute joy to go out in a wee wheelchair. [...] So the thought of being in a wheelchair, it isn't, it's not, it's almost crept on me, it's just not a big issue, is it.

Ben (Patient 2: Interview 2)

But he still voiced concerns at the possibility of future deterioration:

At the minute [I'm] walking and getting into the chair. [...] [If] there was a dependence that I couldn't get up stairs or couldn't get out of the seat, [...] I just can't imagine what that's like.

Ben (Patient 2: Interview 2)

The SEIQoL data provide useful support for this analysis. Patients' quality of life is related to the relation between what they perceive as 'tolerable' on the one hand, and their experience of the actual circumstances on the other (Twycross 2003). When experience falls below 'tolerability', one could expect an assessment of a poor quality of life. However, as Table 7.1 shows, the patients I interviewed consistently rated their quality of life as high. The results of my very small sample fit with the findings of Levack *et al.* (2004), who found a median SEIQoL score of 66 (maximum 100) across their sample of 180 patients with metastatic spinal cord compression. Levack *et al.* are surprised by their result, and, although they use it for a basis to recommend that professionals should not judge quality of life on behalf of patients, they are unable to explain it. Taking account of patients' strategy of 'revising downwards, however, we can understand the way in which high quality of life scores are perfectly consistent with deteriorating function. As patients deteriorate, they revise downwards their conception of what counts as tolerable, and quality of life remains high.

Table 7.1: SEIQoL data

Patient	Interview 1	Interview 2	Interview 3
Alf	78.52	72.05	-
Ben	Not done	79.42	Not done
Celia	74.3	-	-
Derek	66.2	64.48	-
Eddie	77.6	-	-
Frank	77.21	Not done	-
Gill	Not done	Not done	74.11
Hugh	68.72	-	-
Ian	73.61	-	-

7.2.3.3 Finding possibilities

There were situations in which life-at-present came close to being intolerable, and, to varying degrees, patients expressed sorrow, frustration and regret about their loss of physical capability and the consequent loss of opportunities. To deal with this, they found things to look forward to. These future possibilities encompassed both the quotidian and the more exotic, the imminent visit of a grandchild, or the prospect of travelling around Canada in a camper van. In the following example, Derek began by describing his feelings about his deteriorating function:

*Derek: I can't raise myself [sit up in bed] now, without any help. So I felt that going and I thought God this is it. You know from my toes, right up to my chest. Phew. This is it ...go and get the gun. [...]
Yeah. I can't see, I mean, I'm going to lay here, not knowing what's going to happen to me, well, I*

don't know, for ever, you just don't know. Nobody can tell me. [Derek then spoke about his understanding of his prognosis and his family's encouragement. I returned to his earlier statement.]

Interviewer: I want to go back to something you said earlier... at the risk of speaking about something that's painful. When you said, 'It went, from my chest, down to my legs,' and you said after that, 'time to reach for the gun.'

Derek: Yep. [...5s pause...]

Interviewer: Can I just ask you about that... I want to make sure I'm understanding what you meant. [...8s pause... Derek nods but does not speak] ... What I understood you to be saying, was that being disabled to that extent...

Derek: Yeah.

Interviewer: ...made you think differently about... about living.

Derek: Yeah.

Interviewer: Have I got that right?

Derek: Yeah. Yep, yep, yeah.

Interviewer: That... that... and so, it would be difficult having to live... with this kind of disability which meant that there were things you wouldn't be able to do for yourself.

Derek: Yep.

Interviewer: Can you tell me a bit more about what that prospect made you feel like?

Derek: Terrible. Absolutely terrible. Oh, you get into these occasionally. Sometimes I got into a real trough. Oh God, you know, absolutely down in the dumps, you know. I come out of it, snap myself out of it. [It happens] at night mostly. When the pain's bad.

Derek (Patient 4: Interview 1)

Having presented this bleak picture, he then identified a simple pleasure to which he was intently looking forward:

This is one of the best hospitals I've ever been in. [...] What's the time now, half past eleven? [...] Normally about 11 o'clock they come around with a drinks trolley [...] and they have an array, whiskey, rum, sherry. Cor Jeez, it's unbelievable! [...] They put a glass of Glenfiddich... when I say a glass, of course not a glass, but, and that sat there, kept having little sips of it and that sat there all day.

Derek (Patient 4: Interview 1)

For some patients, this looking to future possibilities involved having clearly specified aims and goals; for others it was more generalised.

I want to walk before the year is out.

Frank (Patient 6: Interview 1)

It's getting more difficult getting around. I can't, you know I can't not say that. That does, it is a bit of a bugbear, but hey ho. [...] I think it's important, that you know, I get up in the morning, I have my bath, I do my hair, I put my face on. Because it's something I've always done, and why shouldn't I do it now. [...] My mum and dad are coming up tomorrow. I've said to them that I need to get a few things from the shop, and probably tomorrow we'll get the ramps out for the front door and my mum will take me over to town.

Gill (Patient 7: Interview 3)

In many cases, as with Derek, daily pleasures were simple: reading, watching television, using the internet, banter with the nurses on the ward, diversions offered by visitors.

It did not seem to matter whether these goals are achieved or not. There was enjoyment simply in their anticipation. At times, in fact, it seemed that patients avoided putting themselves to the test: they enjoyed looking forward to something happening at some unspecified time in the future, and did not want to confront themselves with how difficult it might be to achieve in reality. Gill imagined that she would go on an excursion; but when the

opportunity presented itself, there were reasons why it wasn't convenient 'just right now. Another time.'

Prior to his admission to Sobell House inpatient unit, Derek had been a regular attender at the day hospice. He had been offered the opportunity to visit it whenever he wished while he was on the ward. I asked whether this was something he would like to do. He agreed that a change of scenery would be welcome:

Yeah. [...] Oh yeah, no doubt about it. Yes there are things I could do [...] at the Day Centre. I just can't [today]. I'm just checking my legs out. I know I don't need legs, but I still have a lot of pain.

Derek (Patient 4: Interview 2)

In this deferment of a situation which might disconfirm the hypothesis ('I can do this'), there is again an implied resistance to the image of oneself as disabled, and an effort to maintain a sense of normality.

7.2.3.4 Demarcating safe spaces

Ben became increasingly housebound as his illness progressed. The second time I interviewed him, five months after his diagnosis of spinal cord compression, he had stopped driving his beloved sports car, and went out only when accompanied by trusted friends. His early attempts to explore the community (working out boundaries) had not been encouraging. In particular, a fall in a department store had significantly dented his confidence:

[I had] a bad moment [shortly after the first interview]. I went up to Marks and Spencer, crazily, and I just got completely stuck, completely stuck there, it was awful. [...] I had to get a woman to rescue me and get me a trolley, and I just couldn't get home. I couldn't walk. My legs completely failed me it was

awful, it really was.

Ben (Patient 2: Interview 2)

Ben declared himself contented at home – a space that felt safe. He employed a nurse who lived in his home with him in the months before he died. Neither Ben nor Gill – both paraplegic – aspired to being independent wheelchair-users, although both had the physical capacity.

Celia coped with increasing disability through her faith that God would cure her. In the last six months of her life, Celia stopped going to church, saying she saw no point: she couldn't dance and take part in the service. She withdrew from attending the day hospice when it became too difficult to use her stair lift. By the time I interviewed her (three months before she died), her world had retreated to her upstairs bedroom, which she was arranging to her satisfaction: having satellite television fitted to watch the Christian channels, and installing a couple of comfortable armchairs for visitors.

Frank lived in a bungalow at the end of a cul-de-sac. He and Felicity had converted the living-room, which had a view down the length of the road, into a bedroom. Frank liked the room very much:

Well I can read, and read and read and read. And watch the television. The sport. And see what's on down the road. I can see them all. Everybody comes down the road to go through to the shops and they all wave as they go down the alleyway and that's nice.

Frank (Patient 6: Interview 1)

Gill – as I shall explain further in Chapter 11 – became more and more reluctant to leave her bedroom. Unlike Ben, Celia and Frank, her only visitors were health care staff (Macmillan

nurse, home carers, district nurses, her GP) and, occasionally, her parents. She and her husband became increasingly estranged, occupying different spaces within the house; something which caused her great pain. While she felt safe in her room, she became increasingly isolated and distressed, and at one point was admitted to the hospice in-patient unit with a large pressure sore, and depression.

In some cases, then, the demarcation of a safe space appears desirable and protective; in others, it seems limiting and isolating, and a cause for concern. I shall address this issue in Chapter 12.

In this section (7.2) I have described three dimensions of the patients' orientation to disability: 'acknowledging', 'not acknowledging' and 'managing the tension'. I will now turn to the health care professionals, and ask what sense they (and specifically the rehabilitation staff) made of the patients' response to disability.

7.3 The professional perspective

As one might anticipate, health care professionals were quick to recognise when patients were 'acknowledging the problem'. Here, for example, are some comments on the patients' need for information:

He had lots and lots of questions [...] So my initial [...] meeting with him was very much him asking me lots and lots and lots of questions rather than me trying to do an initial interview. He was bombarding me with questions and I was having very much to go back and structure it a bit more. [...] He had so many different things to ask he didn't know where to start or who to ask, or if he was asking the right person, so [...] there was loads of issues really within that first session.

Jacqui (Hospital Occupational Therapist)

Similarly, there were many accounts of patients testing out physical boundaries (with some prompting from rehabilitation staff), to establish what they could and could not do.

Often [...] it is only when we start to do things like transfers out of bed, and getting from bed to chair without being able to stand up, or we stand them in the standing frame, [...] that they then really... because they're doing activities with you, it hits them far more readily. They have to face that fact that right, well yes, you're standing me but my legs aren't moving, and you've getting me two to help me stand up. And then it kind of dawns on them.

Penny (Hospital Physiotherapist)

A lot of my role seems to be to explain to them that, yes you can kick your legs in the air and you can do this, that and the other, but when it comes to the crunch and you actually have to get up and walk, your coordination's shot. And you're not actually mobile. You have good strength but you can't coordinate with that strength. [...] I mean they need a reality check to some extent.

Pat (Hospital Physiotherapist)

This last remark is revealing, because it is an allusion to the other side of the patients' response: 'not acknowledging the problem'. The rehabilitation staff recognised this reaction, too, but they tended to describe it as 'unrealistic' at best, and as being 'in denial' at worst.

I think it's just difficult. I suppose some patients are just completely in denial really, and just think, 'I'll be completely cured by radiotherapy and manage absolutely fine and everything's going to be a bed of roses.' And other patients are a bit more accepting on the surface. But I'm sure they're not really underneath.

Pat (Hospital Physiotherapist)

I mean you get people who are euphoric and very unrealistic, you get [...] the total spectrum of: 'Oh yes if I work really hard at this I'm going to get lots of movement back,' when you know they are not, and no matter what you say they will not take that on board in their mind at the moment. [...] And then for

other patients they're like: 'Well, okay I know I'm not got going to be able to move my legs but there are loads of things I want to do outside, so what do I need to learn to have the tools to survive outside.'

Penny (Hospital Physiotherapist)

It is interesting that this last respondent saw 'acknowledging/not acknowledging' as a distinction between two different types of patient – when in fact, as I observed earlier, most patients do both at the same time. But, generally speaking, the evidence suggests that health professionals were more likely to construe the patient's response as indicative of a certain type of person, a certain type of character. They did not see 'acknowledging/ not acknowledging' as twin facets of a complex response to appalling circumstances, or as something which every patient engages in to one degree or another.

This can be seen quite explicitly in some reflections on individual patients, when the professional tried to explain the fact that they are 'unrealistic':

Jenny: And there might be – this is just a stab in the dark – but there might be an element of he doesn't want to be wrong and he doesn't want to realise his limitations, and doesn't want to realise that, yeah, maybe this isn't just short term, maybe it is long term and that's probably quite frightening for him.

Interviewer: Why do you think that is?

Jenny: Why do I think he doesn't realise that?

Interviewer: Why do you think he would be so determined to be independent in the face of all evidence to the contrary?

Jenny: I think obviously his character and his personality and I think it's just him.

Jenny (Hospital Occupational Therapist)

This explanation by reference to 'character' sometimes took a more specific form, with particular personality traits being invoked:

He was a difficult [patient] [...] in terms of completely not wanting to accept that he actually needed help. [...] And he is also very, a little bit antagonistic... you know, he was kind of a bit in your face and a bit sort of... could be a bit aggressive and a bit challenging, and liked to sort of make people uncomfortable. And a funny dry sense of humour. [...] So he didn't listen very much if you tried to say anything to him.

Pat (Hospital Physiotherapist)

In summary, then, the rehabilitation staff recognised the patient's 'acknowledgment' of the problem, and they were open to the patient's need to determine what limits the disability had set. However, they were inclined to represent the equal and opposite reaction – 'not acknowledging' – as unrealistic; and they tended to discriminate between patients whose *characters* prompt this 'denial' and those who were more accepting of the consequences of their condition. The idea that the same patients evinced both strategies, and that this ambiguity was typical of most patients, seemed to elude them. This is a topic I will take up again in Chapter 12.

7.4 Summary

The patients' orientation to disability incorporates two apparently inconsistent attitudes. One is a recognition that something significant has changed and that, as a consequence, new self-management skills must be learned, functional boundaries must be explored, useful information must be sought. The other is a determination to hang on to an established identity, associated with the patient's sense of normality. This identity embraces the idea of competence and resourcefulness, the events, activities and pleasures that one looks forward to, and the wish to avoid burdening others. It is not a 'disabled' identity. To some extent, these two attitudes are in tension, as one implicitly acknowledges disability while the other,

implicitly or explicitly, resists it. Consequently, patients try to find ways of resolving this tension, by 'revising downwards' their expectations, by constantly deferring the anticipated pleasures, and by avoiding situations in which their abilities might be put to the test, or the sense of normality be disconfirmed. It seems plausible to suggest that this 'double-tracking' of attitudes to disability is something that rehabilitation professionals need to understand if attempts to engage patients in rehabilitation are to be successful.

In Chapter 8, I will turn to what actually happens on the ward.

Chapter 8

Inpatient rehabilitation

This section reviews several aspects of the patient's time on the ward. It begins with data drawn from the audit, giving an account of the demographics of the patients admitted, their diagnoses, lengths of stay on the ward, mobility difficulties and patterns of referral for rehabilitation. In the second half of the chapter, I turn to the interview data to explore the way in which various routines and procedures, such as referral to occupational therapy or physiotherapy, and the relationships between the different professions, helps to shape the patient's view of rehabilitation. This view is closely related to the typical 'orientation to disability' (discussed in Chapter 7), in that each tends to reinforce the other.

8.1 Patient characteristics and rehabilitation processes

8.1.1 Demographics

Between 1st July 2003 and 30th June 2005, 82 patients were admitted to the Frank Ellis Unit with diagnosed or suspected spinal cord compression. Following further investigations, six patients were found not to have cord compression, and three sets of notes were untraceable. The figures that follow relate to the 73 patients' notes included in the audit.

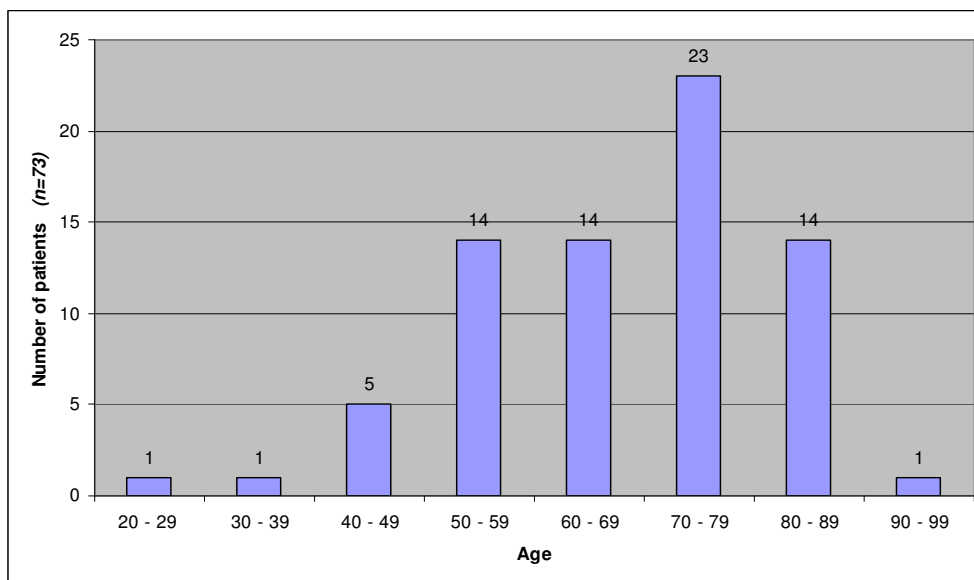
Table 8.1 shows the number of admissions, age, and age range of patients. In this and subsequent tables (8.2, 8.3 and 8.4), the first column of figures refers to the 24 month audit carried out as part of this research study. Scott-Brown's (2002) figures from the six month audit carried out in 2002 are shown in the second column, to provide a comparison.

Table 8.1: Demographics

	24 months 03-05	6 months 02
Total Admissions	82 (73)	21
Male	50 68.5%	14 66%
Female	23 31.5%	7 33%
Average Age	68.00	68.95
	Range 29-94	Range 42-85

	24 months 03-05	6 months 02
Age Range	<i>n=73</i>	<i>n=21</i>
90-99	1 1.4%	0 0
80-89	14 19.2%	2 9.5%
70-79	23 31.5%	9 42.9%
60-69	14 19.2%	7 33.3%
50-59	14 19.2%	2 9.5%
40-49	5 6.8%	1 4.8%
30-39	1 1.4%	0
20-29	1 1.4%	0

Figure 8.1: Age distribution (24 months 03-05)

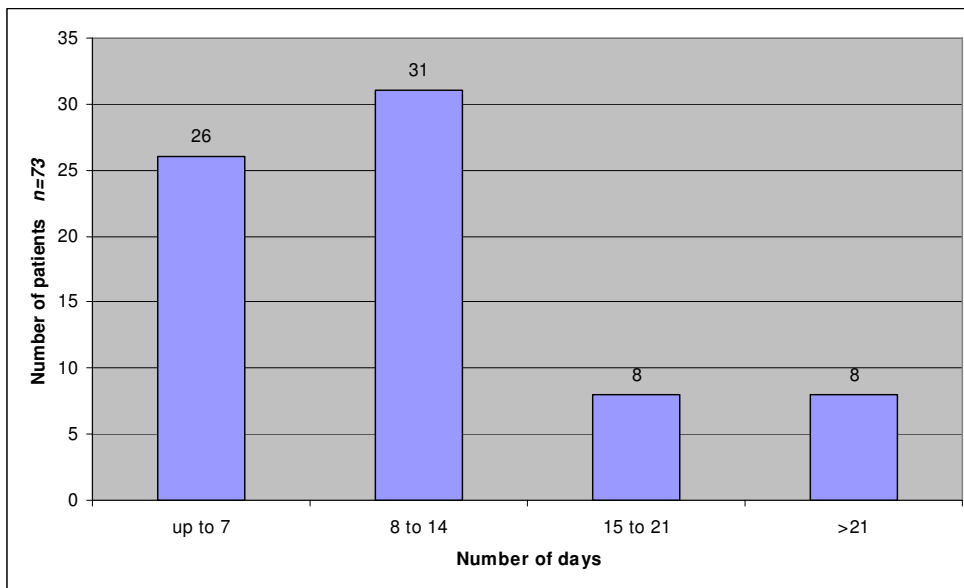


Patients spent an average of 12 days on FEU, (range between one and 55 days).

Table 8.2: Length of stay

	24 months 03-05	6 months 02
Average Stay	12.04 days	10.71 days
Length of Stay	<i>n</i> =73	<i>n</i> =21
Up to 7 days	26	
8 – 14 days	31	
15 – 21 days	8	
More than 21 days	8	
	Range 1-55	Range 2-36

Figure 8.2: Length of stay



The sites of primary cancers and level of lesion in the spine are consistent with figures in published studies and reviews (Abrahm 2004; Cowap *et al.* 2000; Hicks *et al.* 1993; Byrne 1992), with prostate, lung and breast cancer predominating, and most metastatic deposits found in the thoracic region (Loughrey *et al.* 2000; Hill *et al.* 1993; Gilbert *et al.* 1978).

Table 8.3: Site of primary cancer

	24 months 03-05		6 months 02	
Primary cancer	<i>n=73</i>		<i>n=21</i>	
Prostate	27	37.0%	7	33.3%
Lung	11	15.1%	2	9.45%
Breast	9	12.3%	2	9.45%
Myeloma	4	5.5%	2	9.45%
Lymphoma	3	4.1%	2	9.45%
Kidney	3	4.1%	0	0
Melanoma	2	2.7%	1	4.8%
Colon	2	2.7%	1	4.8%
Pharynx	1	1.4%	0	0
Rectum	1	1.4%	0	0
Cervix	1	1.4%	0	0
Oesophagus	1	1.4%	0	0
Thymus	1	1.4%	0	0
Bladder	0	0	1	4.8%
Stomach	0	0	1	4.8%
Thyroid	0	0	1	4.8%
Unknown	7	9.6%	1	4.8%

Table 8.4: Level of lesion

	24 months 03-05		6 months 02	
Level of Cord Compression	<i>n=73*</i>		<i>n=21</i>	
Cervical	4	4.8%	2	8.0%
Thoracic	53	63.9%	13	52.0%
Lumbar	19	22.9%	7	28.0%
Sacral	3	3.6%	2	8.0%
Unknown	4	4.8%	1	4.0%
<i>*8 patients had lesions at two levels; 1 had lesions at three levels.</i>				

Table 8.5 Survival rates by diagnosis

	<i>n</i> =	RIP as in-pt		Alive 1 month		Alive 3 months		Alive 6 months	
Prostate	27	3	11%	22	81%	13	48%	10	37%
Lung	11	3	27%	5	45%	3	27%	1	9%
Breast	9	0	0%	7	78%	5	55%	3	33%
Myeloma	4	0	0%	4	100%	2	50%	1	25%
Lymphoma	3	0	0%	2	67%	0	0%	0	0%
Kidney	3	0	0%	2	67%	1	33%	0	0%
Melanoma	2	1	50%	1	50%	0	0%	0	0%
Colon	2	0	0%	1	50%	0	0%	0	0%
Phrarynx	1	0	0%	0	0%	0	0%	0	0%
Rectum	1	0	0%	1	100%	1	100%	0	0%
Cervix	1	0	0%	1	100%	0	0%	0	0%
Oesophagus	1	0	0%	0	0%	0	0%	0	0%
Thymus	1	0	0%	1	100%	1	100%	1	100%
Unknown	7	1	14%	3	43%	1	14%	0	0%
Total	73	8	11%	50	68%	27	37%	16	22%

Just over two thirds of patients (68%) survived one month from diagnosis; just over one third (37%) survived three months, and around one fifth (22%) were alive at 6 months. Median survival was 53 days, with a range of 4 – 896 days.

8.1.2 Mobility

Without exception, all of the 73 patients admitted in the two year period of the audit had some degree of mobility difficulty both on admission and on discharge. This ranged from minor difficulties with balance when walking to complete bed-bound immobility. For a minority of patients (23.3%), mobility improved during their admission, but none were fully mobile on discharge. As measures of function and independence are not routinely used on the unit, this data was taken from physiotherapy assessments recorded in patients' hospital records, and from the ward staff's descriptive entries in notes. As such, the data is rather rough-and-ready. My intention here is to give an indication of the extent to which spinal cord compression patients admitted to the unit encounter some level of impairment.

Table 8.6: Mobility on admission and discharge

	Admission		Discharge	
Mobility	<i>n</i> =73		<i>n</i> =73	
Walks independently, some unsteadiness	6	8.2%	4	5.5%
Walks with aid	24	32.9%	30	41.1%
Uses wheelchair independently	1	1.4%	2	2.7%
Uses wheelchair, needs assistance	30	41.1%	20	27.4%
Not mobile – bed bound	12	16.4%	9	12.3%
RIP	–		8	10.9%

8.1.3 Referral to occupational therapy and physiotherapy

All patients are routinely referred for physiotherapy on admission, with the rare exception of patients who are acutely unwell. There is an incentive for making a physiotherapy referral: the physiotherapist is required to provide advice on safe moving and handling on the ward, together with an indication of patients' potential for discharge. Referrals to occupational therapy are made when it appears that patients' disability might impede discharge, or when an item of equipment, such as a wheelchair, is required for use on the ward.

Timely and safe discharges from the ward are the institutional priority for the rehabilitation staff. Rehabilitation interventions are therefore directed, almost exclusively, towards achieving the level of independence, mobility and care (if required) that is necessary for discharge.

There is a substantial difference between the numbers of patients referred to, and seen by, the physiotherapists, in comparison with the occupational therapists.

Table 8.7: Referrals to physiotherapy and occupational therapy

	Physiotherapy		Occupational Therapy	
	<i>n=73</i>		<i>n=73</i>	
Referred	68	93.1%	43	58.9%
Seen	67	91.7%	29	39.7%
Percentage of referrals seen	98.5%		67.4%	

91.7% of spinal cord compression patients were seen by the physiotherapists; only 39.7% of patients were seen by the occupational therapists. Of the patients referred for physiotherapy, 98% were seen. Of the patients referred for occupational therapy, 67% were seen. The reason for this discrepancy is not readily apparent, but may be accounted for by the fact that, unless the patient's intended discharge destination is home, they are not a priority for occupational therapy intervention.

This is to some degree confirmed when patients who were discharged home are compared with patients who were discharged to another hospital. 72% of those discharged to another hospital were *not* referred to the occupational therapist, compared to only 22% of those discharged home. And of those discharged to other hospitals who *were* referred to an occupational therapist, 57% were not, in fact, seen (compared with 33% of those discharged home and referred). There were no comparable differences in referrals to physiotherapists.

Table 8.8: Discharge destination and occupational therapy referrals

	Referred to OT and seen	Referred to OT but not seen	Not referred to OT
Discharged home	52%	26%	22%
Discharged to hospital	12%	16%	72%

The number of times patients discharged home were seen by occupational therapists can also be compared with the number of times patients discharged to other hospitals were seen. The

mean number of contacts, in each case, is shown in Table 8.9. The difference is significant at the 1% level. Again, there was no difference between the mean number of contacts by physiotherapists to each group.

Table 8.9: Mean number of contacts by an occupational therapist

For patients who are:	Mean contacts
Discharged home	1.63
Discharged to hospital	0.24

When further comparisons between occupational therapists and physiotherapists were made, there were substantial differences in the time to referral (see Figure 8.3), the time taken to respond to referrals (see Figure 8.4), and the number of physiotherapy and occupational therapy contacts (Table 8.10, Figure 8.5).

Moreover, the frequency of physiotherapy and occupational therapy interventions also varied. A ratio of length of stay : number of contacts was calculated for each patient. As can be seen from Table 8.11, the physiotherapist saw the patient, on average, once every three days, but the occupational therapist saw the patient, on average, once every eleven days.

Figure 8.3: Days between admission and referral

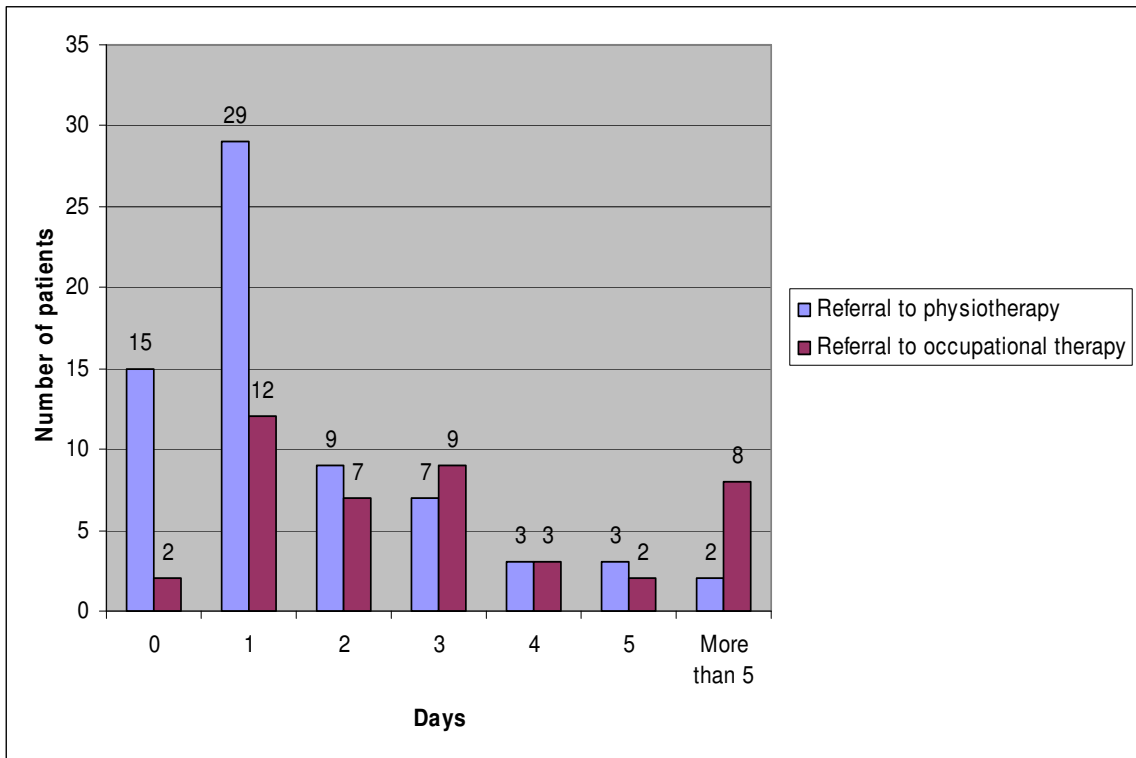


Figure 8.4: Days between referral and first contact

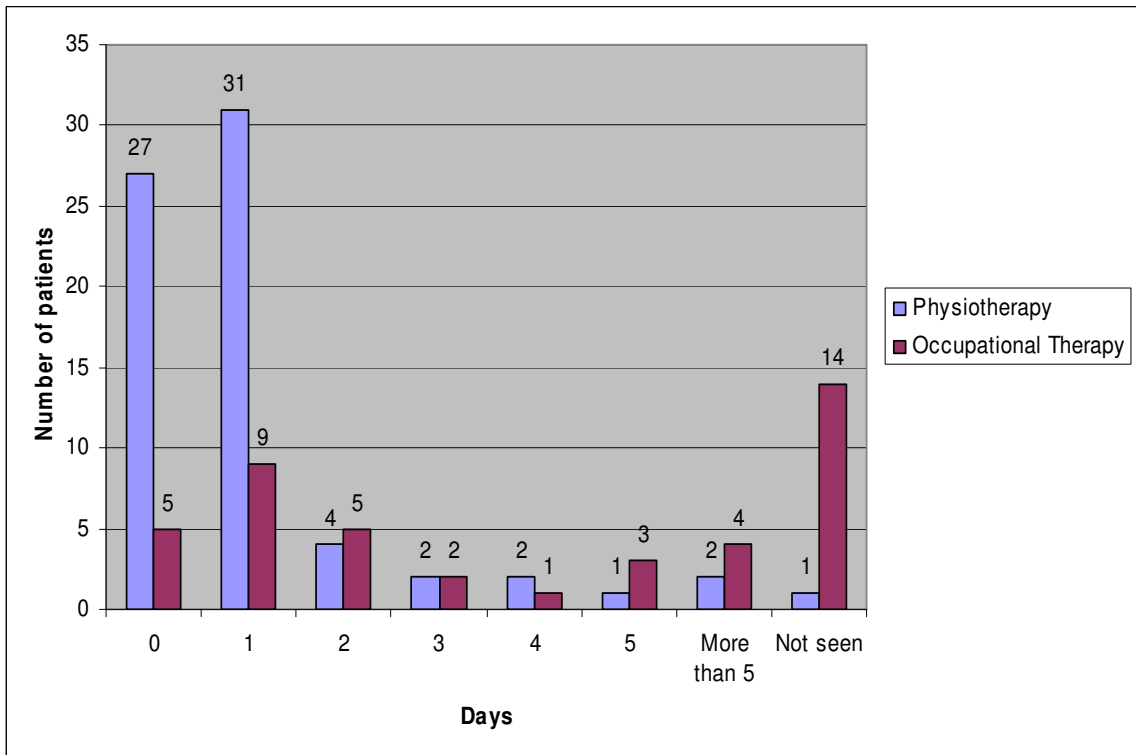


Table 8.10: Number of times seen by physiotherapists and occupational therapists

Number of times seen	<i>n</i>	Minimum	Maximum	Total contacts	Mean	Std deviation
By physiotherapists	73	0	18	314	4.30	3.75
By occupational therapists	73	0	12	73	1.00	1.92

Figure 8.5: Number of times seen by physiotherapists and occupational therapists

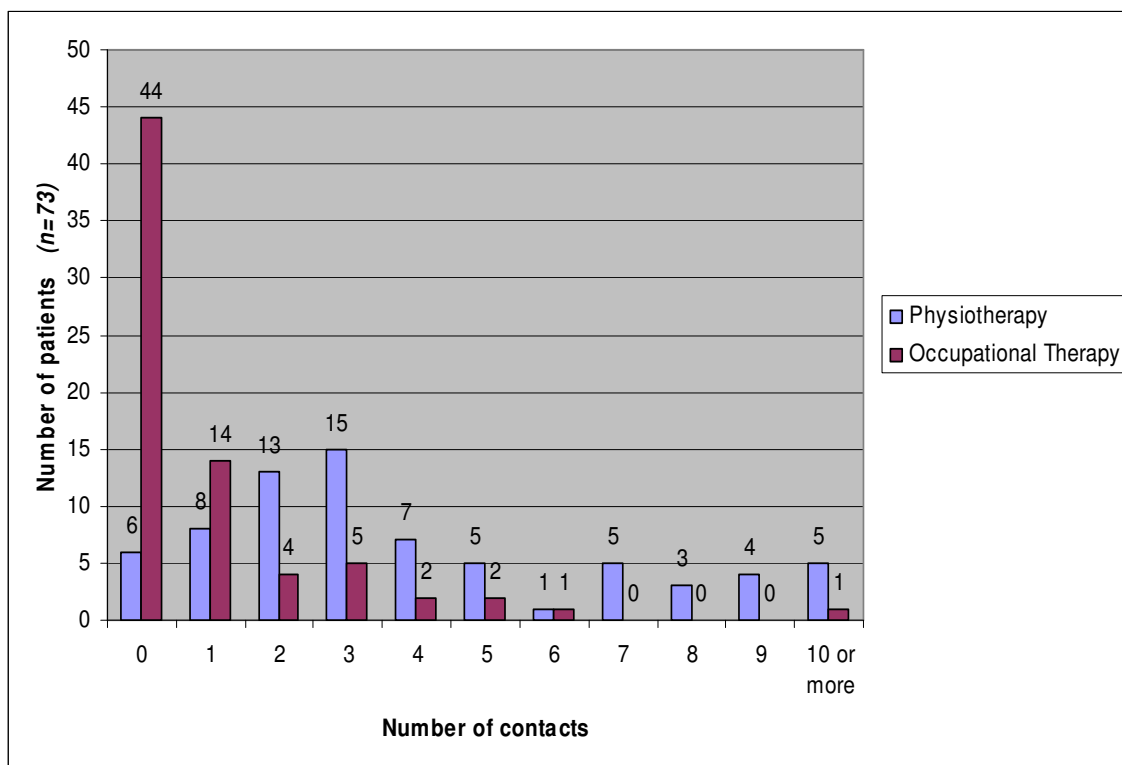


Table 8.11: Comparison of length-of-stay: contact ratios

	Mean	<i>n</i>	Std deviation
Physio ratio	2.94	29	1.34
OT ratio	10.88	29	9.64

In summary, it can be seen that, while physiotherapy is a routine intervention on the ward, occupational therapy is not. It is less likely that a referral to occupational therapy will be made, and less likely that the occupational therapist will see the patient, even when there has been a referral. When the patient is seen, the time that has elapsed since the referral is likely

to be greater; visits from the occupational therapist are more infrequent; and occupational therapists make, on average, fewer visits in total. Occupational therapists are more involved when the patient is due to be discharged home, and hardly involved at all when the patient is discharged to another hospital.

8.2 Patient and staff approaches to rehabilitation

8.2.1 Patients' accounts of rehabilitation

We can now turn to the patients' own accounts of inpatient rehabilitation. As we have seen in Chapter 7, patients wished to explore their capabilities, restructure their activities and seek information. In the main, they found ways to do this themselves. Where help was forthcoming from rehabilitation staff, it was accepted (to varying degrees), but it was not sought. We have also seen that there was a marked tendency for patients to resist the idea that they were disabled, and to present themselves as competent, resourceful and resilient. This determined resistance to the 'disability identity' predisposed them not to recognise the need for rehabilitation. From the outset, it was not something that held much interest for them and, in a number of cases, their subsequent experiences of rehabilitation on the ward were not such as to increase their confidence in its value. Indeed, patients were somewhat perplexed by the rehabilitation staff – physiotherapists as well as occupational therapists.

I was a bit puzzled by the physiotherapist to be honest. They came round at nine o'clock and said they'd be back at ten and they didn't come back until nearly five in the afternoon. They spent a lot of time with – do you remember this guy Harry next to me? [...] They spent a lot of time with him. Maybe they just didn't know I needed it or something. Their sole concern was whether I could go up these three steps and whether they could let me go home. They didn't seem to be engaged with me at all. There might have been a good reason why they didn't come back to me but they never explained to me why not.

Ben (Patient 2: Interview 1)

It is worth reviewing, however, the reasons why patients might not have been motivated to take an interest in what rehabilitation staff have to offer:

- As already noted, a wish to retain a view of themselves as 'normal', resourceful, resilient and coping, a view which is not consistent with a perception of themselves as 'disabled' and in need of support.
- The distress caused by events leading up to diagnosis, and the shock and overwhelming disappointment of the diagnosis itself.
- Significant co-morbidity, so that achieving adequate symptom control is often difficult. Pain, fatigue and incontinence are particularly distressing problems.
- Uncertain prognosis. While in broad terms, a prediction about prognosis can be made on the basis of tumour biology and functional status on diagnosis, it is extremely difficult to give individual patients a clear indication of anticipated outcomes. Both staff and patients tend to err on the side of optimism. Patients have a natural and appropriate desire to hope for the best. It is difficult to plan for the future when you don't know what the future may hold. While in hospital, patients are playing a 'waiting game', unsure of the extent to which radiotherapy will improve mobility and independence.

As a consequence of all this, patients had what might be called a 'default motivation': that is, no particular interest in rehabilitation. It is not something they are conscious of, and not something they enquire about. This default position would not be a significant factor if nursing and (particularly) medical staff were clear about the purpose and value of rehabilitation, and if they could communicate this purpose successfully to patients.

However, as we shall see in a moment, this does not appear to happen. As a result, the default motivation continues, largely unaffected by ward-based events and conversations.

8.2.2 The representation of rehabilitation to patients

The staff interviewed described good team working on the ward, and good relationships between nursing and allied health professionals. The nurses felt well supported by the medical staff. While the unpredictability of the timing of consultants' ward rounds could sometimes be an issue, this was, to a large degree, compensated for by the full-time presence on the ward of two rotational senior house officers and a permanent staff grade doctor. A regular (weekly) meeting was held on the ward to discuss treatment and care plans for each patient; this was attended by the nurses, ward-based doctors, physiotherapist, occupational therapist, social worker, chaplain and the hospital palliative care clinical nurse specialists.

We work very closely with the doctors in here, I'm quite impressed actually. [...] The doctors [the senior house officers] are around all the time, they're always ward based. [...] And then there's the consultants as well and they're very approachable. You can ask them a stupid question and they're quite nice about it.

Meera (Staff Nurse, Frank Ellis Unit)

However, a significant aspect of interdisciplinary working on the ward was the almost complete absence of opportunities for interaction between the senior medical staff and the occupational therapists and physiotherapists.

I've never been with the consultants [...] or the registrars when they've told the patient that they have spinal cord compression. So [...] I don't know what they say to them. [...] It would be interesting [to know] because then you know what you're up against or what information they know. [...] I talk to the

registrars occasionally. [...] [but] the consultants, I have no idea what they look like.

Julie (Hospital Occupational Therapist)

I wouldn't be able to name all the consultants. I wouldn't be able to recognise them, whereas I could, where I've worked before. [...] I know they do ward rounds, but that's sort of once a week isn't it? [I would go on the ward rounds] but I don't know if they're on the days that I'm working, I've never been. It might be a good thing, but we've never been invited on ward rounds. That's another time thing as well.

Paula (Hospital Physiotherapist)

Paula was clearly waiting for an invitation. The consultants, meanwhile, appeared to be waiting for the rehabilitation staff:

Interviewer: Would there be any mileage [...] when you're seeing a patient with cord compression patient, who [...] was likely to have some disability issues, to have a joint conversation with the patient with yourself and the OT or physio?

Trevor: Yes. I mean, this is the problem. [...] I rarely see the OT or the physio on the ward. I [...] do my ward round later this morning, if they're there I'll see them. But if not, you know I won't see them. And I mean I don't mind, if an OT or physio wants to come and see a particular patient in clinic I wouldn't have any problem at all with that. I'd welcome it. Because it can only be better can't it?

Trevor (Oncology Consultant)

Sometimes, the rehabilitation staff's attempts at direct communication with the doctors were discouraging. While Julie might say she does not regard the doctors as unapproachable, her description of their response to her seems a little contradictory.

I do try and communicate with the doctors. If there are issues and a doctor is there I will tell them. [...] But if they're not there then I don't think about it. They're not unapproachable. I don't feel anxious or nervous about approaching them, but they're not very good at responding to what you say and are very

good at ignoring you. Some of them are quite rude and don't actually appreciate what you're doing. [...] [Anecdote about a change of plans regarding a patient, and communicating this to the senior doctor.] I just thought well they're on the ward round they're just about to go and see him. So I said, "I'm Julie the OT, I was going to do a home visit, but actually it's not indicated anymore, so I don't need to do it, so he can go home." And he grunted at me. I thought, okay, you don't speak, you grunt.

Julie (Hospital Occupational Therapist)

Communication, then, was limited; and, on the face of it, when it did happen it was not such as to inspire more. However, it could be argued that this does not necessarily constitute an insuperable problem: the occupational therapists and physiotherapists obtained the information that they needed from nurses, the ward doctors and medical notes (although, as we shall see, it appears that medical notes are not always examined very closely).

However, the lack of contact between medical and rehabilitation staff does have implications for the way that patients perceived, and engaged with, rehabilitation. Patients understood their situation, and made decisions for the future, largely on the basis of their interaction with their consultant or senior medical staff. While they would seek information and support from a wide variety of sources, they relied on the consultant to provide, as the case may be, progress checks, key information on future expectations, or a stamp of approval.

There's sort of a medical thing – checking on a daily basis what my legs feel like, and I would like to discuss that with someone, but I know if I did call up Dr Upton [consultant], he'd say, 'What have they been like?' and I'd say, 'They feel a bit, like, dead today,' and, well, nothing's really going to happen. Emotionally that would be nice, but... it's strange, but I don't think that calling a Macmillan nurse would really have the same effect as Dr Upton just because of the perceived status and power sort of thing. [...] If Dr Upton could come round my house every night at five o'clock that would be nice, but

[laughs] you know, let's be realistic. He can't do that for everyone.

Ben (Patient 2: Interview 1)

The rehabilitation staff themselves commented on the consultants' pivotal role in the patients' decision-making:

He very much was keen to go home, wanted to get home, there wasn't really an option that he wasn't going to go home. He had made that decision, the doctors had said he was going, and it was: what we could do to get him home quickly and safely, really.

Jacqui (Hospital Occupational Therapist)

Patients were particularly responsive to doctors' suggestions that they could go home, irrespective of the rehabilitation staff's view of this:

[The patient was] busy making plans to go home. I don't know what the doctors had said to him, possibly [...] the nursing staff or doctors said that once you've had your radiotherapy you can go home. [They are] not maybe saying [as well]: but you have to be able to do x, y and z [before you can go home] as well as well as feeling okay medically. [...] It would back up what we – me and the physio – were trying to do.

Jenny (Hospital Occupational Therapist)

Consultants, then, were key in setting the priorities for treatment and care, and patients allow 'what the doctor says' to override any concerns expressed by rehabilitation staff. So it is tempting to suppose that a consultant incorporating rehabilitation into current and future plans, or the patient observing the consultant and physiotherapist jointly discussing future rehabilitation during a ward round, would contribute towards creating a space for rehabilitation on the patient's agenda (I will discuss this proposal further in Chapter 10). In the absence of such contact, however, the patient's default motivation remains in place.

Clearly, then, the way rehabilitation is represented to patients is important. A patient who is told that the occupational therapist will provide a commode for discharge is not led to anticipate that the occupational therapist's remit might include enabling social participation, satisfaction and fulfilment in life. Instead, the impression is created that the occupational therapist is essentially a technician whose role is to make discharge feasible.

And to a considerable extent, in practice, this is true. Given that the institutional priority is discharge, the main activities of the rehabilitation staff on the ward were geared (as we shall see in a moment) towards improving mobility and transfers, and providing necessary equipment.

I think it's fair to say that it's not the priority during the initial hospital admission. The priority is the initial medical treatment. [...] And there is a need to move people on [...]. A lot of the discussion with every patient revolves around their discharge planning. You sometimes think that's a priority over and above actually looking after the patients. I don't think you should say that, but that's slightly the impression you get sometimes.

William (Oncology Consultant)

Patients, however, described rehabilitation-related needs that extend well beyond discharge planning; for example, the need to work out boundaries, to minimize dependence on others and to learn self-management skills. The extent to which it is possible or appropriate to achieve this during an in-patient stay is limited but, in principle, the groundwork could be carried out at this stage, with a view to providing support – recognised as useful by the patient – in the future.

However, the fact that rehabilitation is not represented to the patient (by medical and nursing staff) in a way that would explain its significance is not the only reason why the

patient's attitude towards rehabilitation remains an incomplete and sceptical one. There is also the matter of differing priorities, and divergent views of risk.

8.2.3 Goal-setting, priorities and the assessment of risk

We have seen that, on the whole, patients want to retain a view of themselves as resourceful and capable, and to have a view of the future that incorporates hopeful possibilities. Patients might not, therefore, consistently engage with a process of identifying problems and setting the sort of goals that rehabilitation staff would see as appropriate. In some contexts, patients will agree that 'My goal is to be able to manage the toilet independently'; but they are equally likely to say: 'I'm wondering whether I should re-mortgage the house and travel around Canada.'

8.2.3.1 Setting goals

Therapists are concerned with goals being realistic and achievable:

I say [to patients] that there's still a possibility, there's always a possibility that things will improve a bit. But normally I'll be saying to them, I think it's unlikely that you'll walk again, but you might get good enough to get from the bed to the chair on your own. [...] We need to sort of bring the goals back a little bit and sort of be a little bit more realistic.

Pat (Hospital Physiotherapist)

The process of setting explicit goals, as advocated in the literature, appeared absent, for several reasons. Therapists were concerned that asking a patient about his or her goals could hinder, rather than assist, their intervention:

I'd like to be able to sit down with people and ask them what their goals are [...]. But that's overshadowed by [...] thinking: 'I've really got to get you out of hospital. We can talk about the fact that you'd like to go to the library and read your books and stuff, but that really isn't going to help me

in getting you out of hospital and the doctors are going to get really annoyed with me if I talk to you about all these things.

Jenny (Health Care Professional – Hospital Occupational Therapist)

I think I haven't done it [asked about Frank's priorities] because I'm worried that if I do, what it will open up that I can't then enter into.

Janet (Health Care Professional – Palliative Care Occupational Therapist)

Therapists commented that they found it difficult at times to establish patients' goals, and they noted that 'what patients said' about future aspirations did not always translate into 'what patients did'. For example, Frank had been emphatic that his goal was to walk again. Janet, the occupational therapist, had decided that she would make use of the opportunity presented by his admission to Sobell House for respite to work on achieving this. She recalls:

I saw him [...] two or three times during that week [...]. The first day I came in and said, 'Do you want to have a go today?' And he really wasn't keen and I had to push a little bit and eventually I said, 'Well, shall I come back in an hour, shall I come back in an hour and a half?' And he said, 'Okay.' And then when I went back we did the transfer and he did appear to enjoy the time in the wheelchair. The next day [...] when I went back he declined completely that day. He said his legs felt sore and he was tired because he had had a bath.

Janet (Palliative Care Occupational Therapist)

Janet was puzzled by this:

I'm not sure why, I couldn't quite rationalise in my mind why his legs being a bit painful, because he wasn't lying in bed grimacing and asking for pain killers, why that stopped him doing a transfer where actually he doesn't usually use his legs.

Janet (Palliative Care Occupational Therapist)

Seeing this situation in terms of Frank resisting putting his ability to walk to the test, and enjoying the (unchallenged) possibility of walking again 'at some point in the future', could help Janet to make sense of the situation.

8.2.3.2 Differing priorities and risk assessment

As I have mentioned, one of Ian's priorities was to refurbish a camper van and travel with his wife. Not surprisingly, the physiotherapist had more immediate concerns about mobility on the ward – precarious even with the help of a walking frame – and with the 15 steps he had to negotiate to his front door at home.

The patient's need to – for example – demonstrate resourcefulness, explore boundaries, find possibilities for the future and assert normality, was at odds with the staff's perceptions of responsible risk management both on the ward and in planning discharge.

[On the ward at the moment] I'm not allowed to get out and walk to the toilet, anywhere, even with a frame. [...] I feel I could, with, I'd need someone with me perhaps, but that hasn't been possible. I am dependent on somebody being there, even if all I need is a bottle. I could manage a bottle at the bedside myself, but it's a bit difficult with the ward being open. I mean I'm not sure, I haven't discussed it with anybody, what is the etiquette using the bottle, which I can do quite discreetly But I can't pull the curtain around the bed. So I have to summon the nurse.

Hugh (Patient 8: Interview 1)

For the staff, it is important to keep both themselves and patients safe; and, although the need for patients to be as independent as possible is recognised and – in theory at least – supported, in practice it can be difficult to achieve.

There are patients who [...] no sooner have you got the commode there they're struggling to stand up. And the message we give is you're putting us at risk because you really can't do this, so just sit down

and let us handle you. [...] We try to stop them in order to (a) to protect ourselves, (b) to a degree to protect them, and (c) to kind of get through [the work]. And actually this is where I think if you had the right teamwork, if you had all the right people around informing the care plan, being involved, then actually you could then say, [...] 'We think we can maximise your ability in x by doing it this way. Let's have a go, let's do that.' You're giving the power back to them to move. And it could be as simple as a banana board, or you know, whatever, that enables them to do it without putting themselves at risk. And potentially getting to a point where you can say, 'Well you can do that now.' So you know, 'Call us if you want us, but, hey, there's the banana board you get on and do it.'

Ursula (Nurse Manager)

Staff were naturally concerned with patients' ability to manage basic daily living activities at home without putting themselves at risk of harm. The occupational therapists and physiotherapists had a significant role in assessing and advising on patients' potential for a safe discharge. As a consequence, patients frequently saw this decision as resting with the ward staff, rather than one which they made themselves on the basis of informed choice. To this extent, occupational therapists and physiotherapists were viewed as 'gate-keepers' rather than collaborative partners in facilitating participation in daily life.

The issues around differing priorities and assessment of risk were particularly acute when it came to discharge planning. An immediate consequence of spinal cord compression-related disability, and one which was of concern to both staff and patients during hospital admission, was whether or not living at home remained an option. Assessing patients' fitness for discharge, and planning discharge, is a priority for all staff, but particularly the rehabilitation staff. It is symptomatic of patients' experience of in-patient rehabilitation that patients saw this as having to pass some kind of test.

They will complete the radiotherapy treatment on Tuesday. On Wednesday I will do various tests particularly with the physios [...]. So there'll be an assessment whether they've been able to get the house into a state to be able to get home [...] [That's what] happened last time, and then I passed with flying colours last time, and it's not going to be flying colours this time.

Hugh (Patient 8: Interview 1)

8.3 Safe discharge: a case study

In the discussion so far, I have presented a number of 'inpatient rehabilitation' themes in a relatively fragmented way. The statistics of admission, discharge and mobility have been reviewed, together with measures of the patients' contact with occupational therapists and physiotherapists. We have seen that patients are not 'rehabilitation conscious', and that they are often puzzled by the contact they have with relevant staff. I have suggested that, as a result of the different priorities of patients and rehabilitation staff, marked particularly by the rehabilitation staff's attitude to risk, patients see occupational therapists and physiotherapists as little more than gatekeepers, setting tests which the patient must pass before he or she can go home. Finally, I have argued that the lack of contact and communication between medical and rehabilitation staff serves only to reinforce the patient's very limited view of what rehabilitation can achieve.

Before closing this chapter, I would like to present a brief case study, tracing the experience of one patient over the course of ten days, in order to illustrate the way in which these disparate elements connect together. The case study is based on the medical notes for this patient (taken from the audit data), as this is the only way to develop a narrative which focuses on the assessments made by the health professionals, and their various

communications with each another. By examining the case study, we can see in greater detail how the themes I have traced interweave, and with what result.

Sue Mitchell (not her real name), a 35 year old woman, was admitted to the Frank Ellis Unit with a one week history of back pain and leg weakness. The initial entry in her notes by the senior house officer (SHO) records her past and current medical status, as well as a brief comment on her social situation:

3/2/06 (Friday) SHO:

Admitted today as emergency.

Previous medical history: Exophytic Cervical tumour IIA diagnosed Aug 05. Surgery, Chemotherapy (Cisplatin) Sept 05. Radiotherapy Aug 05 & Oct 05.

Current problems: Back pain and leg weakness, numb lower abdomen, bottom and legs. MRI this afternoon shows metastatic deposits T8 T9 T10 T12 involving bodies and neural arches. T8 collapse and compression. Had 20Gy [radiotherapy] to T7 T8 T9 today. Constipated. Finding it difficult to urinate.

Lives with partner and 2 young children. Previously independent in activities of daily living.

A nursing entry the following day indicates that this is a patient with whom the ward staff have developed a relationship over preceding months:

4/2/06 (Saturday) 13h40 Nursing:

Sue well known to ward – has been admitted monthly for chemotherapy since October '05. Transferring independently but remains unable to mobilise.

The entries over the weekend and into the following week describe Sue's physical problems, and the importance to her of time spent with her family. She and her partner wished to get married, and the medical and nursing staff offered support to achieve this.

4/2/06 (Saturday) 21h00 Nursing:

Visited by family.

Required oramorph for breakthrough pain.

5/2/06 (Sunday) 13h05 Nursing:

Reports improvement in sensation in toes and has not required oramorph this morning.

Has spent lots of time with family and remains in good spirits. Sue's main concern is her son aged six who she has only told on this admission that her cancer is terminal.

6/2/06 (Monday) SHO:

Pain well controlled. Very constipated. Struggling to pass urine. Discussed catheterisation – Sue not really keen.

6/2/06 (Monday) 18h30 Nursing

Remains settled and self caring with general needs. Has been referred to physio and OT who will see her tomorrow.

7/2/06 (Tuesday) Nursing:

Urinary output good. Transferring independently to commode. Remains constipated ++. Sue declined Movicol – feels it gives her gripey stomach pain. Would prefer Guinness!

7/2/06 (Tuesday) Consultant Ward Round:

Bowels opened this morning. Straining to pass urine. Will need physio and OT prior to discharge. Sue and partner are arranging to marry. I will write to Registry Office for permission to hold ceremony outside Office if Sue not fit enough to travel.

7/2/06 (Tuesday) 13h20 Nursing:

Tearful on return from radiotherapy. In pain and feeling bloated / achy. PV bleeding persists. Visited by family and son.

On Tuesday afternoon, the physiotherapist begins her assessment, and flags up Sue's need for a wheelchair to enable her to move around. Wheelchair provision is the remit of the occupational therapy department, and an occupational therapy assistant leaves a wheelchair on the ward.

7/2/06 (Tuesday) 15h30 Physiotherapy:

Reports ↓ sensation from T8 down. (L) leg weaker and also ↓ sensation. Sensation and strength fluctuates depending on position – sitting out causes ↓ sensation.

Session cut short with arrival of visitors. Will review tomorrow.

7/2/06 (Tuesday) 20h30 Nursing:

Spent afternoon with family in day room. Remains low in mood when family not present. Transferring bed to chair with supervision. Seen by physio. Needs wheelchair from OT.

Entry undated. Occupational Therapy Assistant:

Pt issued with 8L wheelchair and Vicair [pressure cushion] on request of physiotherapist. PLEASE RETURN WHEELCHAIR AND CUSHION TO OT DEPT ON DISCHARGE.

8/2/06 (Wednesday) 13h10 Nursing:

Sat out in wheelchair for the first time this morning. Wheelchair supplied by OT – uncomfortable – needs alterations. Family visited – brighter in mood.

8/2/06 (Wednesday) Physiotherapy:

Pt well. Agreed to try new wheelchair provided by OT. Transfers independently into wheelchair. Taught self-propelling and manoeuvring in chair. Discussed with Sue about mobilising in her house. She does not walk because she is worried about left leg giving way. Says she has been going up and down stairs on her bottom. Advised her that we do not recommend this as not safe but ultimately it is patient's choice. Likes wheelchair but needs back cushion as pain increases when sitting.

8/2/06 (Wednesday) 21h30 Nursing:

Sue has required oramorph x 2 this evening with good effect. Has been sitting out in wheelchair.

9/2/06 (Thursday) 04h50 Nursing:

Sue feels leg pain has increased. Left leg appears swollen around knee and ankle.

Feels her leg gives way when transferring – advised to ask for assistance. Has commode for use overnight.

The second wheelchair also proves unsatisfactory. The need for occupational therapy was signaled on Monday, but it is not until Thursday that the occupational therapist sees Sue. At this stage, the urgency for discharge has increased: Sue continues to have periods of feeling low in mood, and her mobility is not improving. She very much wants to be at home with her family, where it will be easier for her to organise her wedding. In discussing her discharge with the nursing staff, she identifies the need for a commode, and the occupational therapist is contacted to supply one as soon as possible.

9/2/06 (Thursday) 11h00 Nursing:

Sue feels very uncomfortable in her wheelchair with the cushion she has been given. Also footplates are at different heights. Awaiting OT to review.

Left leg feeling very numb and she did not manage to transfer on her own from chair.

Sue wants to go home tomorrow – understands risks – wants to arrange wedding. OT needs to see re commode. Does not want a care package. Family will be on hand to help.

It is worth noting here that Sue's experience of occupational therapy to this point has been the provision of two unsuitable wheelchairs. She has not met an occupational therapist, and appears to have no reason to expect the occupational therapist to do anything other than

provide commode to assist her at home. The occupational therapist, however, is concerned about Sue's safety at home:

9/2/06 (Thursday) 12h35 Occupational Therapy:

Saw pt and husband in day room with friend. Keen to return home at weekend.

Home environment:

- *13 steps road to front door. Rail on right.*
- *13 steps (approx) ground floor to bed & bath.*
- *Pt reports minimal access throughout house for wheelchair especially upstairs.*
- *Prior to admission was sleeping downstairs on sofa.*
- *Sue wants a commode for discharge.*

Problems for discharge:

- *Access for wheelchair into and around property.*
- *Ward sister reports wasn't able to weight-bear this morning. OT may have to provide hoist.*
- *Needs physio review ?ability with banana board.*
- *An OT assessment visit would be required before discharge. As pt lives out of area [outside of Oxfordshire], this would take some time to organise.*

From family descriptions discharge home would be difficult to achieve due to environment and function.

Recommendation:

- *Discharge home this weekend would currently be UNSAFE.*
- *OT feels a rehab / community hospital would benefit Sue more.*

This seems at odds with the assessment of the doctors, nursing staff, physiotherapist and of Sue herself. A combination of the occupational therapist's concern about safety, and also her apparently poor knowledge of Sue's prognosis, social situation and priorities (the reference to 'husband', for example), leads her to the conclusion that Sue should be discharged to a community hospital. The provision of a commode – apparently the main reason for the

occupational therapy referral – is not mentioned, and the physiotherapist reiterates the need for this after she talks to Sue a few hours later.

9/2/06 (Thursday) 15h30 Physiotherapy:

Desperate to go home on weekend. Happy to go on weekend leave and come back on Sunday night if necessary to plan discharge properly. I have advised her to stay downstairs – safer than being lifted upstairs by family. Sue is still desperate to go home and will stay in living room once inside house. She will need a commode and wheelchair from the OT.

Counter to the occupational therapist's advice, the discharge goes ahead, supported by the consultant. It turns out that the occupational therapist is unable to provide either a wheelchair or a commode.

9/2/06 (Thursday) 21h30 Nursing:

Consultant contacted re Sue going home on weekend leave. He is happy for this to proceed. Need to contact district nurses tomorrow. Family arranging wheelchair and commode for home as OT cannot provide equipment for patients out of county. Sue will return on Monday to plan discharge.

However, Sue declines to return to the ward following her weekend at home.

13/2/06 (Monday) Nursing:

Telephone call to ward from Sue. She does not want to be readmitted as it will be much more difficult to organize the wedding if she is outside of the county where she lives. Discussed with consultant. He is happy to discharge Sue and see her in out-patients if necessary.

Sue does not want community OT follow-up.

Through this sequence of events, we can see the key themes I have discussed earlier in this chapter: a lack of direct communication between medical and rehabilitation staff (here compounded by the occupational therapist's apparent failure to read the notes closely

enough); the mismatch of priorities, with the rehabilitation staff's emphasis on Sue's physical safety; the four day delay between referral to occupational therapy and the therapist making contact; and the representation of rehabilitation as the provision of equipment or the proffering of safety advice. As a consequence, Sue's experience of rehabilitation consists of: three visits from the physiotherapist; a single delayed visit from the occupational therapist; two uncomfortable wheelchairs; the inability to provide either a wheelchair or commode for her at home; the need for Sue to negotiate, and make assurances in order to secure a discharge; and, in the final instance, her rejection of the offer of further community occupational therapy follow-up.

8.4 Summary

The patients' resistance to the idea that they are 'disabled', and its psychological consequences, interacts with events, procedures and conversations on the ward. Given that safe and speedy discharge is a priority, focusing attention on the most basic functions, patients remain unimpressed, and sometimes baffled, by the role that rehabilitation staff play. If this applies to physiotherapists, it applies even more to occupational therapists, with whom patients have far less contact, and who are almost exclusively concerned with making discharge home feasible. The patient's attitude towards rehabilitation is therefore neutral at best, reinforcing the view that rehabilitation is not, in any case, something they need. Nursing and medical staff might put a dent in this view if they could communicate the idea of rehabilitation, its purpose and value, successfully; but the procedures adopted on the ward have the opposite effect, seeming to marginalise rehabilitation. As a result, patients regard physiotherapists and occupational therapists as discharge gatekeepers, rather than as people who could help them in ways they *can* recognise, such as learning self-management

skills, minimising dependence on others, and engaging in fulfilling activities. We will see in the next chapter that patients take this perception with them back to the community, and that it is one reason why rehabilitation is no more in evidence there than in the hospital.

Chapter 9

Hospital to community

The preceding two chapters have dealt with the patient's attitude to disability, and the way in which this interacts with events on the ward. Though no-one intends it, the overall effect is to keep rehabilitation off the agenda: the patients do not recognise its significance, and little that happens while they are on the unit provides them with any sense of its potential value. This chapter deals with the situation beyond discharge, and I begin with some background facts and figures.

9.1 Admission and discharge

9.1.1 Source of admission and discharge destination

Patients are admitted to FEU from Oxfordshire and the surrounding counties.

Table 9.1: Origin of admission and discharge destination

	Oxon (n=27; 37%)		Wilts (n=26; 36%)		Bucks (n=15; 20%)		Other (n=5; 7%)		Total (n=73)	
Admitted from:										
Home	25	94%	11	42%	2	13%	1	20%	39	53%
DGH	0	0%	13	50%	11	73%	2	40%	26	36%
CH	1	3%	1	4%	0	0%	0	0%	2	3%
NOC	1	3%	0	0%	2	13%	2	40%	5	7%
Hospice	0	0%	1	34%	0	0%	0	0%	1	1%
Discharged to:										
Home	11	41%	11	42%	4	27%	1	20%	27	37%
DGH	0	0%	9	35%	7	47%	1	20%	17	23%
CH	9	33%	2	8%	1	7%	1	20%	13	18%
Hospice	2	7%	3	11%	1	7%	2	40%	8	11%
RIP	5	19%	1	4%	2	13%	0	0%	8	11%

(DGH = District General Hospital; CH = Community Hospital; NOC = Nuffield Orthopaedic Centre)

Overall, 37% of patients were discharged home, 23% to a local district general hospital, 18% to a community hospital, and 11% to a hospice. 11% died on the ward. As I noted in Chapter

8, all patients had some degree of mobility impairment on discharge. To recap: 46% of patients were walking with some form of assistance, 30% were wheelchair dependent, and 12% were immobile (see Table 8.6).

As can be seen from Table 9.1, there was a certain amount of variation associated with the patient's county of residence. Almost all Oxfordshire patients were admitted from home, as one would expect; this is true of only about half of patients from the other counties. Equally, patients from adjoining counties were more likely to be discharged to the district general hospital, although 33% of Oxfordshire patients were discharged to a community hospital. About 40% of patients from Oxfordshire and Wiltshire returned home; only 25% of patients from other counties did so. Given the way in which cancer services are organised in the Thames Valley area, this is neither surprising nor problematic. However, it has implications for rehabilitation provision both on the ward and following discharge, as we shall see.

9.1.2 Incentives for discharge

Rehabilitation services are county-specific: care, equipment (such as commodes or hoists), wheelchairs and community physiotherapy or occupational therapy must be obtained from the health or social services suppliers in the patient's county of residence. The ward staff experienced difficulties arranging services efficiently and effectively for patients outside Oxfordshire. Each county, and sometimes each area within a county, has its own system, and it can be difficult and time-consuming to find one's way through many different administrative configurations. Thus, where patients living outside of Oxfordshire have care and equipment needs, there was a strong incentive to discharge them back to their referring hospital, or to their local community hospital or hospice, to wait for local arrangements to be made.

Whilst they're in hospital the process of getting longer term care underway starts and that usually involves the medical staff, the nursing staff, the physiotherapy and occupational therapy if appropriate. Often it's a question of actually trying to liaise with, well many of my patients come from Wiltshire, so liaising with the services in Wiltshire rather than directly with the services on the ground. Some of those patients will be transferred back to the district general hospital in Swindon for further rehabilitation, particularly if they're fairly disabled..

William (Oncology Consultant)

While equipment is relatively easily obtainable for patients living in Oxfordshire, community care could be more difficult to arrange; and where a care package was needed, there was again an incentive to move the patient to a community hospital bed rather than to aim for home.

Where home was not the agreed discharge destination, patients become less of a priority for active rehabilitation interventions on the ward. This was particularly the case for occupational therapy, where the common understanding was that limited staffing resources necessitated prioritising those patients requiring services to enable discharge home.

A lot of my patients are out of county patients. Thinking about it now. There is only a few that actually go home within the Oxfordshire area. [...] I've got this chappie for instance, doesn't live in Oxfordshire. So I've got his referral, I've written out his details and looked at his medical notes, and [...] my plan is at some point to go and talk to him about whether he would actually like to get into a wheelchair. [...] But [this] isn't on the top of my list of priorities.

Julie (Hospital Occupational Therapist)

Some occupational therapists took this a step further, citing a departmental embargo on seeing patients who are not destined to go home.

There are limits [to what we can do]. [...] Because it is a regional centre, lots of people are from outside Oxfordshire and they just go back to whichever hospital referred. And we're not really allowed to see them, because the OT policy is to see people who are going to their homes.

Jacqui (Hospital Occupational Therapist)

However, the occupational therapy manager confirmed that no such policy existed. While noting the problematic service-delivery issues mentioned earlier, she gave one example of the value of early occupational therapy contact.

Obviously that is a perception [...] [that occupational therapists are unable to see patients who are returning to other hospitals]. And it's not the case, so we need to do something about that perception. There are some very practical reasons – Wycombe and Swindon are both miles away. So the reality is if there is any work to be done, it's more easily and appropriately done from there. But of course [...] some of the ground work, what [the patient is] going home to, some contact with the person at the receiving hospital would go a long way.

Vivien (Occupational Therapy Manager)

The physiotherapists, who were more likely to be involved with the patient (as we have seen, patients were routinely referred for physiotherapy on admission), would continue to have regular contact, but this would be at a fairly low maintenance level.

9.2 Rehabilitation follow-up

9.2.1 Assumptions about follow-up

The limited extent to which rehabilitation can be provided on an acute hospital ward was recognised and accepted by staff. However, this acceptance was partly based on the assumption that rehabilitation needs would be identified and dealt with after patients leave the ward.

[After they leave us] I imagine their support in the community continued in some way or other, with on-going support from OT, physio. But I'd have to be honest and say, I don't really know.

William (Oncology Consultant)

Melissa: There is the community OT, and community physio also, but I don't know how often they pick up spinal cord compressions. We usually get the Macmillan nurse involved and district nurse [...].

Interviewer: Do you have any feel for what the follow-on community rehabilitation for patients is like?

Melissa: No, we get very little feedback.

Melissa (Staff Nurse, Frank Ellis Unit)

Nursing and medical staff anticipated that rehabilitation needs would be picked up as a matter of course, and a sentence to the effect of 'further rehabilitation required' was often included in the SHO's discharge summary letter. This, however, was little more than a conventional form of words, and (as we shall see) did not trigger any kind of intervention. More specific referrals for follow-up rehabilitation, which came from physiotherapists and occupational therapists, were only made in very particular circumstances, such as when there was a clear and immediate problem that was amenable to a specific intervention (for example, work on independent bed-to-chair transfers), or when the patient had expressed a wish for further intervention. Specific referrals of this type were very seldom made. In only four out of the 73 cases reviewed in the audit was a specific request for on-going rehabilitation intervention after the patients' discharge from FEU.

In the absence of specific referrals, there was no incentive for community staff to respond to general recommendation that 'further rehabilitation is required'. The ward staff's assumption that patients' rehabilitation needs are 'picked up' in the community turned out to be unwarranted.

It should also be noted that community-based occupational therapists and physiotherapists saw relatively few cancer patients, and in some cases felt they lacked sufficient knowledge to work effectively with spinal cord compression patients.

I was told it was a myeloma and that it was causing compression on the spine. [...] I didn't really have at all a clear idea in my mind exactly what that meant. It sounded so dramatic that I wasn't sure whether she was going to die immediately, or what. [It's different to] something like multiple sclerosis [...] because I've seen lots of people with multiple sclerosis. [...] I mean obviously it's up to us to look into it, look it up. [...] I usually do look it up as much as possible, but I didn't have a feel for it.

Janine (Community Occupational Therapist)

9.2.2 The sequence of 'no rehabilitation'

The 'discharge incentive' constitutes the first step in a sequence which leads to failure to provide any meaningful rehabilitation. At each stage of the process, rehabilitation is 'deferred' to a more suitable or appropriate time. In many instances, this leads to nothing being initiated, and therefore to nothing being done. Here is an outline of the sequence of events.

- Provision of rehabilitation in the acute environment is limited by patients' shock at diagnosis, co-morbidity, the pressure for swift discharge, and patients' orientation to disability.
- For patients returning home, only specifically identifiable problems warrant referral to community rehabilitation services. There may not be any such issues at the time of discharge. Problems might arise as the patient deteriorates, but the rehabilitation services are not able to deal with issues which, at this stage, remain in the category of 'potential difficulties'.

- As already discussed, patients' experience of 'rehabilitation' on the ward does not incline them towards seeking more of the same in the community. At best, they appreciate efforts to assist with practical concerns about managing disability; at worst they are frustrated by therapists apparently failing to engage with them and understand their priorities. They are not inclined to accept the offer of follow-up rehabilitation services in the community when these are offered, or to seek them out when they are not.
- If a patient is discharged to another hospital, the assumption is made that disability-related problems will be automatically picked up, and that these problems are in fact best left to staff with better knowledge of patients' local services at the hospital to which the patient has been transferred.
- The exception to this sequence, to be described shortly, is where patients are referred on to specialist palliative care teams for follow-up, either as hospice in-patients or through community palliative care (Macmillan) teams.

Given this background, we can now turn to the patients' experiences of living in the community, once they have been discharged from hospital.

9.3 Preparation for community living

9.3.1 Patients' experiences

While in hospital, it was difficult for patients to foresee the problems that they might encounter in the community. This was compounded by, first, the desire to maintain an optimistic orientation to the future and, second, the cursory rehabilitation they experienced on the ward, which terminated at the point of a discharge. All of which contributed to

patients being poorly prepared for the practical and emotional realities of managing disability.

[Before I left the ward] they didn't say very much at all, actually. They just said, 'You can do the stairs now, go home.' Alice [wife] said she could look after me if I needed looking after, you know, I could wash myself, toilet myself, and all that.

Alf (Patient 1: Interview 1)

The lack of preparation for community living, coupled with patients' wishing to 'explore boundaries' could have undesirable consequences.

I mean I did have an issue with the wheelchair. [...] The first time I [used] it, it was the wrong move really, because we went to Tesco and Tesco was busy, and there I was down, you know, in this wheelchair and all of these people, I just felt all these people coming towards me. [...] And it was like – oh, and I had no control. It was... it was terrifying, absolutely terrifying and I just wanted to get out.

Gill (Patient 7: Interview 3)

Patients' ability to cope with situations like this varied. Some described personal resources, and family and professional support networks, which enabled them to make pragmatic adjustments to managing daily life; others expressed despair.

Well I have a lot of friends where I live as well as good family support, so I think the concentration will be on getting the house and the pattern of life set up so I can keep on with the things I can practically do, some of it writing things, I can do at a desk. Seeing people, visitors [...] and [...] getting in and out of the house and in and out of a car so I can participate in life.

Hugh (Patient 8: Interview 1)

I see myself as a person living with this disability, and it is obviously taking over my life, even more so during the last four weeks. During my stay, my last few days in Sobell and my two weeks here at home, because I can't do anything and I can't get any where and I'm feeling ... (20s)... [tears] I feel useless.

Gill (Patient 7: Interview 1)

9.3.2 Carers' perspectives

Carers, meanwhile, felt that their perspectives and needs were not taken into account sufficiently. This was particularly the case for family carers who were unable to visit patients on the ward, for example those living some distance away in other counties, or those without independent means of transport. Family members who had the ability and the resources to participate in decision making, and in the planning of future care, were positive about their experience; those who did not felt that rehabilitation staff were insufficiently proactive in making contact with them and consulting them about future care.

The only indication we've had, and I've been asking, [...] is that hopefully by the end of [...] this week, [my father] will be able to go home, beginning of next week. [...] What I'm finding difficult is that because I have to get back to work, because I've only got these two weeks, I'm trying to think ahead and to say, 'What are we likely to need? Can we have an assessment now?' And then at least we know what we're looking for. [...] [If he needs] a single bed with the electric back, [...] right, I can do that, I can spend time now and get that in, this week, if only somebody would talk to me, answer my questions, let me know. And that's been a struggle.

Erica (Carer Patient 7: Interview 1)

I didn't know what to expect when Alf came home, really. I think because I live far away and our son could only take me [to the hospital] in the evenings I never got to see the doctors or people looking after him. [...] He [Alf] phoned one day and said, 'I'm coming home tomorrow,' and it was like, there it was.

Alice (Carer Patient 1: Interview 1)

He never came home again. That was the worst thing. The very worst thing. Terrible. On the Friday when I left the Churchill he was standing there with [patient] and they sort of waved me off and that's the last time I saw him standing up. I didn't go in on [the weekend]. [...] We thought he was coming home, I thought [...] Tuesday you're home, I won't go in. [On Tuesday] I got back from getting all the shopping and he phoned and said, 'I'm not coming home.' I said, 'What do you mean?' He said, 'They won't let me come home, it's an unsafe discharge, I've got to go to [community hospital].' I didn't know who made that decision. It wasn't discussed with me at all. [...] [The community hospital] had no idea why he'd gone to them. [Frank Ellis Unit] said he'd gone for intensive physiotherapy and [the community hospital] said well he's on the wrong ward then. They had no idea why he'd gone. The handover was that bad.

Irene (Carer Patient 9: Interview 1)

9.4 Patients' access to services following discharge

As I have noted, patients were able to find solutions to many of the problems they encountered, and welcomed the assistance of staff in gaining access to resources they found they needed. At the time of my second interview with Ben, he had lived at home with increasing paraplegia in the five months since his diagnosis of spinal cord compression. During this time, he had had help, briefly, from an occupational therapist (Jacqui) in obtaining rails and a wheelchair. Jacqui recalls:

We got it done very quickly. Because of the fact he had his brother-in-law there, I didn't have to wait for [the equipment suppliers] to put in rails, I literally went out, marked rails, [...] I gave him the number, I told him where to go. [...] And equally, with the [wheel]chair, [...] a phone call to the Red Cross got all that sorted and he went and collected the chair.

Jacqui (Hospital Occupational Therapist)

On the face of it, a good result. However, the wheelchair provided to Ben by the Red Cross was a heavy, much used chair with four small wheels, requiring it to be pushed by a helper, affording Ben no independence. I asked him whether he had, at any stage, been offered a light-weight, self-propelling wheelchair. He firmly rejected this idea: he did not need (or want) to own a wheelchair, and was intending to return this one when he became stronger and no longer required it. In this situation, Ben's psychological orientation to disability prevented him from pursuing a course of action that would have enabled greater freedom of movement. Also, as I shall demonstrate in Chapter 11, a therapist's assessment of a patient as competent and resourceful can sometimes lead to potentially helpful interventions and solutions not being offered. In this instance, there is the possibility that arranging the 'loan' of a lightweight sports wheelchair, and creating an acceptable opportunity to practise using it, might have enabled Ben to be more mobile, without him having directly to accept any long-term requirement for a wheelchair.

However, the ability of rehabilitation staff to be pro-active in this way depends on their having the skills, resources and organisational permission to identify patients who could benefit from this kind of intervention; and, according to occupational therapists, the necessary permission is not forthcoming:

Julie: The criteria is that once they go home from hospital then you don't go out and see them, because you need to pass them on to the community team.

Interviewer: Whose criteria?

Julie: The Trust I suppose. I've never actually read it though. [...] It used to be that we followed up until two weeks [after discharge]. But my senior colleagues told me that actually you don't do that any more, you have to pass on immediately. But I do make follow-up phone calls, I have broken rules

occasionally. We are not even allowed to give out equipment [if patients realise they need something after they have been discharged].

Julie (Health Care Professional – Hospital Occupational Therapist)

This account clearly echoes the claim that there is an embargo on further contact with patients who are transferred to another hospital (section 9.1.2), and it is no more true. As the occupational therapy manager observed in that instance, the practical difficulties have to be acknowledged, but undertaking follow-up does not count as breaking the rules.

I noted earlier that patients who were referred to the specialist palliative care services had a rather different experience of rehabilitation, as I shall now explain.

9.5 Specialist palliative care rehabilitation

There are two key differences between the organisation of ‘generalist’ rehabilitation services and the organisation of specialist palliative care rehabilitation.

Firstly, generalist rehabilitation services are fragmented: between acute hospitals and community hospitals, between hospitals and community rehabilitation services, between health and social services, and across county boundaries. Patients moving between services are handed from one team to another, and then to another. The palliative care service in Oxfordshire, on the other hand, has a number of teams operating from a single base. For example, a patient with palliative care needs admitted to one of the acute hospitals would be referred to the hospital palliative care team. On discharge, the patient might be transferred to the care of the community palliative care team, or to the day hospice. These teams do not operate as separate entities: they share members of staff (the consultants and occupational therapists, for example), and are part of the same organisation, based in the same building.

This not only facilitates communication, but also establishes a shared culture and a consistent approach to patient care. Even when patients are discharged across county boundaries, there is good co-ordination of care as palliative care staff tend to have strong links with colleagues in other palliative care centres.

Secondly, as we have seen, a referral to a rehabilitation service requires a clearly specified problem and an indication of the proposed solution. Referral to a community Macmillan nurse, on the other hand, can be made on the basis that, while the patient might not have an immediately obvious problem, the fact that they have a life-threatening illness suggests future deterioration and the need for support. The Macmillan nurse will seek to establish an understanding of the patient's and family's circumstances, their actual and potential problems, and their preferences and future orientation, with a view to enabling difficulties to be predicted and, as far as possible, pre-empted.

I am not for a moment proposing the organisation of palliative care services as an ideal. As a model of service-provision, it has numerous drawbacks. It is resource-intensive and therefore expensive, and prioritises the needs of a minority of 'complex' patients over the needs of a wider population, to mention just a couple. However, there appeared to be considerable differences between patients' experiences of specialist palliative care rehabilitation and their experience of the generalist services, prompting the obvious question: do patients who are referred to specialist palliative care services on discharge from hospital fare any better – in terms of rehabilitation – than those who are not?

9.5.1 Patients' experience of specialist palliative care rehabilitation

It is outside of the scope of this study to provide a comprehensive answer to this question; however, drawing on the case study data, we can see that those patients who received specialist palliative care services post-discharge (Celia, Frank, Gill and Hugh) appeared to have a better experience of rehabilitation, with the involvement of the hospice occupational therapists and physiotherapists. This could be attributed to a number of factors:

- The multi-professional palliative care team is able to provide continuity of care and, in anticipation of deterioration, to remain involved even when there are no active problems. Problems can frequently either be anticipated or responded to very quickly.
- The team members have regular and frequent opportunities to meet together and share information. Although one member of the palliative care team will take a lead (key-worker) role in patient care, the relationship that is established with the patient and family is on behalf of the whole team. This greatly facilitates other members being brought in when needed.
- The palliative care occupational therapists and physiotherapists are able to respond flexibly in rapidly changing situations; they are less preoccupied with patients' physical safety, and they appear less concerned to ensure that patients are 'realistic'.

In some situations (Celia and Gill, for example), the provision of social services' housing adaptations (such as stair-lifts and wheelchair access inside and out) was coordinated by the hospice day-centre occupational therapist, facilitating prompt action. In Hugh's case, his Macmillan nurse was able to keep in close contact with the hospice occupational therapists and physiotherapist during his last weeks at home, enabling him to retain some independence while at the same time acknowledging and supporting his deterioration.

Frank's hospice physiotherapist was able to take a less risk-averse approach to Franks' mobility. Frank very much wanted to be able to transfer from his bed to his wheelchair independently since that would reduce the number of carers' visits he required through the day. Pam, the hospice physiotherapist, referred him to a community physiotherapist. A month or so after the community physiotherapist first saw him, he was still not managing the transfer.

I spoke to [the community physio] and I was frustrated because I felt that it was quite sad that Frank was at home and he was in bed and I knew he was having physio, but he hadn't done a transfer or anything in that whole space of time, I think it was four or six weeks or something. So I went out to see him [...] with the consent of the [community] physio [...]. And I said to him, 'Can you transfer?' I took a board with me, and he did it straight away and was perfectly okay to do it. I don't know why he hadn't done it with the community physio. It was just a question of technically explaining how to position the chair, how to position the board, where to put your hands, where to put your body, where to actually shift your body weight, and he was across in a jiffy. So it took about two minutes and he was fine. I would have thought when he left here he would have been able to reach that stage [...] within two weeks. [...] The [community] physio said that she was working on strengthening and that. [...] I mean, she asked me if I was prepared to take responsibility for anything that happened, so I said I was. [...] I said, you know, something may happen, he may fall out of his chair, he may fall down on the way. That's life, you can't just wrap everybody in cotton wool. The chair might slide, he might drop down in the middle. [...] So we had certain parameters, ways of kind of establishing things to make everything as safe as possible, it didn't really feel that he would fall [...]. He's quite strong and he's aware of what's going on, you know, he's a sensible guy.

Pam (Palliative Care Physiotherapist)

There are, then, indications that the involvement of specialist palliative care rehabilitation may produce better outcomes for patients. However, the lack of a consistent and reliable mechanism for identifying patients' ongoing rehabilitation needs, and ensuring that available support services are effectively used, means that where good services are provided, this is more a matter of luck than good planning.

9.6 The place of specialist rehabilitation centres

As discussed in Chapter 1, there is some evidence in the literature that spinal cord compression patients who undergo in-patient rehabilitation in specialist rehabilitation units, such as spinal injury units, make functional gains comparable to people with traumatic spinal cord injuries. The majority of these studies have taken place outside of the UK, predominantly in mainland Europe and North America, where differences in health care systems and funding create very different structures for providing services.

None of the patients included in my study was referred to a specialist rehabilitation unit during the two-year period of the study. One patient had been previously referred (her first episode of spinal cord compression had occurred some months before the study commenced). This patient was offered an assessment at the Oxfordshire Centre for Enablement, but declined it. Patients who were interviewed some time after diagnosis were asked whether they felt that admission to a specialist rehabilitation unit would have been desirable. None would have wished this, on the grounds that time which could be spent with family was precious.

It is outside of the scope of the study to make recommendations about the desirability of admission to specialist rehabilitation centres for patients with spinal cord compression who

are referred for treatment at the Oxford Cancer Centre. This would require a further, separate investigation. However, if there is a group of patients (albeit a minority) who could benefit from the rehabilitation approach of a specialist rehabilitation unit, as the literature discussed in Chapter 1 suggests, a more pro-active approach to identifying these patients, with a view to referring them to such a unit, might be feasible. This is a point I shall pick up on in Chapter 13.

9.7 Summary

Hospital staff, recognizing the limited extent to which rehabilitation can be undertaken in the acute setting, tend to assume that rehabilitation needs will be identified in the community, and imagine that appropriate services will be provided. They therefore make very few specific referrals for rehabilitation. However, community rehabilitation professionals generally have little experience of cancer patients, and less of cancer patients with spinal cord compression; and they have only fragmented networks with unreliable systems of communication. For the most part, then, rehabilitation needs are not 'picked up', as hospital staff suppose they will be. As for the patients: on their return to the community, they initially retain an optimistic orientation, associated with a continuing resistance to the idea that they are 'disabled'. They also remain unimpressed by their experience of rehabilitation in hospital, having little or no idea of its potential value. They are not, therefore, motivated to request rehabilitation services when, as usually happens, none materialise spontaneously. As a consequence of all this, patients are ill-prepared for life in the community, and assume that they have to manage on their own. Some manage this relatively well; for others, the experience can be quite traumatic. The variations between the organisation of (and patient's experience of) palliative care rehabilitation on one hand and generalist rehabilitation services

on the other, suggest a number of issues for consideration in tackling the problem of delivering appropriate rehabilitation services for patients with metastatic spinal cord compression.

PART IV
DISCUSSION

Chapter 10

Complexity

10.1 A summary of summaries

At the end of each of the last three chapters, I offered a brief account, summarising the findings of the chapter concerned. It is worth repeating these three summaries now.

10.1.1 Chapter 7

The patients' orientation to disability incorporates two apparently inconsistent attitudes. One is an acknowledgement that something significant has changed and that, as a consequence, new self-management skills must be learned, functional boundaries must be explored, useful information must be sought. The other is a determination to hang on to an established identity, associated with the patient's sense of normality. This identity embraces the idea of competence and resourcefulness, the events, activities and pleasures that one looks forward to, and the wish to avoid burdening others. It is not a 'disabled' identity. To some extent, these two attitudes are in tension, as one implicitly acknowledges disability while the other, implicitly or explicitly, resists it. Consequently, patients try to find ways of managing this tension, by 'revising downwards' their expectations, by constantly deferring the anticipated pleasures, and by avoiding situations in which their abilities might be put to the test, or the sense of normality be disconfirmed.

10.1.2 Chapter 8

The patient's resistance to the idea that they are 'disabled', and its psychological consequences, interacts with events, procedures and conversations on the ward. Given that safe and rapid discharge is a priority, focusing attention on the most basic functions, patients remain unimpressed, and sometimes baffled, by the role that rehabilitation staff play. If this

applies to physiotherapists, it applies even more to occupational therapists, with whom patients have far less contact, and who are almost exclusively concerned with making discharge home feasible. The patient's attitude towards rehabilitation is therefore neutral at best, reinforcing the view that rehabilitation is not, in any case, something they need. Nursing and medical staff might put a dent in this view if they could communicate the idea of rehabilitation, its purpose and value, successfully; but the procedures adopted on the ward have the opposite effect, seeming to marginalise rehabilitation. As a result, patients regard physiotherapists and occupational therapists as discharge gatekeepers, rather than as people who could help them in ways they can recognise, such as learning self-management skills, minimising dependence on others, and engaging in fulfilling activities.

10.1.3 Chapter 9

Hospital staff, recognizing the limited extent to which rehabilitation can be undertaken in the acute setting, tend to assume that rehabilitation needs will be identified in the community, and imagine that appropriate services will be provided. They therefore make very few specific referrals for rehabilitation. However, community rehabilitation professionals generally have little experience of cancer patients, and less of cancer patients with spinal cord compression; and they have only fragmented networks with unreliable systems of communication. For the most part, then, rehabilitation needs are not 'picked up', as hospital staff suppose they will be. As for the patients: on their return to the community, they initially retain an optimistic orientation, associated with a continuing resistance to the idea that they are 'disabled'. They also remain unimpressed by their experience of rehabilitation in hospital, having little or no idea of its potential value. They are not, therefore, motivated to request rehabilitation services when, as usually happens, none materialise spontaneously. As

a consequence of all this, patients are ill-prepared for life in the community, and assume that they have to manage on their own. For some, the support of family and friends makes this possible; for others, the experience can be traumatic. The organisation of palliative care services – very different from that of rehabilitation services – suggests one way in which this problem might be tackled.

These three summaries can, perhaps, be précised as follows:

Disability is a serious problem for patients with spinal cord compression; but it is one problem among many others, not the least of which are the physical and emotional consequences of life-threatening illness. In an attempt to deal with these consequences, patients twin-track their attitudes to disability, acknowledging but at the same time resisting the idea of themselves as disabled, and adopting a series of psychological devices to manage the tension. They are motivated, then, not to recognise rehabilitation as something they need, a view which is confirmed by the cursory form of rehabilitation experienced in hospital, and by the marginal significance (apparently) attributed to it by nursing and medical staff. On discharge, hospital staff assume that rehabilitation needs will be identified in the community, although the way in which community rehabilitation services are organised virtually guarantees that this will not happen, unless a specific referral is made (as it is in only 5% of cases). The patient, meanwhile, remains unaware of the potential value of rehabilitation, and has no incentive to request rehabilitation if no-one offers it. They are consequently unprepared for life post-discharge, and assume that they (and their families) must manage on their own.

In summary, the current model of service provision (in Oxfordshire and the adjoining counties) does not work. Patients with metastatic spinal cord compression have specialist rehabilitation needs, requiring the attention of staff skilled in cancer and palliative care rehabilitation. Under the present system, there is no reliable method of ensuring they will get it.

I think it is reasonable to suggest that this précis represents a compressed answer (no doubt subject to various qualifications) to the research questions formulated in Chapter 3.3, which were:

1. What are the consequences of disability for patients with metastatic spinal cord compression?
2. What strategies do patients themselves use to manage disability?
3. What do health care staff, particularly rehabilitation professionals, understand to be the consequences of disability for this patient group, and correspondingly, what are their views on the significance and provision of rehabilitation?
4. To what extent is rehabilitation being provided to these patients, and with what effect?
5. Where rehabilitation is not being provided, why is this the case?

In suggesting this answer, I have implicitly offered an explanation of certain clinical outcomes, and in particular the very limited extent of rehabilitation provided to these patients, whether in the hospital or in the community. It is not, I must admit, the explanation I anticipated at the beginning of the study; but neither is it the outcome I envisaged when I was designing it. I had assumed that some patients would benefit – or at least appear to

benefit – from rehabilitation; and I hoped it would be possible to indicate how and why (equally, I hoped to be able to indicate reasons why other patients had *not* benefited). In saying ‘indicate’, I am taking into account the fact that I studied a small, non-generalisable number of cases, and that a significant aim was to formulate a rehabilitation protocol for spinal cord compression patients which could subsequently be evaluated, in line with the MRC framework (Medical Research Council 2000a). What I have ended up with, somewhat unexpectedly, is an account of why these patients do not, for the most part, receive rehabilitation in the first place; so the question as to whether any of them benefited from it is largely academic.

The explanation proposed is a little rough and ready: it has a broadly narrative form, and makes much reference to the psychological states of both patients and staff (motivation, resistance, awareness). Is this consistent with my earlier emphasis on ‘mechanisms’, and the idea (taken from Pawson and Tilley 1997) that outcomes are the result of mechanisms interacting with contexts? Or is the explanation just an informal and slightly speculative piece of psychology, combined with some basic facts and figures from the audit? Or could it be that the apparent difference between a ‘mechanism’ explanation and a ‘psychology’ explanation is illusory, and that they amount to more or less the same thing? This is an important question, because I need to defend the claim that I have described a real process, and not just a set of subjective attitudes and perceptions which do not admit of causal connections. To put it at its most general: if I have offered an explanation of the ‘not much rehabilitation’ outcome, what *kind* of explanation is it? How can it be construed in terms of current debates about the nature of explanation in sociology and social theory? This is the question which the present chapter will attempt to answer.

For reasons which will become clear later, I will begin with a brief account of one particular form of explanation which is common in the health care literature.

10.2 Deficiency explanations

In the health care literature there are very few discussions of what *counts* as an explanation, and hardly any analysis of the *types* of explanation that can be offered. However, there is one very popular type of explanation which is routinely adopted in situations of a certain kind. The situations I have in mind are those in which, broadly speaking, 'something isn't working properly'. Perhaps something is happening that shouldn't be happening, or alternatively something *isn't* happening that should be. It is the kind of situation, in other words, in which 'something is amiss', the outcome is 'not what we want' or, as Gall (2002: 5) puts it: 'Things Aren't Working Very Well'. Clearly, the 'not much rehabilitation' outcome fits this general description perfectly: something isn't happening (or isn't happening very much) which we, the health care professionals, think should be happening (and which we had imagined *was* happening). It is an outcome that is generally regarded as surprising and unwelcome.

The popular form of explanation for 'unwelcome outcome' situations is one I shall call the 'deficiency explanation'. At its simplest, the logic seems to be this: if how we do things has wrong consequences, then there must be something wrong with how we do things. If there is something negative about the result, then there must be something negative about what produced it. Deficient outcomes must have 'deficient' explanations. Because, clearly, if there was nothing wrong with the process, there would be nothing wrong with the product.

This is an assumption which runs deep in the health care literature. For example, a deficiency of time has been used to explain: why primary care staff do not make use of electronic

information resources (Doney *et al* 2005); why community mental health nurses do not achieve their goals with patients who have dual diagnosis (Coombes and Wrattton 2007); why hospital nurses do not include health promotion in their work with people over 65 years of age (Kelley and Abraham 2007); and why practice nurses do not advise patients on physical activity (Douglas *et al* 2006). Similarly, deficiencies in communication have been used to explain: why public health nurses do not provide good quality care in the community (Markham and Carney 2007); why medication errors occur in an intensive care unit (Sanghera *et al* 2007); why children's nurses do not negotiate extensively with parents in family-centred health care (Corlett and Twycross 2006); and why aggressive behaviour occurs in mental health wards (Duxbury and Whittington 2005).

The deficiency explanation is a theme with variations. One particularly common variation is what we might call the 'barrier account'. This type of explanation is often used when something that should be happening isn't, the idea being that there must be barriers which are preventing it from happening. It turns out that these barriers are always, or almost always, deficiencies in something. They might be deficiencies in individuals, deficiencies in resources, or deficiencies in the structures and procedures adopted by the organisation in question. But, one way or another, there will be something there isn't enough of, something that's done poorly, or something that somebody gets wrong. Here are some of the usual suspects: insufficient funding, insufficient time, restricted facilities, lack of knowledge, lack of skills, lack of confidence, lack of understanding, lack of awareness, lack of support, poor attitudes, poor co-ordination, and poor communication.

It is interesting that many research projects take the 'barrier' assumption for granted. Researchers go 'barrier hunting' – they start with a research question which takes the form

‘What are the barriers to X?’ – and end up with a list of blockages and bottlenecks, all of which are deemed to be preventing the right result.

Typically, in this kind of study, barriers are identified via the perceptions of interview respondents or, in other words, self-report. One familiar topic in this genre is the barriers to research utilization (just a brief selection of recent contributions: McKenna *et al.* 2004; Micevski *et al.* 2004; Olade 2004; Veeramah 2004; McCleary and Brown 2003; Metcalfe *et al.* 2001; Oranta *et al.* 2002). Almost all of these studies ask health professionals what they think the barriers to incorporating research into practice are; and the vast majority of them report identical findings: time constraints, lack of awareness, insufficient authority to change practice, lack of managerial support, lack of leadership, inadequate critical appraisal skills, and so on. The predictability of this list is also worth noting: no time, no authority, no support, no leadership, no understanding. These, along with poor communication and faulty attitudes, can be described as ‘off-the-peg’ explanations: ‘off-the-peg’ because they’re easy, available, convenient and cheap, and people are always willing to believe them.

10.2.1 Characteristics of deficiency explanations

I have identified two characteristics of barrier – or more generally, deficiency – explanations: they account for unwelcome outcomes by suggesting deficits in people and processes; and they are always available, capable of being wheeled out to cover any eventuality. This convenience is a consequence of two other features. Deficiency explanations tend to be both global and highly unspecific. Time, for example, can always be represented as scarce, just as knowledge can always be improved, there is never enough money, and communication difficulties never completely evaporate. I am not, of course, claiming that ‘not enough time’

is never true. What I am saying is that, persuasive or not, it is global: it can always be invoked.

Also typical of deficiency explanations is their lack of specificity. They frequently take the form of lists of factors with no explanation provided of how these factors interact, and with no indication of how they combine, in a particular context, to produce the unwanted outcome. A list of factors will not help in understanding whether there are any conditions and circumstances which reduce (or enhance) a barrier's inhibiting power. If we are told that 'lack of knowledge' is a barrier to client-centred practice in occupational therapy (Wressle and Samuelsson 2004), we have learned very little. We still have no idea what knowledge is required, why it is necessary, through what medium it is conveyed, and what precisely the effect is on the relationship between therapist and client. The 'explanation' is, at best, a gesture towards an enormously wide range of possibilities, none of which is spelled out.

In summary, deficiency explanations point to deficits in people and processes in a global and highly non-specific way. They imply that a deficit must be repaired: somebody needs educating (Paley 2007b), attitudes need changing. More time, more money, better facilities are required. Co-ordination, communication and managerial support should all be improved. In short, there is a fault which must be corrected.

10.3 Mechanisms and systems

One area of enquiry in which deficiency explanations have traditionally been prominent is the study of drug administration errors. In this particular case, the deficit has most commonly been seen as residing in individual health care professionals, usually nurses. More recently, however, a systems approach to the reduction of medication error has been

proposed, reflecting safety procedures routinely adopted in other high-risk industries (Anderson and Webster 2001). Other examples of this type of approach – applied to resource allocation, stroke recovery, and interfaces between health and social care – would be Allen *et al.* 2004a; Allen *et al.* 2004b; Hart 2001; Hughes and Griffiths 1997. The advantage of the systems approach is that it switches the focus of attention to the way in which errors are caused ‘by an interaction of many factors, most unrelated to the individual [...]. Only when systems considerations are taken into account will we understand the full story of how accidents happen, allowing effective and lasting improvements to be made to reduce the potential for error in the future’ (Anderson and Webster 2001: 35). It is this idea of a system, rather than a list of perceived short-falls in time, communication, management support, skills, budgets and staffing that I would like to explore.

I would like to develop the contrast between a deficiency explanation and the systems approach further. In the first place, a systems explanation requires a detailed account of how the various components and factors interact to produce the outcome. Rather than listing factors, it will show how they link together – like ropes, pulleys and cog wheels, to use Elster’s (1989) metaphor – in a certain structure. There are different kinds of system, as well as different approaches to explaining them; but they all have this in common: the parts combine in an identifiable way, and in doing so generate the behaviour associated with the system as a whole (Sterman 2000; Beer 1981; Checkland 1981). The analysis of a system does not involve suggesting that there is not enough of one or more resources; it involves pointing out how each component connects up with the others to produce a certain result.

Second, the explanation is usually specific to a particular context. No doubt partial generalisations may sometimes be possible, but the exact relation between system

components is highly unlikely to be the same in one organisation as it is in another. A systems explanation will therefore be limited (at least in the first instance) to a given site or setting. It will show how, in a certain organisational context, certain mechanisms operate in a certain way, resulting in certain outcomes.

Third, deficiency explanations presuppose that, if there were nothing wrong, then the outcome would be welcome or acceptable; the fact that it is not welcome or acceptable is what prompts the search for a deficiency. Systems explanations, however, allow for the possibility that the outcome is an unintended consequence of a system in which there is nothing that counts as 'deficient'. If this is true, we will not reach an understanding of how the outcome is produced by looking for deficits, flaws and barriers. Instead, we should regard the system as an effective method of generating the outcome it does generate – however unwelcome that outcome is. As Berwick (1996: 619) puts it: 'every system is perfectly designed to achieve the results it achieves'. The implication is: don't look for the defect, analyse the mechanism.

As this way of describing systems has already implied, and as I noted in Chapter 4, there is a strong link between systems thinking and 'mechanisms' thinking. For example, I have just suggested that 'in a certain organisational context, certain mechanisms operate in a certain way, to produce certain outcomes'; and this way of putting it clearly reflects the Pawson and Tilley (1997) model introduced in Chapter 3. Their formula is $[C+M=O]$, where C is the context, M the mechanism(s), and O the outcome. On my interpretation, when a series of mechanisms operate in a specific context, in such a way as to produce a regular pattern of behaviour, that *is* a system. Similarly, the way in which the components of a system interact *is* the mechanism (as Hernes 1998: 74, would agree: 'a mechanism is... an assembly of

elements producing an effect not inherent in any one of them'). The actual outcome is dependent on the organisational environment (or context) in which the interaction is taking place. On this interpretation, then, 'component' refers to a physical thing, while 'mechanism' refers to a process of interaction. The language may be somewhat different, but the ideas do overlap to a considerable degree.

The conceptual link between 'mechanism' and 'system' is not, then, an unfamiliar one. As Hedström and Swedberg (1998b: 2) note, during the nineteenth century 'the term "mechanism" was disconnected from the metaphor of the machine and instead became linked to that of the system'; and 'mechanism' is frequently used in the systems theory literature (Skyttner 2001; Pattee 1973b; Boulding 1956). Admittedly, there is disagreement even among advocates of the idea of social mechanisms as to what exactly this involves (Manicas 2006); but it is clear that some mechanisms, or some combinations of mechanisms, are the equivalent of certain types of system.

10.4 Social mechanisms and individual actors

As I have suggested, I do not want to portray my explanation of the 'not much rehabilitation' outcome in deficiency terms, although a superficial reading of the situation might suggest inadequate skills on the part of rehabilitation staff, poor communication between different health disciplines, lack of time, lack of resources, and so on. Instead, I want to persist with the idea of mechanism and context, and with the idea of a certain kind of system. However, a question remains from earlier in the chapter: is this approach really consistent with an account which makes such essential reference to the psychological states of individual patients and staff? What is the relationship, if any, between social mechanisms and the awareness, intentions, abilities, and motivations of particular agents?

In an influential essay, Hernes (1998) identifies two sets of abstract elements in a social mechanism: one set of assumptions regarding the specification of the actors, and another regarding 'structures'. The first set is generated by answers to the following questions: (a) What do they want? (b) What do they know? (c) What can they do? (d) What are their attributes? This seems relatively straightforward. But what of the structure assumptions? It turns out that there is a considerable overlap between the two, as structure assumptions include 'the number of other actors, the number of relations they can enter [...], the alternatives they confront, options they face, or constraints they encounter' (Hernes 1998: 94). Some of these, Hernes adds, include 'norms, rules and laws'. It would appear, then, that there is no clear-cut difference between the 'actor' assumptions and the 'structure' assumptions, since the latter essentially refer to more actors, and to the relationships between one set of actors and another.

The analysis offered by Hernes is characteristic of recent thinking about mechanisms, which sees them as a bridge between the 'macro' and the 'micro'. For example, Hedström and Swedberg (1998b: 23) provide a typology of mechanisms in which this bridge is explicit. There are, first, what they describe as 'action-formation mechanisms', a type of mechanism which 'shows how a specific combination of individual desires, beliefs and action opportunities generate a specific action'. There are 'transformational mechanisms', in which 'a number of individuals interact with one another', and thereby produce some kind of 'collective outcome, be it intended or unintended'. Finally, there are 'situational mechanisms', responsible for the way these collective outcomes, now represented as social situations, influence the beliefs, desires and action opportunities, which lead back to action-formation mechanisms.

At first sight, and as Hernes (1998) concedes, his approach to mechanisms looks rather like a return to methodological individualism, a view associated with Weber, and Popper, among others, and more recently revived in a different form by Elster (1982, 1989). However, there is a significant difference between the macro/micro approach and methodological individualism. The latter is associated with rational choice theory, which abstracts from the personal characteristics, beliefs and motives of social individuals, and attributes to them only a capacity for rational decision making (Olson 1965; Elster 1989). On the macro/micro view, by contrast, individuals have a variety of beliefs, respond to a variety of incentives, and are constrained by a variety of rules. While there is still something of a parallel, in that social patterns and structures are depicted by both approaches as the outcome of individual behaviour in aggregate, in macro/micro models the basis for individual action is much wider than 'pure' rational choice (Boudon 1998).

At this point, I want to make another connection. The macro/micro approach has to show the precise ways in which individual actors produce social outcomes as the result of identifiable mechanisms-in-context. One form this might take, I would like to suggest, is captured in the idea of complex adaptive systems (CAS). What is sometimes called 'complexity science' has recently emerged from its origins in biology, mechanics, dynamics and artificial life, and been adopted by the social sciences, especially management studies (Wheatley 1992; Marion 1999) and, latterly, health care (Munday *et al.* 2003; Kernick 2002; McDaniel and Driebe 2001). In the next section, therefore, I want to explain what a CAS is, in order to suggest that it represents one important way in which the actions of individuals can combine to produce (not necessarily intended) social outcomes. For reasons which will

become clear later, it is crucial to begin this account with the statement that reference to a CAS is supposed to be *explanatory*.

10.5 Complex adaptive systems

A complexity explanation applies to any system in which a certain kind of order is evident, and it turns out that this order is the result of a number of elements independently following a short series of simple rules. A system of which this is true can be described as a 'complex adaptive system'. A CAS is one in which: 'simple agents following simple rules [can] generate amazingly complex structures' (Johnson 2001: 15). Johnson identifies two features of complex adaptive systems: the 'elements' or agents, and the rules, and I will explain these further.

The 'agents' to which Johnson refers are, roughly, the system's components. They might be the birds in a flock, the ants in an ant colony, the water molecules in a whirlpool, the neurons in a brain, the people in an organisation. In all these cases, the agents interact in a particular way, and the interaction creates the order evident in the system, whether this is a certain type structure or a certain pattern of collective behaviour. It is important to recognise that the order in the system is the result of the agents acting *independently*, even as they 'interact'.

The idea is that each agent individually follows a set of 'rules', instructions that tell it, in a quite specific way, what to do. I will illustrate this briefly with one of the literature's most familiar examples: how do hundreds of birds manage to fly in formation? 'Whenever I ask a group of managers... the usual reply is that they are following the leader' (Stacey 2003: 239). This answer is almost certainly wrong, as was first suggested by a computer simulation

(Reynolds 1987) which showed that flocking behaviour could be modelled using three simple rules for each individual bird (or 'Boids' in the simulation):

- (a) Maintain a minimum distance from other objects in the environment, including other Boids.
- (b) Match velocities with other Boids in the neighbourhood.
- (c) Move towards the perceived centre of mass of the Boids in the neighbourhood.

When each Boid follows these rules, flocking results. There is no leader, no overall plan. Nevertheless, these rules, operating individually and purely locally, produce globally coherent patterns which look as if someone, or something, is directing them. The computer simulations have since been confirmed by several ethological studies (Weimerskirch *et al.* 2001).

Comparable combinations of computer simulation and observation have shown that complex structures such as termite nests and ant colonies are produced in a similar way (Pratt and Sumpter 2006; Drogoul *et al.* 1995; Hofstadter 1980). In each case, a structure which looks as if it must have had both a designer, and a 'manager' capable of organising the work, in fact turns out to be the result of individual insects following simple rules locally and independently. There is no central design, no planning, and no organisation, whether democratic or hierarchical.

Of course, it is not claimed that birds, ants or termites consciously follow rules of this kind. Rather the 'rules' give expression to instinctive, learned or habitual forms of behaviour, which may be physically represented in the brain, the chromosomes, or something else biological. Similarly, if CAS translates to the human context (a question which will be

discussed below), the 'rules' will not necessarily be explicit regulations, laws or statutes, but the individual's habitual behaviour, incentives, procedures, unreflectively routine ways of doing things, and so on.

In summary, complex adaptive systems consist of agents (ants, genes, chemicals, neurons) following simple rules, unaware of the order they are producing. This is described as a network of disparate agents which 'exhibit coherence under change [...] without central direction' (Holland 1995: 38); or as a form of problem-solving which makes use of 'masses of relatively stupid elements, rather than a single, intelligent, "executive branch"' (Johnson 2001: 18); or 'the emergence of structure through the activity of microscopic units that do not have access to global patterns' (Cilliers 1998: 94). It is what the literature on complexity calls self-organisation.

A controversial question is whether this form of explanation can be applied to people and organisations (see McKelvey 1999 and Stacey *et al.* 2000 for some healthy scepticism about this). It has been proposed that it can, but that it needs to be applied with caution (Paley 2007a; Duncan *et al.* 2007). For this reason it is necessary to distance the view being taken here from the use which the health care literature has made of complexity theory in recent years. I need, if only briefly, to explain why.

10.6 Complexity in the health care literature

The idea of complexity has appeared in the health care literature in recent years, as it has in many disciplines other than those in which it originated (mainly dynamics, biology, artificial life, chemistry: see Gribbin 2004; Flake 1998; Holland 1998; Kauffman 1993; Poundstone 1987). This development was given a considerable boost by the publication of four highly

influential articles in the British Medical Journal (Fraser and Greenhalgh 2001; Plsek and Greenhalgh 2001; Plsek and Wilson 2001; Wilson and Holt 2001).

Influential as the BMJ articles are, however, they appear to misrepresent complexity thinking. This can be illustrated in a number of ways. Take the concept of self-organisation, for example. As I have already suggested, this is the term used to refer to the way in which order is created in a system by each of the agents acting unilaterally. The system 'self-organises' into order, and *not* as a result of any intention on the part of the agents. This is obviously true for ants and water molecules, but it is also true for people, if we are to analyse bits of organisational behaviour in complex adaptive systems terms. However, for the BMJ writers, self-organisation is a process whereby doctors and other healthcare professionals get together, discuss things, agree goals, plan a strategy, and so on. This is what you might expect 'self-organisation' to mean, before reading the complexity science literature; but it misses the point spectacularly. Self-organisation in complex adaptive systems has nothing to do with plans, goals, or negotiation. It is something that happens when agents in a complex adaptive system just get on and do their own thing. Aims and objectives don't come into it.

Another example is the 'rules' favoured by the BMJ authors. These are borrowed (in simplified form) from an American source (Institute of Medicine 2001), and include items such as: 'safety is a system property'; 'needs are anticipated'; 'the patient is the source of control'; 'decision making is evidence based'; 'care is based on continuous healing relationships'; and so on (Plsek and Wilson 2001: 748). But it is obvious that these 'rules' are not like the precisely coded instructions followed by the Boids (and ants, termites, water molecules in a vortex, probably neurons). They are general guidelines, suggesting (for

example) that the health care system should be able to accommodate differences in patient preferences and encourage shared decision making.

More importantly, these rules are not offered as explanations of anything. The point of the rules followed by agents in a CAS is that they *explain* the order visible in the system. The rules referred to by Plsek and Wilson (2001), however, do not explain anything. Instead of accounting for emergent structures, or collective patterns of behaviour, they are principles which are essentially normative, guidelines intended to deal with 'health care situations in general'. There is nothing wrong, of course, with being normative, but such guidelines have nothing to do with CAS-style explanations.

In a moment, I will translate my own explanation of the 'not much rehabilitation' outcome into CAS terms. In doing so, I will attempt to avoid these misapplications of complexity thinking. Instead, I will be suggesting a framework of self-organisation that is independent of the aims and objectives of health care staff, with organisational order being a consequence of agents, like ants or Boids, following a set of simple rules, oblivious to the way in which this process generates a certain structure or pattern. Obviously, there are some problems in proposing this kind of order, particularly with people (like palliative care staff) who value multi-professional collaboration and decision-making to achieve shared goals. However, I will come to the implications of adopting this form of explanation later. First, I will provide the translation.

10.7 A complexity explanation of 'not much rehabilitation'

Although I want to reject deficiency explanations of the 'not much rehabilitation' outcome, certain deficit accounts do suggest themselves. For example: (i) Rehabilitation staff do not

have the skills or experience to deal with a complex and relatively unfamiliar condition; this is the 'lack of knowledge' version of deficiency. (ii) Professionals assume (whether consciously or unconsciously) that there is little point offering rehabilitation to these patients because their prognosis is so poor; this is the 'inappropriate attitudes' version. (iii) Patients don't understand rehabilitation, so don't expect it, and certainly don't request it; this is 'lack of understanding'. We might also consider other familiar possibilities: lack of resources, lack of time, patients too sick, poor communication, and so on. As I said earlier, these are off-the-peg answers because they are routine, always available, convenient, and have a one-size-fits-all feel to them.

I am not going to claim that these answers are completely wrong; but they are incomplete and, at the very least, misleading. In particular, they do not show, concretely, how a certain set of mechanisms and contexts produce a certain outcome. At this point, I will provide a quick reminder of the answer I offered at the beginning of this chapter:

The patients' resistance to the idea of themselves as disabled, and their resulting lack of interest in rehabilitation, is reinforced by events and conversations on the ward, and by the discharge-driven encounters with acute sector rehabilitation staff. Furthermore, discharge procedures ensure that rehabilitation needs will not be 'picked up' in the community, as hospital staff assume they will be.

The essential observation here is the way in which the patient's psychology interacts with everyday routines and procedures, both on the ward and in the community.

Is it possible, then, to translate this explanation into an explicitly CAS format? To do this, we need to be able to formulate the 'rules' that people are following, in roughly the same way

that the 'Boid' rules can be formulated. Here is an attempt to do that, for some of the key groups involved:

Patient

- *Take cues for future management from the consultant.*
- *Regard disability as peripheral.*
- *Aim to get home as soon as possible.*

Nurse

- *Refer all patients to the physiotherapist on admission, unless too unwell.*
- *Refer to OT only if (i) equipment is needed, or (ii) discharge problems are evident.*
- *Don't offer further rehabilitation unless the patient specifically requests it.*
- *Arrange for discharge as soon as treatment is completed and symptom control achieved.*
- *Assume that disability-related problems will be picked up in the community.*

Physiotherapist and occupational therapist

- *Assume that your responsibility stops at discharge.*
- *Do not seek opportunities to speak directly to the consultant.*
- *Do not make specific rehabilitation referrals unless patient explicitly requests this.*

Occupational therapist

- *Do not see patients who will be discharged somewhere other than home.*

Doctor

- *Discharge as soon as treatment is completed and symptom control achieved.*
- *Assume that disability-related problems will be picked up in the community.*

Several comments on this are necessary. First, CAS rules in an organisation will be of two principal kinds: explicit policies and protocols, from which individual incentives are derived, and customary procedures and routines, on which habits of thought and action are based. Agents are likely to be conscious of the former, for at least some of the time, but are likely to remain unconscious of the latter, in the absence of any prompting or a special effort. The outcome, whatever it happens to be, is the result of a form of compliance: agents adhere to policy or protocol, acting on the associated incentives; or they conform to custom and practice in habitual patterns of decision making and behaviour.

An example of a customary procedure is: 'Don't seek opportunities to speak directly to the consultant'. There is no policy, or any other regulation, which implies this rule. Nor do the consultants have any rule (or policy) of their own which forbids contact with rehabilitation staff. It is just that 'speaking to the consultant' is something occupational therapists and physiotherapists 'don't do', an observation confirmed by the reaction of some of my respondents when asked about this.

Second, not only do agents not, in general, recognise the rules they are following *as* rules, but they are also unaware of the connection between what they do, the rules they follow, and the 'no rehabilitation' outcome, even though this outcome is inevitable once they start following the rules. The system is not, in this sense, transparent to them, which is what the CAS model requires. The system self-organises, without any intention on the part of the agents who comprise it.

Third, the most significant rule is the 'discharge' rule – 'Discharge as soon as treatment is completed and symptom control achieved' – which all the professionals follow. It takes the

form of an explicit, policy-governed incentive, designed to free beds as quickly as possible, and increase patient throughput. It is, of course, matched by one of the patients' rules: 'aim to get home as soon as possible'. For both sides, then, discharge is always the first priority.

Fourth, it is important to see how the rules interact. Consider, for example, 'Don't seek opportunities to speak directly to the consultant' (rehabilitation staff), 'Take cues for future management from the consultant' (patients), and 'Assume that disability-related problems will be picked up in the community' (doctors). Since consultants rarely, if ever, mention rehabilitation, and since they are never seen with rehabilitation staff – they certainly never do joint ward rounds – the patient has no reason to think that rehabilitation might be significant.

Fifth, the unwelcome effect of the interaction is to keep rehabilitation off the agenda, not because anybody is trying to achieve this aim, but because the rules people are following have that as a natural, but unintended, consequence. By and large, nobody is doing anything wrong, education is not required, the main cause of the problem is not 'deficiencies that need correcting'. What everyone is doing is quite reasonable in the circumstances, given the mix of policy rules and custom-and-practice procedures they are complying with. Rather than any deficit, there is an intelligible rule-following process which includes nothing which can be described as 'wrong', 'faulty' or 'defective'.

Sixth, notice how patient-centredness, or a version of it, is a key part of the system. Rules such as 'Don't offer rehabilitation unless the patient identifies a need for it', along with 'Don't make specific rehabilitation referrals unless patient explicitly requests this', can be justified in these terms; but in this system they conspire, in effect, with the patient's rejection

of the 'disability identity', and the result is that rehabilitation remains off the agenda. It is, I think, essential to re-examine aspects of the 'patient-centred' and 'patient participation' rhetoric in this kind of context. I will take this point up again in the next chapter.

Finally, at the risk of labouring the obvious, this is a very simple and readily intelligible set of rules. That, of course, is the point. Yet it explains the order of the system, the unwelcome 'not much rehabilitation' outcome, in a way that a list of 'barriers' or 'deficiencies' could not.

10.8 Overview

A brief overview of the argument of this chapter would be useful at this point, before I go on to discuss some of the practical consequences.

The literature often resorts to what I have called 'deficiency explanations' to account for unwelcome outcomes, the implication being that there is not enough of some particular resource – money, support, skills, time – and that the deficit can, in principle, be put right by an increase in the amount of resource concerned. Following an alternative line of thought, which has recently been introduced into the study of drug administration errors (for example), I have suggested a more systems-oriented approach, which focuses on how the components of a system interact to produce a certain pattern of outcomes, without necessarily presupposing any deficiency in how the system is organised. I have also pointed out that this approach is consistent with the current interest in social mechanisms, apparent in the literature on social theory and research methods.

Borrowing particularly from Hernes (1998), and from Hedström and Swedberg (1998*b*), I have proposed that the actions and psychological states of individuals are implicated in – and frequently constitute – these social mechanisms, both in terms of what the individual

believes, and is motivated by, and in terms of the 'structures' to which actions collectively, but unintentionally, give rise. Indeed, these 'structures' turn out to be relations between agents, along with the various options and constraints which those relations produce and define. This concept of what 'social mechanisms' involve does not collapse into methodological individualism because it does not depend on 'rational actor' theory. Instead, it permits a range of psychological states and processes to be among the 'nuts and bolts' (Elster 1989) referred to in 'social mechanism' explanations.

An interesting, and potentially useful, variation on this theme can be based on complexity theory, and in particular the idea of a complex adaptive system (assuming that it is plausible to apply this idea to human beings and organisations). In this variation, the sources of action are conceived, not directly as beliefs and desires, but indirectly as 'rules' which are 'followed' by individual agents. In the context of organisations, these rules will fall into two main categories: explicit protocols, generating incentives and consciously complied with; and habitual patterns of behaviour, unreflectively engaged in. The CAS variant achieves a number of things. It compels us to be very specific about what individual agents do, and how their actions produce unintended and unwelcome outcomes. It acknowledges that many of these actions are performed, not as the result of 'beliefs and desires', but as the result of routines, habits and organisational requirements. Consequently, it implies that there is nothing necessarily 'deficient' in how individuals behave (or in the resources they draw on). They may be acting reasonably, in the circumstances (and a lack of resources may have little or nothing to do with the outcome).

Finally, I suggested that my explanation of the 'not much rehabilitation' outcome could successfully be translated into a CAS framework.

10.9 Some practical implications

In the final section, I will consider some of the practical consequences of this account. In general, the implications of any research study turn on what explanation has been offered: I will therefore compare the implications of a deficiency explanation with those of a complexity explanation.

Consider again the explanations offered in the literature I referred to earlier: time constraints, lack of awareness, insufficient authority to change practice, lack of managerial support, lack of leadership, inadequate critical appraisal skills, and so on. What is striking about them is that the problems they cite would take a lot of putting right, probably at considerable expense. We would need to find ways of creating more time (additional staff, changed priorities, reduced demand); designing education and training programmes; changing the culture of the organisation; redesigning jobs and management structures; and changing information systems. At the very least, it is a daunting prospect.

Compare this prospect with what the implications of the CAS analysis of rehabilitation in Oxfordshire might be. We cannot, of course, change all the rules: the discharge rule is not negotiable. But custom-and-practice is less immutable. 'Don't seek opportunities to speak directly to the consultant', for example, the rule that prevents medical and rehabilitation staff being seen together, could be a target. The consultants would not object to this rule being dropped (I have already asked), although the physiotherapists and occupational therapists might take a bit more persuading. Joining medical staff on ward rounds would be possible, and could be trialled in specific cases.

Equally, 'Refer to the occupational therapist only if equipment is needed, or if discharge problems are evident', and 'Don't make specific rehabilitation referrals unless patient explicitly requests this', should not prove too hard to amend. There is no reason in principle why referrals to an occupational therapist should not be as automatic as referrals to a physiotherapist, and discharge summaries to the primary care team could become standard. The same is true of 'Don't offer further rehabilitation until the patient identifies a need for it'. The problem is: the patient is not going to identify a need for it, so this 'rule' can also be dropped; and it should not prove overly difficult to find methods of introducing patients to the idea of rehabilitation, even if (in view of their resistance to the 'disabled identity') they do not immediately see why it is necessary. For example, a nurse's suggestion that 'The occupational therapist can help with ideas for keeping you mobile' is probably more effective than 'I'll get the occupational therapist to give you a wheelchair' (which is what is said at the moment).

What of the patient's rules? We cannot, obviously, change those directly. But we can change the environment in which they operate. For example, rehabilitation staff joining medical staff on ward rounds takes advantage of the rule 'Take cues about future management from the consultant'. It works *with* the rule, so to speak, rather than against it. But there are further things we can do. Patients' ideas about managing independently, contributing to their sense of themselves as resourceful, should be supported. Rather than contradicting patients' ideas, whether implicitly or explicitly, rehabilitation staff should work alongside patients' schemes and plans, while keeping a focus on short-term achievable goals. For example, instead of indicating to Eddie that his plans to build his own trolley in his workshop (p122-123) are unrealistic, we could reframe the message as: 'That sounds like an excellent idea. In the

meantime, and just to see you through the first couple of days at home, how about...?' The starting point should be: 'What do you want to achieve, and how can I help you to do that...?' rather than: 'I am here to provide...'. All of which plays to the patient's ambivalent attitudes, and the rule that says 'Regard disability as peripheral'.

All of these suggestions are relatively simple, and would not require substantial investment. I am not, of course, underestimating the amount of work that needs doing; but I am pointing to the fairly marked contrast with what most deficiency explanations imply. Moreover, there is a psychological advantage, to the extent that nobody is being blamed for anything, explicitly or implicitly: with deficiency explanations, there is always the sense that someone is at fault – whether the professionals, who do not know enough or who communicate poorly, or the managers, who don't provide the necessary support, or who designed the system badly in the first place. A CAS explanation implies the opposite: everyone is acting reasonably, on the basis of rules which are generally taken as norms. It turns out that acting on these rules has unintended consequences, and this might be amenable to change.

However, I wish to end this chapter on a cautious note. I said earlier that the question of whether or not CAS explanations can properly be applied to organisations was controversial, and I stand by that. The chapter is intended, at least partly, as a contribution to the debate on this question: not just whether it can be done, but (if so) how. I am not claiming, for example, that all organisational behaviour can be understood in CAS terms. That would be unreasonable, and it is demonstrably inaccurate. There are different types of system, and not all of them are CAS. Equally, there are different types of explanation, which can be applied to different types of circumstance; and which explanation applies to which circumstances will always be a matter for empirical enquiry. However, I hope to have shown that a

complexity approach may have some advantages and that, in certain situations at least, it is preferable to explanations which appeal to deficiencies.

Chapter 11

Patients' stories and their consequences

11.1 Introduction

In Chapter 10 I proposed that an analysis of mechanisms provided an alternative and, arguably, more fruitful, way of thinking about health care situations which generated an unwelcome outcome than deficiency explanations. I now wish to take one aspect of this idea further. Listening to the stories of the patients, carers and health professionals I interviewed, it became apparent that one of the mechanisms at work concerned the way in which patients positioned themselves in the stories that they told, and the effects that this achieved. In narrating their stories, patients portrayed themselves – implicitly and explicitly – as coping, resourceful, resilient and creative. And, as I elaborated in Chapter 7, health care professionals responded by categorising patients in various ways – for example, as ‘realistic’ or ‘unrealistic’ or ‘in denial’.

In this chapter, I will look more closely at patients' stories, introducing ideas of ‘narrative’ and ‘story’ as they relate to health care and to this study. I will note various approaches to the analysis of narrative, explaining why none was entirely satisfactory in the context of my study. I will suggest an alternative approach which draws on techniques used in literary criticism to demonstrate the way in which the textual features of a story can account for its particular effects. I will then apply this approach to particular narratives in my study, to show how the interaction between patients' stories and health care professionals' responses contributed significantly to a shortage of meaningful rehabilitation.

11.2 Narrative and story

The ideas of 'narrative' and 'story' have been extensively discussed in the recent literature of health care. They are represented as a resource both in the clinical relationship (for example, Greenhalgh and Hurwitz 1998a) and in health-related qualitative research (Hurwitz *et al.* 2002; Frank 2000). More specifically, the palliative care literature includes discussions of the significance of narrative in clinical practice (Devery 2006; Maddocks 2003; Barnard *et al.* 2000; Quill 1996), although there has been somewhat less attention paid to its role in research methods. Beyond the health care disciplines, narrative ideas have been developed in sociology, especially the sociology of health and illness (Bochner 2001; Bury 2001; Mattingly and Garro 2001, Hydén 1997), social research (Elliott 2005; and three landmark texts: Riessman 1993, Polkinghorne 1988, and Mishler 1986), cultural studies (Andrews *et al.* 2004), history (Roberts 2001), and psychology (Yancy and Hadley 2005; Fireman *et al.* 2003). Not surprisingly, there is also a great deal of cross-disciplinary activity (Bortolussi and Dixon 2003; Carbaugh and Brockmeier 2001; Nash 1994). All of this work has drawn, to some degree, on writing about narrative and narratology in the field of literary criticism (including Rimmon-Kenan 2002, Prince 1982, Genette 1980, Chatman 1978 and Booth 1961).

However, there is an ambiguity in the term 'narrative' as it appears in the health care literature. On the one hand, it has a relatively narrow sense, referring to an account of past or fictional events in roughly chronological order. On the other, it is used broadly to signify virtually anything a layperson (usually the patient) might say. The former is 'narrative' as a literary critic or historian might understand it; the latter is an elastic idea approximately equivalent to 'non-medical utterance'. Although it would appear sensible to differentiate the two kinds of usage, it is not uncommon for authors to oscillate between them, even in the

same paper (Greenhalgh and Hurwitz (1999) is a notable example). In referring to 'narrative' I have the narrower, more technical sense in mind: narrative as a reported sequence of events, not as a portmanteau term for non-technical discourse.

A further distinction I wish to draw is that between 'narrative' and 'story'. This is a necessary step, since a major problem inherent in any discussion of narrative is the sheer variety in terminology. Even in the field of literary criticism, the use of the term 'narrative' is inconsistent, and different authors have radically different conceptions of what it means, and what it can be applied to (Abbott 2002). Here, I take 'narrative' to be the recounting of two or more real or fictitious events, some of which are causally related. In this context, the idea of 'causation' should be interpreted broadly. It does not, for example, mean that events occur in a mechanistic way, merely that some of the events described should (implicitly or explicitly) be the consequences of others. This way of construing narrative reflects narratological writing in literary criticism, both regarding the recounting of multiple events (Rimmon-Kennan 2002), their real/fictitious nature (Prince 1991), and the causal relation between some of them (Richardson 1997).

To count as a story, a narrative must meet other criteria. First, the causal claims inherent in the narrative provide an explanation of something. Second, there is at least one character who is centrally involved in the events described, and this character is confronted with a situation in need of resolution. Third, there is a link between the central character and the explanation, in the sense that the explanation will either account for the character's problem, or show how it is resolved. Finally, the configuration of character, problem and explanation – in other words, a 'plot' – makes possible, and is usually designed to elicit, an emotional reaction from the reader. For example, by portraying the central character in a certain light,

the storyteller may arouse the reader's sympathy, disapproval or admiration. These features meet the criteria set out by Prince (1991: 72), who argues that plot is 'the global dynamic (goal-oriented and forward-moving) organization of narrative constituents which is responsible for the thematic interest... of a narrative and for its emotional effect'. And it is the organization of narrative constituents responsible for an emotional effect that is essential to the concept of a story, irrespective of whether the story is an account of something that happened, or a work of fiction (for a more in-depth discussion of the relation between 'narrative' and 'story', see Eva and Paley 2006, and Paley and Eva 2005).

There is, at present, considerable enthusiasm for stories in health care. What there is less of, however, is an analytical approach to them, an approach which applies the techniques of discourse processing (Emmott 1999), literary criticism (McQuillian 2000) or linguistics (Herman 2004) to health care stories, tracing the ways in which various features of the narrative elicit various responses in the reader/audience (though examples of this approach in medical ethics include Hunter 1993, Chambers 1994, and some of the papers in Charon and Montello 2002). As a result, there is sometimes a certain naivety about the warm reception afforded to narrative by health care writers, the general tone being celebratory rather than interrogative or critical; and in consequence, there is a tendency to romanticise stories, and to construe narrative as the authentic voice of the patient (Taylor 2003) or a type of 'unalloyed subjective truth' (Bury 2001: 281). To make my own position clear: I am interested in how a patient-narrator deploys a range of narrative devices to a particular effect.

11.3 Traditions in narrative research

There is a research tradition, in both sociology and social psychology, which has a similar interest. The writers in this tradition take as their focus the construction of a 'narrative identity' (Kelly and Dickinson 1997; Plummer 1995; Denzin 1989; Gergen and Gergen 1988), and are influenced by the philosophical work of Ricoeur (1984, 1988). However, given the aims of the present study, it is not clear that this tradition represents quite the right emphasis. From my point of view, it has three limitations.

First, it tends to concentrate on narrative identity through time, and the construction of a self over the span of a lifetime. While this does have some relevance to my own study – patients did sometimes tell me their life stories – it is somewhat restricting, in that they also told me stories about particular happenings and experiences, in ways that sought to convey a certain impression of themselves without constructing an autobiography.

Second, much of the work in this tradition is devoted to establishing an ontological thesis: that the 'self is autobiographical narrative' (Kelly and Dickinson 1997: 254); it is not merely *represented in* autobiographical narrative. On the one hand, however, I find myself out of sympathy with this claim, for reasons akin to those presented by Strawson (2004). On the other, my focus is quite different: I am not particularly concerned with ontological matters, being much more interested in how patients represent themselves using the resources narrative provides. As I suggested in Chapter 4, this means that I can afford to take a non-committal view of whether the 'constructed self' really *is* the self, or whether it is just a representation. At any rate, *representing-yourself-in-narrative* is something that can be studied independently of any ontological inquiry into what the self *is*.

Third, this tradition does not, for the most part, employ the resources of literary criticism to understand how the elements of narrative create effects on an audience (Bortolussi and Dixon 2003), but rather searches (not unreasonably) for sociological themes in narrative texts. This strategy, however suited it may be to the ontological project, seems less suited to a study in which one objective was to determine how the patient's 'narrative identity' influences their understanding of, and attitudes towards, disability and rehabilitation (as well as the attitudes and responses of health care professionals towards them).

11.4 How narratives work: speech act theory

In this study, therefore, I have made use of techniques borrowed from literary criticism to examine the ways in which patients construct narratives in order to create impressions of themselves and others. In doing so, I have assumed that stories are not necessarily accounts of 'how it seems to me' – this is how many authors (for example, Bailey and Tilley 2002; Leight 2002; Sakalys 2000; Blumenfeld-Jones 1995) construe them – but that they are, much more, accounts of 'how I want it to seem to you' (Paley and Eva 2005). It is worth noting here that a special case of 'you' is oneself: stories can be as much an exercise in self-persuasion as they are in persuading others.

This idea can be developed by applying speech act theory (Austin 1975; Searle 1979) to stories. Austin's central claim is that all modes of speaking and writing are performative. Anything said or written has three dimensions: the locution, the illocution and the perlocution. The locution is the sense of what is said, the illocution is the act thereby performed, and the perlocution is the effect of the performance. If, for example, I say to somebody, 'I promise to pay you back', the 'locution' is what this sentence means. But to utter the sentence is to perform an act: it is to *make* a promise. That is the illocutionary force

of the sentence; and if, when I make the promise, the other person feels relief, or scepticism, or gratitude, that is the perlocution, the *effect* which uttering the sentence has. Take another example: 'I'm sorry I'm late. I stopped to help my neighbour with a flat tyre.' Here the perlocution is to reduce possible irritation at one's tardiness, and this is (arguably) achieved by presenting oneself as a kind, helpful person. The illocution would be to offer an excuse. In general terms, other illocutionary acts include betting, naming, warning, questioning, advising, agreeing, asserting, confirming, and of course many more.

To this list we can add narrating and storytelling. Ohmann (1971) was the first to formulate this view, but it was given extended treatment by Pratt (1977), and speech act linguistics have continued to exert a powerful influence on narratological theory (Herman 2004; Toolan 2001). Telling a story, whether in spoken or written form, is an illocutionary act, whose perlocutionary force is the emotional cadence (Velleman 2003) which is in fact produced, and which may well be intended by the storyteller. Stories can, of course, be told purely to entertain; but perlocution is a way of referring to the fact that they are frequently intended to manipulate – not necessarily in a pejorative sense – those who hear them. 'Stories are not innocent', observes Chambers (1984: 7): they have a 'performative function', eliciting audience reaction by means of 'narrative seduction'.

One critical form of narrative analysis, then, is to understand how a story's textual features are processed by the reader in a way that secures this reaction. This is the approach that was introduced, from a slightly different angle, in the discussion of 'psychonarratology' in Chapter 4. It does not deny that different audiences will respond to the same narrative in different ways. However, given that textual features do impose certain constraints on interpretation, I would argue that the range of possible responses is not endless.

11.5 Narrative vigilance

To illustrate the power of stories, I will use – for the sake of brevity and convenience – a very short generic palliative care story written by David Cameron, a doctor who works in rural Southern Africa (Becker 2005: 52).

Home-based care? Flies circle like lazy vultures parting the air saturated with the smell of cervical cancer. Too weak to sit up, she reached out and grasped my hand, 33 degrees outside, it felt like 40 under the low tin roof. 'Hospital?' I suggested. 'No, people die there.' Six pairs of weary eyes watch my every move.

This story packs a great deal into 57 words, only about 14 of which present narrative action, while the rest fill in aspects of the storyworld (the imaginative realm: see Herman 2004) in succinct detail. To see how rich the selection of storyworld detail is, we can compare it with an alternative narrative account of the same events:

On a hot afternoon, I did a home visit to a woman with advanced cancer. I suggested admission to hospital. She declined.

It is obvious that the impact of the story has completely disappeared. The original story, unlike the bare narrative of the second version, creates a richly textured world, describing the heat, the flies, the smells, the weariness of the woman's family so effectively that the reader can almost experience them. An analysis of the story (using the techniques of literary criticism) provides a demonstration of how it achieves its effect. We can see that the story works around a number of parallels and contrasts. It begins with an implied question which the narrative answers – even though that answer is never spelled out. The story's second question, "Hospital?" gets an explicitly negative answer. This has two interesting effects.

One is to provide a dramatically downbeat note of finality; the second is to create two parallel contrasts, one implicit (Home-based care? No), the other explicit (Hospital? No), and a consequent sense of exhausted options. This is echoed in the parallel between the imminence of death in the home (the flies compared with vultures) and the anticipated death in the hospital, completing the general atmosphere of oppressive hopelessness. Arguably, the story is structured around these contrasts and parallels. The final sentence invites us to feel sympathy for the narrator's burden of responsibility.

However brief, then, the story is a powerful one. That, of course, is the point. Stories, well told and well constructed, trigger an emotional response of some kind, sometimes strong, sometimes subtle. That is why they are told. As a consequence, they frequently prompt the impression that insight has been achieved. In this case, for example, it might be tempting to say something like: 'this story conveys an understanding of what health care in certain parts of South Africa is like more effectively than any amount of statistical information'. To which the most appropriate response is: it is certainly more compelling, but whether it is accurate is another question. This is *not* to argue that Cameron has misrepresented anything; it is to repeat, with Velleman (2003), that we should not mistake emotional closure for intellectual closure. The problem with Greenhalgh and Hurwitz's (1998*b*) view that narrative offers a possibility of *understanding* which cannot be arrived at by any other means is that it fails to distinguish between these two forms of 'understanding', and for this reason invites us to confuse them.

Without some analysis, there is a danger that we will mistake 'emotional closure for intellectual closure' (Velleman 2003: 20), and fail to acknowledge that a story 'enables its audience to assimilate events, not to familiar patterns of *how things happen*, but rather to

familiar patterns of *how things feel*'. (Velleman 2003: 19). This is the seductive quality of stories: they are designed to elicit the perlocutionary effect intended by the author, deter serious analysis, and distract the audience's attention away from the narrative machinery that achieves this very outcome.

Of course, stories *may* be true (or accurately reflect a general truth) as well as emotionally resonant. But, equally, they may not be. It is crucial to distinguish between two different reactions to any story: 'emotionally satisfying' on the one hand, and 'likely to be true' on the other; or, conversely, 'emotionally unsettling', and therefore a 'source of suspicion'. The evidence suggests that there is a marked tendency for all of us, if we are not careful, to slide from one to the other. Emotionally satisfying (or unsettling)... and *therefore* (if only subconsciously) likely to be true (or suspect) (Velleman 2003). It is these slides that an understanding of how stories 'work' can help to avoid.

I have suggested that narrators deploy a range of narrative devices to achieve – wittingly or unwittingly – a particular effect. I will now describe some of these devices, and go on to show how an analysis of their use in patients' stories can contribute to our understanding of the particular mechanism at work here.

11.6 Techniques in literary criticism

The basic ingredients of stories are well known: they have characters, contexts, plots, beginnings, middles and ends. Good stories are constructed so that they are coherent. We tend to be more satisfied with stories in which loose ends are tied up, virtue is rewarded, the villains get their come-uppance, and a problem of some kind is resolved. We also like stories which surprise us, stories which are involving, and stories which describe events and

circumstances in an immediate, compelling way (Hills 2000; Davis 1987). All of these contribute to a story's appeal; by the same token, they invite an emotional engagement with the story, and are, as I have argued, reasons for approaching stories with careful attention.

From the vast range of techniques used in literary criticism I can obviously select only a handful to illustrate their use in practice. I am going to focus on three: plot, characterisation and narrative style, especially in terms of its implications for narrator reliability. I am using these as they demonstrate most effectively the interaction between patient-narrator and health-care-professional-listener pertinent to my study. However, I am also drawing on aspects such as close reading, comparisons, disjunctions, inconsistencies and conflict (Rimmon-Kenan 2003; Abbott 2002; Miller 2001 and, particularly, Manlove 1989).

11.6.1 Plot: the logic of the story

Stories, irrespective of whether they are made up or claim to be about real events, have some kind of plot. In identifying plot in narrative, we are pointing to a kind of unity, the way in which events and characters are linked together into a schematic whole. Most plots (and perhaps all: Abbott 2002; Friedman 1975) fall into recognisable categories. The familiar story of Cinderella is a frequently cited example. This type of plot has been termed the 'admiration plot', one in which an attractive hero succeeds and wins the reader's admiration (Friedman 1975). It could also be called the 'virtue rewarded' plot, since the heroine is hardworking, and incredibly patient – given the treatment she receives at the hands of her family – and she ends up marrying royalty. The themes of 'neglect, injustice, rebirth and reward' resonate with many of our deeply held anxieties and desires (Abbott 2002: 42).

We are inclined to connect our thinking about life to a number of masterplots (virtue rewarded, such as this one, or others: a quest, stories of revenge, tales of death and renewal, and so on). As both story-tellers and story-hearers, we have a tendency to overlook raw evidence in favour of establishing a satisfactorily coherent plot framework for a story. In effect, plot is a form of generalisation; and, in identifying the plot, we assign the narrative to a class of similar stories, with whose contours we are already familiar.

11.6.2 Characterisation

Characters reveal themselves in stories through their actions, their motives and their thoughts and feelings. Since we can never enter the mind of a character, the best we can do is to infer qualities from clues dispersed throughout the story (Rimmon-Kenan 2002). A narrator elicits different responses to different characters by the way he or she portrays them, and also invites a response towards himself or herself as narrator.

The way in which the events are narrated, and the way the story is received by the audience, will be shaped by the cultural context in which the story is told, and by the pre-existing preferences of the reader or listener. Individual backgrounds, different experiences, different sets of associations, different fears, different desires can all have an impact on the extent to which we identify with one character or another. Returning, for example, to Cinderella. We are usually invited to identify with the heroine, and to take a dim view of the ugly sisters. But if you grew up as an ungainly, unattractive girl with few friends, and if you had a beautiful little sister who complained incessantly every time anyone asked her to do some modest task around the house, who claimed to be downtrodden and unloved despite the constant attention of a wealthy godmother, and who wound up marrying a prince, then you might see the story in a very different light.

So the portrayal of character and the perspective from which a story is told interacts with cultural and individual proclivities; and the story-teller, whether consciously or unconsciously, shapes the narrative in such a way as to evoke or trigger these pre-existing preferences and expectations.

11.6.3 Reliable and unreliable narrators

In analysing a story, questions can be asked about the reliability or unreliability of the narrator (Booth 1961). Where a narrator shares values with the reader (or listener), and appears accurately to observe and record the world, reader rapport and trust is encouraged. However, a narrator who displays a lack of self-awareness, or who appears to have values at odds with the audience, or who recounts events at odds with other evidence, is seen to be unreliable. When hearing or reading stories, the listener or reader will make judgements about the extent to which the narrator can be relied upon for an accurate account, and react accordingly.

11.7 Stories told by patients

In the remainder of this chapter, I will contrast the stories told by two of the patients in the study: Gill and Eddie. For each of their stories, I will show how an analysis of plot, characterisation and narrator reliability enables us to understand the responses of the rehabilitation staff towards them.

11.7.1 Gill's story

Gill told many stories in which she portrayed herself as competent, resilient, capable and resourceful: how she had prepared for receiving the anticipated news of her initial diagnosis of breast cancer by calling her deputy managers to her hospital bed and giving a thorough hand-over of work for the coming weeks; and her orchestration of the installation of a

custom-built stair lift on her spiral staircase, where she coordinated the efforts of several health and social services agencies. Interestingly, despite her considerable efforts to have the stair lift installed, she rarely used it, preferring to remain upstairs in her bedroom, spending some time sitting in her wheelchair, but most of her time on her bed. In the following story, she describes the arrangements she had made for her funeral following a 'bad news conversation' with her consultant. Whatever else it is, this is a moving story. And without in any way detracting from its poignancy, I want to suggest that we can analyse this story in a way that contributes to an understanding of why a young woman in her mid-forties was house-bound and largely immobile, despite having the physical potential to achieve considerable independence as a wheelchair-user.

Gill: Off I went [to see the consultant] and I waited ages [...]. It was [...] about 40 minutes before she came in and she [...] was just a little bit flustered, a bit more than she normally was and she said, you know, basically there was just no easy way of getting around this, that the disease was really... progressing quicker than they thought. And it was unfortunate, but that they wouldn't be able to do anything else for me. [...] But she did say to me that, 'Gill,' she said, 'I know I've got to know you really well this past year and you're a born organiser, [...] and if you wanted to make any arrangements, be part of arrangements, then you need to do it now.' [...] [It's] my dying wish that, you know, when the time comes, I go into Sobell, I don't want to die at home.

Interviewer: Have you spoken to people about where you want to die?

Gill: Yes, yes. Everything has been arranged, from a to z. I had the funeral directors around, chose my coffin. I love my husband to death, but I love my Mum and Dad to death as well. And [...] it did worry me, you know, what's going to happen here, if I get buried here, then there's nowhere, it's too far for my Mum and Dad to come if they're feeling they want to grieve one day and vice versa, Graham. So I've spoken to both of the vicars who come, and although I didn't really want to get cremated, I'm going to be cremated, and there are going to be two caskets and one will be buried back home and one will be

buried here. So I've got all of those practicalities, paid, you know, and x amount of money towards funeral as well. I've chosen the hymns, chosen the music I want played, I mean the whole service. What one of the vicars did, she e-mailed me the service and all the missing bits I needed to fill in. And it's all done, it's all done. So if God forbid, you know, I take a turn for the worse, today or tomorrow, everything, you know, the i's are dotted the t's are crossed on the service and what I want.

Gill (Patient 7: Interview 3)

11.7.1.1 Plot

Gill has a problem: her parent's home is several hundred miles away from where Gill lives with her husband, Graham. She loves them all very much, and knows that they each want a tangible focus for their grief after she has died. The basic logic then, is a problem, a dilemma which is solved by a resourceful, problem-solving narrator, hence eliciting the audience's approval. Seeing it against a plot type helps to categorise it, and contributes to shaping – probably quite unconsciously – a response. A puzzle is solved. As a generic plot-type, think of Oedipus solving the Sphinx's riddle, or the biblical story of Solomon and the judgement of which mother should keep the baby. We are invited to be satisfied at the resolution of a potentially problematic situation, and to be supportive and admiring of the action of the central character.

11.7.1.2 Characterisation

We can see the essential features of this story – those that contribute to an understanding of what this story is about – as Gill's equally strong feelings for husband and parents (she is a loving wife and a loving daughter); the geographical distance between her parents and husband; her preference not to be cremated, but her willingness to set aside her own wishes in order to meet the needs of others (she is both unselfish and practical); her detailed organisation of her funeral (she is a planner, resourceful, capable of securing the help of

others, like the vicars, when required). All of these elements have to be present for the story to do its work. Through her characterisation of herself, we are invited to see her as meticulous, organised, problem-solving, subordinating her wishes to those of her loved ones, and capable of getting help when needed.

11.7.1.3 Narrator reliability

There are at least two ways in which Gill portrays herself as a reliable narrator. Firstly, she tells us that 'she worried' about what she was going to do. This was no whim, no careless spur of the moment fancy. And secondly, in the lead-in to her story, she describes a recent conversation with her consultant, who, on giving her the news of advancing disease, advised her to think ahead. In this way, Gill enlists the help of another character – a doctor, whose opinions are worthy of respect – to strengthen her characterisation.

11.7.1.4 The response elicited

The response of the health care professionals to Gill's presentation of herself was consistent, as the following extracts show. She was seen to be remarkably organised, and, on the whole, positive. There were times when she was sad and tearful about the injustice of being forty four and dying, but she was seen to be coping.

She was remaining incredibly positive considering what [...] was happening to her, the [...] rapid changes and her loss around becoming a paraplegic. [We talked about] what she was going to be able to manage and what she wasn't going to be able to manage. But yeah my perception was that she was holding it together because that is what Gill does, and that's Gill's personality and you know she's a manager of how ever many [chain of retail outlets] who is a professional lady and has always taken a bright outlook on things as far as she can.

Janet (Palliative Care Occupational Therapist)

She is a very competent person, and she has overcome a lot of the problems herself, in terms of [things like] finding somebody to provide the care that she wants. [...] She's very resourceful, she will not sit there feeling sorry for herself. She will sit there working on ways of achieving what she wants.

Sally (Palliative Care Social Worker)

I said, 'How are you able to do this then, how are you planning to do this?' And she explained about having it all set up. And I thought, well that's typical Gill really. [...] Gill would initiate things, she's a great initiator. She knows how to take things forward and she's very clear about you don't wait around for people to do stuff for you, you get on and do it yourself.

Mandy (Palliative Care Clinical Nurse Specialist)

11.7.1.5 The consequences for rehabilitation

Gill had a warm relationship with her occupational therapist, who had responded quickly and helpfully to her requests for items of equipment – such as the stair lift, and a hoist for the bath. However, Gill's presentation of herself as competent and organised meant that she was, broadly speaking, allowed to manage things for herself.

She then went home adamant that she wanted to be upstairs, which we completely went with because that was her wish, although I know a lot of staff here struggled with that decision, because everybody else felt she should be downstairs and have access to outside and that we should convert the conservatory and so why on earth would you want to be moving her upstairs. My understanding of Gill's reasoning behind her wishes was that the bath was highly important to her and there was no way of having a bath downstairs, and she felt that was a better option.

Janet (Palliative Care Occupational Therapist)

However, the stair-lift became an end in itself, with no further exploration of what it could be instrumental in helping her to achieve; and, despite the concern of her GP and district nurse, she remained in her bedroom for much of her time. In the four months following the

installation of the stair lift she did not venture downstairs more than half a dozen times. During this time, she became increasingly withdrawn, and developed a large pressure sore. Her presentation of herself to others as capable and resourceful, coupled with her sense of safety in her bedroom (a 'safe space', which I shall comment on further in Chapter 12) contributed significantly to an admission to the hospice with pneumonia and depression.

11.7.2 Eddie's story

I met Eddie in hospital, and interviewed him in the week following his radiotherapy, while plans were being made for him to be discharged home. Here, he tells me how he is going to manage one of his most worrisome problems:

Eddie: I always wonder how I'm going to get the rice pudding from the kitchen to my table. Now I've got the problem solved. You know the tea trolley, it's my son's tea trolley I made. Made a table top for it, we used to play cards on it, it's just the right size for dinner for two or three. And when we are done with the dinner we can take the table off. I've got a long six foot work bench that goes on there, that goes on the top, and that's my work bench for inside with a chair. I can work on there on a work bench, so it's got a dual purpose. [...]

Erica (Eddie's daughter): Jenny (the occupational therapist) says she can give you something similar [to a walking frame] but with a tray on the front, Dad. A trolley thing.

Eddie: Eh? Now the tea trolley, that's got four castors on, take back two castors off, build it up, get ordinary piece of wood on the bottom, so that it doesn't slide. I'm sure there's plenty timber down the shed. Make a couple of handles that screw onto the side of the trolley and I can hold on and walk around with the tea trolley. Make it low enough, with the wheels at the front and solid rubber at the back, push, stop, push, stop. Like so. [...] Three o'clock in the morning, wide awake and my head's going round just thinking back at the old place and what I'm going to do. How I'm going to get the rice pudding back from the kitchen.

Interviewer: Are you at all worried about going home?

Eddie: No. Looking forward to it. It'll be an adventure.

Eddie (Patient 5: Interview 1)

11.7.2.1 Plot

Eddie, too, has a problem: he can't manage to walk with his walking frame and carry things at the same time. He proposes a creative solution: he has a trolley which has already demonstrated its versatility, which he will modify further. Again, a dilemma is solved by a resourceful, problem-solving narrator; however, the plot of Eddie's story is not so much one of careful planning, wisdom and pragmatism (as Gill's was), but more of adventurous good fortune. This becomes even more evident if we set Eddie's tea-trolley story against the story he told about some of his life experiences growing up:

I had a happy childhood. [...] We just ran wild. I lived on the quarry more or less. [...] I used to go and see the Sid the blacksmith and watch him pump his bellows when I was seven. I learned more in that fitting shop there, when I did get a job at the factory at fourteen I knew more than the other young starters. As much as I could have done, so I did really well. Fortunately, everything is just fortunately, I meet a good gang of kids, there were about fourteen of us all together and we were a good set, they didn't go drink, they didn't go chasing women or anything like that, they were really good lads. Used to go camping together, swimming together, pictures together. The chaps at work, I always met the best ones, I was always put in to work with the best ones, I don't know why, but everything seemed to work out right for me. As regards the shipping company Alan – my tandem partner – his sister had a husband was in the [...] Merchant Navy, she knew all the ship companies and said, 'What do you want?' and I said, 'I want a company in a ship that travels all over the world, every little port you can find, not just there and back there and back, I want to wander around.' Which I did. I've been to practically every country in the world, it paid well, we ate well. [...] The blokes on there were really good fellows, took care of me.

Eddie's life had not been without adversity: his son was killed in a car accident aged 27; he had nursed his wife through more than a decade of Parkinson's and Alzheimer's; and he had lived with the unpleasant effects of cancer and its treatment for several years. In his telling of all of these stories, the plot type is one of 'triumph over adversity', a subcategory in Friedman's (1975) terms of the 'admiration plot', where again we are invited to respect and applaud the narrator.

Oh, well, I had, nine years ago, I had prostate cancer, and I had radiotherapy. It burnt, it was bad, it was horrible, it, really at that time it ruined everything, because it ruined my sex life. I had to have local anaesthetic just to go to the toilet and into the bath afterwards. And for six to eight weeks I was very bad. It started to burn all up the side of the groin, burnt and raw with pants and anything rubbing. My back passage was damaged. It still is today. I survived all that, come through.

11.7.2.2 Characterisation

Eddie characterises himself as adventurous, lucky, resourceful, popular, a survivor. In both his childhood and adult life, he has had opportunities and good fortune. Things had always worked out well for him in the past, and we are invited to believe, along with him, that they will continue to do so in the future. He presents himself as someone who is capable of – and prefers to – solve his own problems: note his peremptory dismissal of the occupational therapist's trolley.

11.7.2.3 Narrator reliability

However, Eddie's account of himself is not accepted as entirely convincing. His stories blur the boundary between past triumphs and his present day situation. For example, it had been

some years since he ridden a bicycle (according to his daughter); however, the present tense beginning and end to this story serves to frame an event which occurred sixty years previously into his current perspective.

And I ride a bike, don't I? Another chap and I had a tandem between us. And we used to do about 140 to 150 miles on a Sunday. [...] We came down from Newcastle once, we were invited down to Staines for a holiday. [...] We set off about quarter past four on the Saturday and we got there about quarter past five on the Sunday afternoon. One day. Overnight. Didn't sleep. No, just straight through the night. I've been keeping fit all my life.

Eddie (Patient 5: Interview 1)

Similarly, with his plans to adapt his tea trolley, Eddie draws on past skills and capacities to make future plans, appearing to avoid the recognition of any change in his abilities. One can compare Eddie's luck and good fortune: 'fortunately, everything is just fortunately...' and 'I don't know why, but everything seemed to work out right for me', with Gill's much more grounded account: 'you're a born organiser', 'everything has been arranged, from a to z', 'the i's are dotted the t's are crossed'. Unlike Eddie, Gill is not leaving matters to chance; her arrangements have been made. Gill's altruism (her concern for her family) resonates with values of the palliative care health professionals; Eddie's buccaneering spirit, conflicting as it does with his audience's concerns for safety, creates anxiety.

11.7.2.4 The response elicited

Eddie's scheme for adapting his tea trolley was just one of many ideas he presented to the occupational therapist (Jenny) to persuade her that he would be able to manage at home. He also proposed having rails installed around the edges of the counter tops in his kitchen (such

as in a ship's galley), which he could hold on to as he prepared meals. Jenny notes a change in Eddie's outlook over time, perceiving him to become less and less willing to compromise.

[When I first met him] he [...] focused on [...] not so much his functional ability now, but it was [...] significant things like adapting the bathroom, looking into disabled badges was another, and electric beds, big things [...]. He was relatively realistic at that point, saying that he didn't think that he would cope at home as he was [...]. And at that time I said that he needed to be independent with his transfers and mobility [...] and that was the criteria for him to go home with really, and that I would address the other issues that he'd flagged up as and when. [...] When I reviewed him [the following week] he was still needing quite a lot of assistance with his mobility. [...] So we started off doing these transfers and mobility practices daily and he was improving but not by a significant amount. He was getting more and more frustrated I think. He'd finished his radiotherapy and maybe he felt like we were handling him with kid gloves a little bit, saying you know you're not ready to go home, you've got to be able to do this and this. [...] The more conversations I had with him, the less he seemed to understand what we were getting at and that he wouldn't be able to go back to how he was originally. [...] We were saying you've got options: you can either go home as you are but agree not to undertake any kitchen activities, so have care and then have hot drinks left for you, or flasks of drinks left for you and you agree not to use it and you can go home now, or if you want to maintain your independence then we need to maybe make adaptations to the kitchen to allow you more space to manoeuvre, and he was getting very focused on the adaptation side of things. He still wanted to maintain his independence, so he didn't want to go home with the first option and have a flask or anything like that which was fine, but he was saying that he needed a rail on the work surface, things like this that we thought maybe weren't so appropriate because work surfaces aren't really supposed to be used for such weight bearing activities really.

Jenny (Hospital Occupational Therapist)

It appears that the more Jenny and her colleagues reject Eddie's notions of himself as resourceful and capable, the more entrenched he becomes in his position.

11.7.2.5 The consequences for rehabilitation

Eddie's stories, instead of reassuring the rehabilitation staff, particularly Jenny whose job it was to facilitate his discharge, caused some alarm. Jenny insisted on providing an approved trolley from the equipment store, and refused Eddie's request for ship's rails in the kitchen. Jenny attributes his – as she sees it – increasingly unrealistic ideas to poor information, his continuing hopes of recovery, and his wish to be independent:

Maybe it just wasn't explained to him very well or maybe he'd been given hopes from the radiotherapy that he would maybe, you know that his balance would improve significantly. [...] I think he sees himself as a very able man and very independent and really wanted to maintain that throughout which was difficult really for us then, because we were trying – in a way we were taking away his independence by saying, you know, recommending care to go home with, you know saying that he would get home sooner if he would accept those sort of things.

Jenny (Hospital Occupational Therapist)

The staff's acceptance of Gill as a reliable narrator can be contrasted with Jenny's assessment of Eddie. Gill's characterisation of herself is not questioned: 'she is a very competent person', 'she's very resourceful', 'she's a great initiator', whereas Eddie is not seen to be reliable: 'he sees himself as a very able man'. While Jenny can see that Eddie might feel that his independence is being 'taken away', and realises that Eddie does not share her concerns about his safety, she does not fully recognise the way that her lack of support for his presentation of himself as capable and resourceful – in fact her contradiction of it – contributes to his dismissal of her help. Her response to his ongoing efforts to persuade her of his competence is to oppose him even more firmly:

We had to be quite assertive with him to make him understand where we were coming from and why we were saying what we were saying and that it wasn't to take away his independence, even though it was

in the short term, we were trying to do it so that long term he would maybe have some rehabilitation at home as such.

Jenny (Hospital Occupational Therapist)

Again, here we can contrast Jenny's response to Eddie with Janet's towards Gill:

She then went home adamant that she wanted to be upstairs, which we completely went with because that was her wish [...]. My understanding of Gill's reasoning behind her wishes was that the bath was highly important to her and there was no way of having a bath downstairs, and she felt that was a better option.

Janet (Palliative Care Occupational Therapist)

Eddie received a great deal of attention from the rehabilitation staff and from social services in planning his discharge, and welcomed none of it. He grudgingly accepted what the ward said he had to have in order to be allowed home, and refused all community rehabilitation follow-up offered.

I asked him whether he wanted me to make a referral to the [community services] for ongoing rehab at home because I knew independence was really important to him, and I knew that we were taking away elements of that. He declined a referral which was a bit of a shame really but he said that he'd had enough people going in. I tried to explain that it wasn't a matter of them visiting him it was a matter of carrying on the work that we were doing in hospital at home but whether he didn't understand that or still didn't want it. [...] I was really surprised actually, I really thought, I really thought that he'd be very keen on that.

Jenny (Hospital Occupational Therapist)

He struggled at home for two weeks before being re-admitted through A&E to a general medical ward, where he died a few weeks later.

11.8 Concluding remarks

In this chapter, I have provided an analysis of the way in which certain features of narrative contribute to the effect achieved by stories. A remarkably similar feature of the narratives of the patients in my study was the way that they portrayed themselves as resourceful, resilient, problem-solving, organised, able to cope with situations that might have defeated others: 'Yes, there are problems,' they would say in effect, 'but I've got them all worked out.' This way of presenting themselves had one of two consequences, depending in part on whether their audience judged them to be reliable or unreliable narrators. Where patients managed to convey the impression of themselves as trustworthy, their message of 'I'm a capable person,' gained the response of: 'That's fine then, you don't need our help,' and rehabilitation beyond the provision of aids and equipment was not forthcoming. However, where the 'I'm coping,' message was doubted, interventions to ensure physical safety were insisted upon. Usually these met with outright resistance from patients who, after all, believed that they had things under control, and could not see the need for the fuss, bother and intrusion.

In telling stories, patients exploit linguistic, psychological and cultural resources to generate a particular emotional reaction; so there is a link between how a story is structured and our emotional response to it. Equally, there is a range of ways in which we can be invited to identify with, or distance ourselves from, one or more of the characters. The overall effect, then, is to produce a pattern which ties the narrated events together, and which at the same time connects them to a corresponding pattern of emotion.

In Chapter 10, I noted that little rehabilitation was taking place despite the existence of services geared to providing it. In offering an alternative to 'deficiency explanations', I

suggested that understanding the mechanisms operating to produce particular outcomes could provide more effective responses to problems than the perennial calls for 'more resources'. While increasing resources might be of some benefit, leaving it at that misses a vital aspect of the mechanism that is in operation here. This is the patients' portrayal of themselves as resourceful and resilient; and it makes a crucial difference, either because they appear not to need rehabilitation (so are not offered any), or because they do not see themselves as needing it (so reject it when it is offered). There is a deep irony in this, because while hope, optimism and an ability to view the future positively are desirable in achieving a good quality of life, it turns out to be the patients' demonstration of these very qualities that leads to rehabilitation not being provided.

An awareness of this dynamic, and a willingness not to take stories at face value could contribute to rehabilitation staff's ability to recognise that they need to respect and support patients' presentation of self as resourceful, while at the same time finding more oblique ways of 'nudging' patients towards behaviours that would enable a level of participation in daily life which would safeguard psychological and physical well-being.

Chapter 12

Disability and rehabilitation

12.1 Introduction

In Chapter 1, I raised questions concerning the operationalisation of rehabilitation in palliative care, the sense in which patients could participate in the process of rehabilitation, and regarding the relationship between life-limiting illness and disability. I contrasted two models of disability, the 'Social Model' and what I shall term the 'Individual Model', each of which is associated with a particular set of views on the rehabilitation project as a whole and on the patient's role in it. In this chapter, I shall extend the discussion further, in the light of the data presented in Chapters 7 – 9. I shall ask how far either of these two models of disability fits the group of patients with metastatic spinal cord compression. I will suggest that while neither model works without modification, certain of the principles upon which the Social Model is predicated can make a contribution to our understanding of disability in palliative care. Based on this analysis, and drawing on work in social psychology, I will suggest an alternative way in which we might work towards a possible conception of rehabilitation better suited to this patient group.

In extending the discussion, I begin by explaining my distinction between a Social Model and an Individual Model of disability. I then attend to the view of certain concepts within each model:

- What disability is: its causes and implications.
- The aims and conditions of rehabilitation.

- The need for psychological adjustment on the part of the disabled person: the question of 'disability identity'.
- The notions of independence and autonomy, and of participation in the rehabilitation process.

A preliminary summary of these two Models of disability, alongside a theoretical perspective on disability in metastatic spinal cord compression (developed from the results of this study), is presented in Table 12.1.

Table 12.1 Theoretical perspectives on disability

	Individual Model	Social Model	Cord Compression
Causes and implications of disability	Impairment, for which a person requires assistance in compensating.	Social intolerance of difference; requires removal of attitudinal, economic and environmental barriers.	An illness which is life-threatening, unpredictable and pervasive. Patients demarcate safe spaces.
Aims and conditions of rehabilitation	Rehabilitation is instrumental in returning the individual to being a valued member of society.	Rehabilitation harmful: process whereby people with impairments are socialised into believing they are deficient.	Rehabilitation could enable function within safe space while sustaining notion of someone only limited by contingencies.
The need for adjustment	The process of adjustment is disputed, but there is agreement that a person's adjustment to disability is a desirable end-point of rehabilitation.	Society needs to adjust to the changed requirements of the individual.	Beyond basic practicalities, patients have neither the time nor the opportunity to adjust. They have preferences and aspirations should be encouraged.
Independence, autonomy and participation	Strive for executional autonomy. Disabled person's participation in rehabilitation process essential.	Independence and autonomy are rights of all people.	Modified participation and limits to autonomy, avoiding paternalism.

12.2 An Individual Model and a Social Model of disability

For the purposes of this discussion, I will present two perspectives on disability: the Social Model on one hand, and an Individual Model on the other. I realise that in doing so, I risk representing a 'rigid dualism of [...] socially constructed disability [versus] disability grounded in biology' (Meekosha 1998: 175) but, for the sake of the argument which follows, I wish to follow Shakespeare (1996) and Oliver (1990*b*) and make a distinction between a view of disability as a problem located in society, and one which locates it within individuals. Within the Individual Model, then, there is room to argue a case for the utility of rehabilitation. Of course, in presenting these views as a dichotomy, I am over-simplifying the array of positions that exists within the Individual Model, from a paternalistic response to the tragedy of disability, to one which advocates professional support led by autonomous disabled people (Barnes 2003, and see Table 1.3). I shall return to this range of viewpoints later in this chapter, but for now the distinction is useful for heuristic purposes.

In the next three sections, I outline the Individual Model and the Social Model of disability, following which I apply these concepts to patients with metastatic spinal cord compression, drawing out the ways in which these two models both contribute to, and detract from, our understanding of disability in spinal cord compression.

12.3 The Individual Model of disability

There is some characteristic typical of the culture variously labelled as Western (Lawton 2000), Protestant (Charmaz 1983) or Kantian (Benner *et al.* 1994) which is said to value independence, hard work and individual responsibility, and where the ability to maintain or regain a 'normal' life in the face of illness is a measure of a valued self. For both non-disabled

people and people living with an illness or disability, dependence on others is unwelcome and to be avoided.

12.3.1 The causes and implications of disability

In the Individual Model, the cause of disability is impairment, where impairment is some restriction in physical or psychological function or ability that curtails an individual's participation in his or her desired daily activities (Imrie 2004). Disability is thus associated with loss: of function, of independence, and of social roles. It carries the threat of being a burden to others, of limited opportunities, of isolation, and of a poor self-image. The appropriate response to disability is to assist a person to adjust to altered circumstances and to compensate through the use of environmental adaptations (Wade and de Jong 2000).

12.3.2 The aims and conditions of rehabilitation

Rehabilitation can make a significant contribution to a disabled person's participation in society. It provides opportunities to engage in activities that will encourage autonomy and, where possible, promote independence. It enables positive experiences of interactions with others thereby enhancing self-esteem. Ideally, rehabilitation is delivered by a team of healthcare professionals with a wide range of expertise between them, having a reasonably coordinated and structured approach to assessment of patients' difficulties, and to setting and achieving goals (Wade 2002; Wade and de Jong 2000).

Rehabilitation professionals should make their expertise available to assist disabled people in regaining the ability to live their lives as they wish – in so far as this is possible, given their impairment. Taking as a framework the World Health Organisation's International Classification of Functioning, Disability and Health, the ICF, (World Health Organisation 2001), there is an intentional focus on activity and participation which advocates the

fostering of an independence of spirit rather than the mastery of particular tasks. According to Cardol *et al.* (2002b: 1002), 'the most valuable outcomes of rehabilitation are therefore possibilities or 'feasibilities' rather than specific achievements: a person's autonomous rejection of authoritative guidance and refusal to follow professional advice could in some circumstances even be a triumph for rehabilitation.'

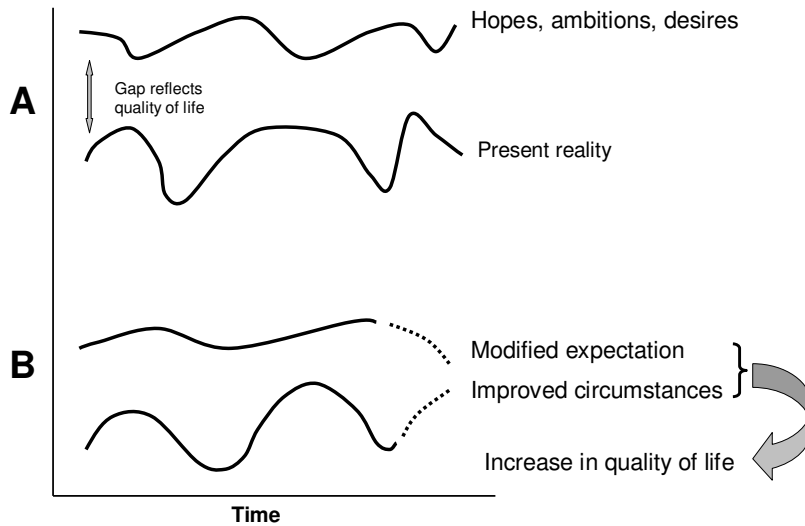
12.3.3 The need for adjustment

Following the onset of disability, some process of adjustment is required, where individuals 'manage, learn from, and accommodate changed circumstances in their lives' Brennan (2001: 2). The process that a disabled person goes through in adjusting to loss has parallels with the experience of a person who has been bereaved (Alaszewski *et al.* 2004; Niemeier *et al.* 2004). In the same way that the bereavement process has been proposed to consist of a number of phases – disorganisation, denial, depression, aggression, anxiety, developing awareness, and resolution – a person's response to disability is characterised by similar responses: shock and disbelief, expectation of recovery, anger, mourning, rationalisation, and, finally, adjustment (Livenh and Wilson 2003; Livneh 2001).

While there is agreement that adjustment to loss is a proper and realisable outcome of rehabilitation, the process involved in its attainment is disputed. Two main models predominate: those in which adjustment follows a series of stages over time (Kübler-Ross 1969); and those which, rejecting a linear model, propose instead an oscillating or pendular response (Papadatou 2000; Stroebe and Schut 1995; Yoshida 1993). Either way, rehabilitation can make an important contribution to the adjustment process by improving the fit between the person's understanding, hopes and expectations on one hand, and 'reality' on the other.

A useful diagrammatic representation of this is given in a popular palliative care textbook, Robert Twycross' *Introducing Palliative Care* (Twycross 2003).

Figure 12.1 Narrowing the gap between aspirations and reality



Twycross (2003: 5) illustrates this idea with two examples:

Thus, a tetraplegic ex-gymnastics instructor is able to say, 'The quality of life is excellent, though to see me you wouldn't believe it. I've come to terms with my loss and discovered the powers of my mind.'

And a 30-year-old man dying of disseminated osteosarcoma complicated by paraplegia comments, 'The last year of my life has been the best.'

Twycross follows this by reinforcing his message that health professionals have a central role in enabling patients to 'come to terms with their loss'.

12.3.4 Independence, autonomy and participation

Enabling a disabled person to be as independent as possible within the limitations imposed by impairment, and to exercise autonomy in everyday life, form the bedrock of rehabilitation practice. Recognising that a person's impairments may rule out independence in the sense of

performing an activity entirely on one's own, a distinction is made between physically doing the activity oneself – 'executorial autonomy' – and being able to control the manner in which the activity is performed – or, in other words, 'decisional autonomy' (Cardol *et al.* 2002a). In other words, I might not be able to put on my trousers without help, but I can exercise my autonomy through choosing my clothes and instructing my helper. This notion has particular appeal in palliative care rehabilitation, where the potential for improving a patient's executorial autonomy is limited by advancing disease, and 'self-determination' is offered as 'an antidote to the loss of control felt as a result of the disease and treatment (Tookman *et al.* 2004: 1024).

In order for rehabilitation to be effective, patients need to participate in the rehabilitation process (Playford *et al.* 2000), and working together with patients to set goals is seen to be key to their involvement (Siegert and Taylor 2004; Nocon and Baldwin 1998; Wade 1998; Schut and Stam 1994). Goal-setting is widely viewed as a *sine qua non* in rehabilitation, and this is even more the case in palliative care, where it is presented without reservation as a necessary and worthwhile process. However, notes of caution have been sounded by some rehabilitation writers. For example, Levack *et al.* 2006 observe that evidence for the effectiveness of goal-setting is in short supply. Kielhofner and Barrett (1998) and Playford *et al.* (2000) point out that, while goal-setting is a meaningful activity for staff, it is less so for patients, who frame goals as 'something to strive for' rather than something that is necessarily achievable:

It felt common to have [...] loose ambitions, such as 'When I've got a new job I'll move to a better house,' but that few people said, 'I'll learn to swim 100 yards front crawl in the first six months of this

year by going to swimming lessons every Tuesday and practicing on Monday and Saturday for an hour.' (Playford et al. 2000: 493)

In addition, it would seem that, despite the substantial enthusiasm in the literature for patient-professional partnerships in goal-setting, in reality patients tend *not* to be directly involved in the goal-setting process (Holliday *et al.* 2005; Wressle *et al.* 1999), and that goals are much more a reflection of the therapist's or physician's agenda than the patient's. It should be emphasised, however, that the conclusion drawn by these writers is not that goal-setting should be abandoned, but that it should be done better.

12.4 The Social Model of disability

In contrast to the Individual Model, the Social Model of disability locates any adverse consequences of impairment as external to the disabled person.

12.4.1 The causes and implications of disability

Disability is seen to be the disadvantage, or restriction of activity, caused by a society which takes little or no account of people who have impairments, and thus excludes them from mainstream activity. Disability is not an individual attribute, but the result of exclusionary practices (Bury 1996). In these terms, it is equated with racism or sexism as a form of oppression (Thomas 2004; Thomas *et al.* 1997).

Disability is a social problem, requiring attention to and removal of attitudinal and environmental barriers. The only legitimate response to disability is political activism and consciousness-raising (Oliver 1990a).

12.4.2 The aims and conditions of rehabilitation

From a Social Model perspective, rehabilitation is not simply a misguided enterprise, it is pernicious. Barnes (2003) refers to rehabilitation as a 'sick joke': sick, because it necessarily incorporates the notion that disability is in some way a health concern; and a joke because of the inadequacy of responding to individual impairments when the real causes of disability are poverty, violence, hazardous environments and discrimination. Disability activists and theorists argue that disability should not be seen as a problem confined to a minority of the population, requiring special and exceptional compensatory measures, but rather that it should be regarded as something that all people will experience at some time in life. On this view, a 'universal' approach should be taken, with accessible environments (social, geographical and financial) being a matter of course for everybody, both those who are disabled, and those who are temporarily able-bodied (Bickenbach *et al.* 1999; Zola 1989; Zola 1982).

Rehabilitation is seen as a key factor in the social construction of disability: it is the process whereby people learn to be disabled within society, creating and reinforcing ideas of dependency, failure and learned helplessness (Pfeiffer 2002; Hughes 2000). Medical and rehabilitation professionals are thus viewed with suspicion, distrust and, at times, hostility. 'We were made to feel that society saw us as unworthy, broken, in need of repair, and doctors were the agents of that repair' (Derksen and Chochinov 2006: 177). This anger with the medical professions is not only related to the immediate personal affronts experienced by disabled people, but also calls upon a collective historical memory, in which the value of a disabled life has been routinely questioned, and where disabled people have been the subjects of brutal experiments and campaigns of extermination (Braddock and Parish 2001).

However, while there is undoubted force to an argument that slides, within two paragraphs (as Derksen's does in Derksen and Chochinov 2006), from criticism of paternalism in the medical profession to doctors as agents of death (with reference to such notorious individuals as Jack Kevorkian, Harold Shipman, Josef Mengele), we should be careful to recognise this for the rhetoric it is.

12.4.3 The need for adjustment

Adjustment is not about the individual coming to terms with his or her impairment, but rather about society responding inclusively to the changed requirements of the individual (Basnett 2001; Oliver 1990a). Any model which proposes the individual as the key to his/her own independence is disempowering to disabled people in its assumption that impairment is automatically and inevitably the cause of any psychological distress (Marks 1997; Albrecht 1992). Shock, for example, can be erroneously attributed to a spinal injury, rather than to the disorientation associated with the unfamiliar environment of a spinal injuries unit. Depression is mistakenly related to loss of mobility, rather than to fears about an employer's prejudices and the financial consequences of losing one's job. Thus, any social or environmental problems are legitimately able to be ignored, and a person who is resistant to rehabilitation can be labelled as 'poorly adjusted', rather than recognising that there could be a mismatch between the patient's and the therapist's goals. Pfeiffer (2002: 985) is scathing:

What does it mean to accommodate [oneself] to a disability? A disability is a normal part of life. A person with a disability must only acknowledge the disability and move on. To talk about dealing with grief or about accepting (whatever that means) a disability implies that disability is tragic, that the person with the disability is the proper object of pity, that a person with a disability is more dependent on others than people without disabilities [...]. None of

these statements [is] true unless the rehabilitation worker perceives it that way and 'teaches' the person with a disability to accept them. The person with a disability who insists on autonomy before the rehabilitation workers are willing to grant it will be seen as uncooperative, unrealistic and not successfully rehabilitated. In such a situation there is no way the person with a disability can become autonomous unless he or she smiles and acknowledges the correctness of the rehabilitation workers and the family.

12.4.4 Independence, autonomy and participation

Where it is linked to individual circumstances, 'participation' as an idea is rejected. Disabled people do not need to 'participate' in interventions in pursuit of 'normalisation'. Participation only makes sense in terms of social and political inclusion (Barnes 2003). Interactions with health care professionals should be characterised by a respect for the disabled person's expertise in the management of his/her body (Crow 1996; Oliver 1996). When it comes to independence and autonomy, there should be no difference between disabled and non-disabled people: none of us is entirely independent of others, and the requirement for some measure of support does not imply inadequacy (Zola 1982).

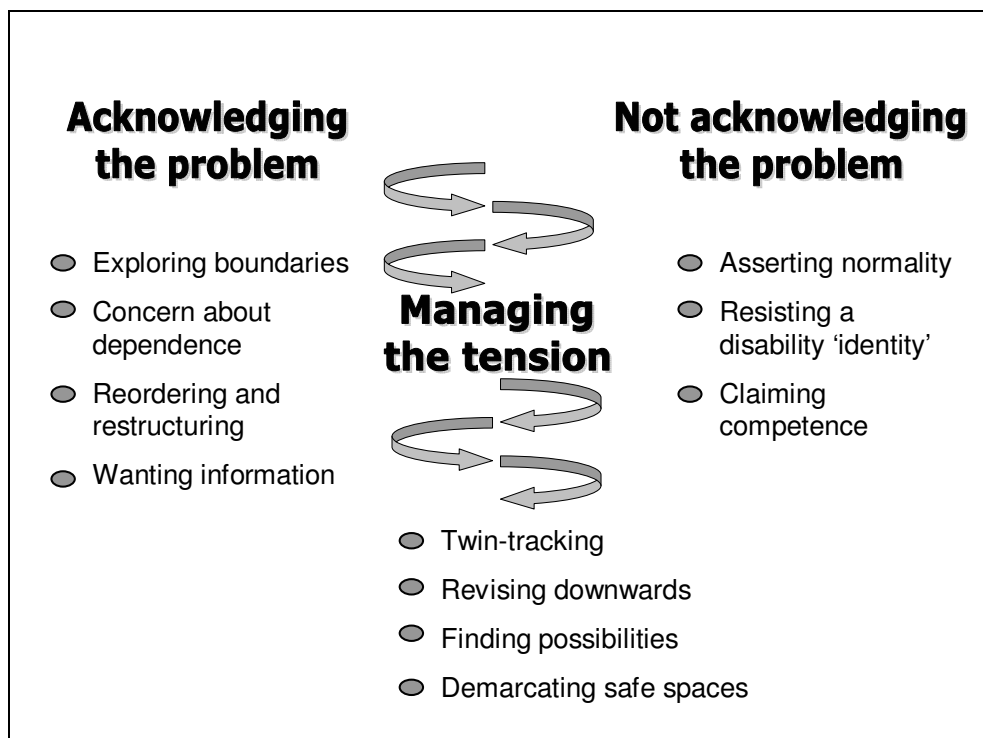
12.5 The relevance of these models in spinal cord compression

We come now to the question of whether either of these models has relevance to patients with metastatic spinal cord compression. In Chapter 7, I described the way in which this group of patients respond to disability by simultaneously 'acknowledging' and 'not acknowledging' disability; furthermore, I demonstrated a number of mechanisms for managing this tension, which I represented in Figure 7.1 (reproduced here for ease of reference).

This is neither a 'stage' model, nor one which implies a pendular or oscillatory movement between two points. Rather, I am developing an insight of Lawton's (2000), here in the context of theorising about disability, in suggesting that patients do both (acknowledging and not acknowledging) simultaneously. They say, in effect, 'I can acknowledge my disability as something which means that I need to make practical plans to manage certain tasks, but I can't in a way that it threatens my sense of identity.'

It would appear that the experience of this group of patients reflects aspects of both the Social Model and the Individual Model, but that neither works in its entirety. In the following four sub-sections, I shall elaborate further.

Figure 12.2 Representation of patients' response to disability



12.5.1 The causes and implications of disability

For patients with metastatic spinal cord compression, the cause of disability is an illness which is life-threatening, unpredictable and pervasive. Disability for these patients is not

'liminal' (Murphy *et al.* 1988); it does not occupy a position at the boundary of illness and health. Rather, it is situated within very serious illness, where it is a personal threat and affront, and where it cannot be externalised to hostile social attitudes and environmental barriers. In contrast to an impairment which can be seen as relatively 'encapsulated' – an entity whose boundaries can be explored, established and, in Individual Model terms, compensated for – spinal cord compression results from advanced, progressive cancer, and patients are uncomfortably aware of death as an unavoidable, all-too-imminent end-point of their illness. Bury's (1996) criticism of the Social Model's shifting of the focus of disability away from the individual – however justifiable – is upheld in this study: any coherent account of disability in contemporary populations will inevitably uncover dimensions of health and illness.

In Chapter 7, I described patients' desire to explore changed physical and psychological boundaries, while at the same time asserting normality and maintaining a conception of themselves as competent individuals. When these imperatives came into conflict, patients responded by demarcating spaces which feel safe, spaces in which 'a patient's self [could] be successfully sustained' (Lawton 2000: 36). For some patients, these spaces are a positive and creative response to their circumstances; for others, they are a retreat from events which have been frightening or threatening. To venture outside of this space risks the potentially unwelcome discovery of how far illness has progressed. For some patients (notably Ben, Celia, Derek and Frank), their 'confinement' appeared to offer security, and to enable a sense of well-being. For others (particularly Gill), it created problems akin to those described by Charmaz (1983: 174): 'The unpredictable course of many chronic illnesses fosters uncertainty and fear, and as a result, some patients voluntarily restrict their lives more than need be'. The

consequence of this is a diminishing self-image where patients have a lack of opportunity for social reinforcement. 'Most importantly,' Charmaz continues, 'living a restricted life fosters an all-consuming retreat into illness.'

A central tenet of rehabilitation is that a 'retreat into illness' is undesirable, and that people should be encouraged to participate as fully as possible in all aspects of life. For patients with spinal cord compression, however, a retreat into a 'safe space' may be an inescapable and necessary response to extreme circumstances. Certainly, patients want to explore boundaries, to maintain their independence, to engage with others – but only up to a point. As Dina Rabinovitch (2007), a journalist with advanced breast cancer, explains: 'I sort of know I should be more active again, but... [...] there's resting because you need to, and then there's resting just because it has started to feel comfortable. [...] There is a great comfort in just lying in bed, feeling quite safe.'

Hence, we can take from the Individual Model an emphasis on enabling function, but only in so far as it does not threaten patients' conceptions of themselves as resourceful and resilient (a requirement which reflects the Social Model's insistence on the competence of people with a disability). However, as Gill's situation indicates, there is the potential for patients to isolate themselves to a degree that causes psychological morbidity; and it might be that there is a role for rehabilitation in pre-empting situations which, through the patient's inability to foresee consequences, cause distress - situations such as Gill's first trip out in a wheelchair to a busy supermarket on a Saturday morning (section 9.3.1). A more gentle introduction to using a wheelchair in public places (around the neighbourhood streets, to the park, to a small local shop) might have developed, rather than undermined, her confidence.

12.5.2 The aims and conditions of rehabilitation

Proponents of a Social Model of disability argue that rehabilitation reinforces the association of disability with the loss of familiar social roles (and attendant status), and the assignment of a negative identity (a social burden), dependent on the help, support and goodwill of others (Murphy 1990). The patients in this study, by and large, resisted a view of themselves as disabled, and consequently rejected rehabilitation interventions which challenged this conception. As we saw in Chapter 11, Eddie refused many of the occupational therapist's suggested home modifications, and declined rehabilitation in the community following his discharge from the radiotherapy unit. He had his own solutions, and the more the occupational therapist disagreed with him, the more tenaciously he held on to them.

Where rehabilitation was able to support patients' notions of themselves as resourceful and competent, and where rehabilitation staff attended to the patients' agenda, useful contributions were made: Celia's home adaptations, for example, and Frank's learning to move without help from his bed to his wheelchair, necessitating fewer daily visits from the home carers. Compensation for functional limitations was welcomed, as were interventions designed to promote a degree of independence, particularly insofar as these enabled patients to remain in the environment in which they felt safe. It is this complex configuration of self-identity – a competent person limited only by contingencies, and who continues to live normally, at least within a safe space – which health care professionals must be able to acknowledge and respect if rehabilitation is to make sense to patients.

Safety emerges as a concern both to the patient and to the health care professional; but each expresses it very differently. For health care professionals, safety is about the avoidance of physical injury; for patients, as we have seen, safety relates to maintaining an environment

which avoids a threat to their conception of a competent, worthwhile self. Where the health professional sees physical risks, which rehabilitation can help to reduce, the patient sees boundaries beyond which his or her identity could be compromised. The professional's criterion of safety concerns, in effect, the body; the patient's need for security has far more to do with the mind.

12.5.3 The need for adjustment

At a basic level, adjustment as 'accommodating changed circumstances' appeared to make some sense to the patients in this study, although not explicitly in those terms. Patients had ideas about what was needed to enable them to manage daily activities, and they pursued these – with varying degrees of purpose. However, adjustment has a temporal dimension; and, for the majority of patients, illness would not last long enough to become a life in itself (Rier 2000). With a median survival (taken from the audit data) of 53 days, patients could begin to try to make sense of an altered, unpredictable body, but would not have the time to incorporate a 'disabled identity' into their sense of self; nor were they able to look forward to recovery. Those who do survive long enough for shock to give way to the need to order and structure daily life are well aware that theirs is not an illness they will be living with for any significant length of time into the future. Their focus is on daily pleasures – 'putting on my face, doing my hair', the daily drinks round on the hospice ward, eating out, the company of friends. Sadness related to being disabled is managed, by and large, by retreating from it to a safe space.

People living with chronic disability seek ways of gaining, or retaining, a sufficiently positive self-image with regard to disability. Both the Social Model and the Individual Model offer mechanisms for achieving this. In Social Model terms, limitations are seen as externally

imposed rather than resulting from personal inadequacy; the Individual Model offers strategies for 'overcoming' impairment and disability. Phenomenological studies of living with chronic illness provide an insight into the 'disruption' of everyday life caused by illness, and the ill person's efforts to formulate an altered self-concept. The work of Bury (1982) and Charmaz (1983) has been particularly influential. Subsequent work by a number of authors (for example, Faircloth *et al.* 2004; McPherson *et al.* 2001; Williams 2000; Pound *et al.* 1998; Carricaburu and Pierret 1995) develops these ideas further, proposing that 'biographical uncertainty' is an inevitable part of life, rather than seeing identity as 'disrupted' by illness (Williams 2000). It has also emphasised individual difference: some patients may perceive disruption, others may 'bracket off' the illness in order to maintain a sense of a coherent pre- and post-illness self (Faircloth *et al.* 2004).

In contrast to work centring on longer-term illness, Rier (2000) offers a first-person account of a life-threatening acute illness, chronicling his admission to an intensive care unit with respiratory and kidney failure: 'Because my illness seemed simply to *replace* my earlier life rather than *compete* with it, I was spared the stress (so prominent in accounts of chronic illness) of trying to manage my normal obligations while ill' (Rier 2000: 72, emphasis in original). Whereas, according to Bury (1982), the construction of a new self occurs in response to the experience of living everyday life with illness, having to (re)negotiate relationships with others and the environment, patients who are acutely ill are required to do neither. While the majority of the patients in my study did not remain acutely ill, their shortened life expectancy militated against any extended process of reconceptualising the self. Disability was, variously, something to be resisted, annoyed about, worked around, feared, succumbed to – certainly not celebrated. None of the patients articulated a positive

image of themselves as disabled people; a positive self-concept was much more related to maintaining a connection with 'the person I am accustomed to being, unencumbered by illness' (section 7.2.2.1).

A change in one's perception of oneself requires time and reinforcement from others. In this study, patients delineated and inhabited spaces in which they were able to feel safe, spaces which reduced the likelihood of interacting with unfamiliar environments where they would encounter attitudinal or environmental barriers. Rather than 'adjustment' or 'constructing a new self' (Hopkins and Tookman 2000), patients rejected a disability identity, remaining optimistic by revising downwards the parameters for a tolerable mode of life, and identifying possibilities for the future.

12.5.4 Independence, autonomy and participation

Independence was a significant concern to patients, particularly insofar as their need for help with everyday activities affected the lives of the people closest to them. This was the area in which rehabilitation made the most sense to patients, and where they were most likely to engage with the process. Each of the patients interviewed in this study was concerned (in different ways) about their dependence on others, and took steps to minimise this. Interestingly, they did not appear mollified by the ability to direct a task as opposed to being able to carry it out. As noted in Chapter 7 (section 7.2.1.2), Alf was particularly vocal in this respect:

You want to know the most frustrating thing since my health's gone? Is having to get people to do things for me. [...] I hate people doing things for me, to be truthful about it. [...] I mean if I could do it myself and you'd done it once or twice, that'd be different. But now I can't do it, it's totally different

altogether. When you don't do a thing it's all right, but when you can't do it it's all got a different meaning.

Alf (Patient 1: Interview 2)

Alf's ability to decide (in this case) how he wanted the wiring to be done was no compensation for not being able to do the job himself. Cardol *et al.*'s (2002a) distinction between executional and decisional autonomy would appear to have limited application with this group of patients. While they would talk about the possibility of doing various things – going shopping, visiting the day centre, going for walks by the canal – for the most part these remained unrealised ideals. In practice and, at times, contrary to their expressed wishes, it was more likely that patients would cease or avoid activities that called their own attention to their disability, than it was for them to compensate or compromise.

The Social Model approach to autonomy and participation – autonomy as a right, and disabled people as experts in their condition – relies on a longer-term view of disability than we find with the patients in this study. In the grip of an illness which was frightening, patients, in this study and in others, relied on their doctors, particularly, for reassurance and the hope of as long a life as possible (Heyland *et al.* 2006; De Ridder *et al.* 1997). Rier (2000: 75) notes that, when acutely ill, 'despite my deep commitment to disclosure, negotiation and patient participation, the reactionary truth is I was too sick to know certain details of my case, too weak to be a partner in decision-making.' This is not to propose a return to a Parsonian conception of authoritative doctor and compliant patient (Parsons 1951), which decades of work in sociology, psychology and (to some extent) medicine have sought to move beyond (Little *et al.* 2001; Crossley 1998). Rather, it is to observe that the notion of 'expert patient' cannot have universal application.

In Chapter 2, I raised several issues related to patient-professional partnerships, and the extent to which patients were invited to, or were inclined to, participate in rehabilitation. I noted that the partnership ideal was promoted in the literature, but that accounts of practice indicated a professionally-driven agenda. In this study, a professional agenda dominated while patients were on the Frank Ellis Unit. Given the organisational imperative to discharge as quickly as possible, this is hardly surprising. There would be little point in inviting patients to set goals when there is so little scope to accommodate goals that are counter to the institutional agenda. However, as I have shown in Chapters 10 and 11, if therapists are either unwilling (or feel unable) to engage with the patient's agenda at some level, the effect can be to encourage the patient's refusal of potentially useful rehabilitation in the future.

It is well known that where services are provided in a way that is perceived as patronising and disrespectful of people's lives and experiences, and where patients feel on the receiving end of prejudicial judgments, the likely consequence is the refusal of assistance (Bartley 2006; Kerstin *et al.* 2000). However, the way in which this happens – as it did on occasion in this study – is subtle. The therapists I interviewed were kind, hard-working, and had their patients' best interests at heart. All of them would wholeheartedly agree with Canvin *et al.*'s (2006) finding that professional behaviours associated with patients' engagement in services include friendliness, a non-judgmental attitude, listening and responding to needs, recognising patients' capabilities, and building self-esteem. But, as I suggested in Chapter 10, a lack of attention to the mechanisms beneath the surface of observable inputs and outputs – in Pawson and Tilley (1997) terms – will not get us beyond the ready-to-hand, and ultimately limited, causal inferences of deficiency explanations: inadequate resources, lack of skill, and (as I shall shortly explain) personality or character.

12.6 Character-based responses to disability

In the preceding sections, I have discussed the varying accounts of a need for patients to make some adjustment to disability. In Individual Model terms, the notion of adjustment incorporates some reference to reality, but this is not something which appears to fit the patients' conception of their circumstances. I have shown how patients both acknowledge, and fail to acknowledge, the practicalities of their situation, and how they employ various devices for managing the tension. As I described in Chapter 7, a consequence of observing this response in patients is that health care professionals are inclined to describe individual patients as 'realistic' or 'unrealistic'. This raises two related questions: the extent to which it may be legitimate for patients to be 'unrealistic', or for them to entertain (putting it another way) 'positive illusions'; and the extent to which professionals are right to attribute 'realism' or 'unrealism' to individual patients.

12.6.1 Positive Illusions

Virtually all of the health care professionals I interviewed thought it was desirable that the patient demonstrated evidence of 'being realistic'. They would find support for this view in the considerable body of literature in palliative care which encourages hope within a realistic framework (Twycross 2003; Penson 2000; Rousseau 2000; Nekolaichuk and Bruera 1998; Fleming 1997; Herth 1990). They could also cite cognitive psychology, which posits contact with reality as a prerequisite for mental health (Jourard and Landsman 1980; Jahoda 1958, Erikson 1950; Maslow 1950).

However, these theories are challenged by work in attribution research showing that people tend to have a strongly self-serving bias, that we incline towards self-perceptions in which we are more successful and more popular than the average person, and that we pay much

more attention to experiences that reinforce a positive self-concept than those which might indicate a negative one (Taylor *et al.* 2000; Taylor and Brown 1988; Taylor 1983). In building an understanding of ourselves, 'instead of a naïve scientist entering the environment in search of the truth [about ourselves], we find the rather unflattering picture of a charlatan trying to make the data come out in a manner most advantageous to his or her already-held theories' (Fiske and Taylor 1984: 88). To put it more kindly, normal human perception and behaviour is characterised by a tendency towards 'positive illusions': mild distortions of reality in which we hold unrealistically positive views of the self, exaggerate perceptions of personal control, and are unrealistically optimistic (Taylor *et al.* 2000; Taylor and Brown 1988). Moreover, these positive illusions appear to have protective psychological effects which contribute significantly to a person's ability to adjust to severely threatening events.

Taylor (1983) contends that adjustment centres around three themes: a search for meaning in the experience, an attempt to regain mastery over the event in particular and over life in general, and an effort to enhance self-esteem. In a study of 78 women with breast cancer (Taylor *et al.* 1984; Taylor 1983), the respondents attributed their cancer to specific causes, such as stress, trauma or hormone medication (the search for meaning); they attempted to take psychological control of their illness, their treatment and their bodies (regaining mastery); and they sought ways to 'enhance the self', chiefly through positive comparisons with others (restoring self esteem). In my study, participants had similar strategies. The women in Taylor's study contrasted their situation with that of other women in such a way as to position themselves as better off than someone else. An older woman described feeling sorry for attractive younger women, for whom losing a breast must be traumatic, whereas a young woman compared herself favourably with single women who would lack the support

of an understanding partner. We can see the same strategy at work with the spinal cord compression patients, revising downwards their expectations of the future, making successive comparisons of their present self with some possible future self. Crucially, for the patients in my study, as for those whom Taylor interviewed, disconfirmation of a previously held belief did not precipitate distress. Where a previously dreaded circumstance became reality, patients explained why it was not so bad after all, and created some future scenario in comparison with which they were currently better off. Ben is a good example (see section 7.2.3.2). Initially, he said: 'As long as I don't have to use a wheelchair, life is tolerable'. But five months later, when a wheelchair had become part of his fixtures and fittings, his view was: 'Using a wheelchair is no problem. As long as I can manage to walk about in the house, life is tolerable.'

In the same way that, in Taylor's account, the women took charge of their cancer through positive beliefs about their ability to control it, the patients with spinal cord compression entertained a number of beliefs, or positive illusions, about their control over the future: plans to travel abroad, ideas about making one's own aids and adaptations, using a wheelchair to go out shopping, resuming previously enjoyed hobbies, being able to walk again. While, in many cases, patients took steps towards achieving these things, they also avoided situations in which their ability to achieve them would be directly challenged.

12.6.2 Character-based evaluation

Taylor's work gives us *prima facie* reason to regard the cord compression patients' 'illusions' as 'positive'. However, health care staff showed a tendency to evaluate – in moral terms – patients' outlook on the future, categorising their responses as 'realistic' and 'unrealistic'. Frustrated with Eddie's 'unrealistic' grand schemes for adapting his home to manage his

unsteadiness, Jenny (his occupational therapist) says the following of his lack of enthusiasm for her suggested alternatives: 'I think obviously [it's] his character and his personality and I think it's just him' (section 7.3). In doing so, she provides a good example of the fundamental attribution error (Ross 1977): the tendency to over-emphasise personality-based explanations for the behaviour of others, paying insufficient attention to situational explanations. In this respect, she is not untypical: rehabilitation staff were generally inclined to represent 'being realistic' or 'being unrealistic' as character traits, ignoring the fact that this group of patients contrives to be both.

Other staff were equally concerned when patients appeared unrealistic, and worried about the consequences of ungrounded hopes:

It's a balance isn't it, all the time. You've got to put some realism in there. Because otherwise it's complete denial and you end up being completely, you're sort of colluding, you know, with the story. And you just think, well hold on, where's this all going to lead? Whereas [...] you don't want to take away their hope. But you've got to make sure that [...] they're going in the right direction, that they do realise that, you know, you've got to face it.

Trevor (Health Care Professional – Oncology Consultant)

The consultant here sees an either-or situation, that realism and illusion cannot co-exist. The data from this study suggests otherwise. Patients' overly-optimistic views of future events do not necessarily prevent them from making sensible, practical plans for the present. In Ros Bye's (1998) study of occupational therapy approaches in palliative care, she quotes one of her participants (an occupational therapist), who says:

One minute you seem to be helping them fight death off and another moment you are helping them to accept death... You are putting things in place to say go ahead, live, get on, get going, and at the same time you are saying to them, well no you can't do this, you really have to appreciate that fact now... You are doing it all at the same time. You are saying get up, get going, and slow up and accept death all at once, which is really contrasting. (Bye 1998: 9)

Bye's respondent recognises the apparent contradiction in her response to patients; however, in both of the examples from my own study, the consultant and the occupational therapist present the responsibility for this 'realistic outlook' as theirs. 'You've got to put some realism in there', '...you are saying to them, well no you can't do this, you really have to appreciate that fact now...' Randall and Downie (2006: 211) offer a different perspective. While acknowledging that professionals have considerable influence over their patients' understanding, through the information they provide, they caution against professionals seeking to control patients' hopes:

Since it is they who hope, because it is they who determine what they desire, and they who ultimately judge its probability, it is the patients themselves who are the origin and the enduring source of that hope, not us. So whilst in choosing what to say we can and do influence their hopes, we must remember that the hope is theirs, not ours.

Taylor and colleagues (2000, 1988, 1983) argue that an 'unrealistic optimism' may be positive and protective. In my study, rehabilitation staff (and others) had a tendency to take the opposite view: positive illusions were to be discouraged for fear that they would cause some eventual damage. Rather than seeing patients' response to impairment and disability, and their wish to present themselves as competent, as a recognisable human strategy (Parry

2004), adopted in response to radical circumstances, staff categorised patients as either 'realistic' or 'unrealistic', and saw themselves as responsible for providing reality checks. On occasion, this repudiation of patients' aspirations led to the rejection, by the patients, of a potentially useful resource.

12.7 Disability, psychology and space

It is clear from the preceding discussion that neither the Individual Model nor the Social Model fits patients who have a disability as the result of metastatic spinal cord compression. One reaction to this analysis would be to point out that (as I conceded earlier in the chapter) I have created a somewhat artificial distinction, whose basic implausibility is something a number of writers have commented on (for example, Williams 1999). The debate, it might be suggested, has already moved beyond this simplistic polarisation between the individual and the social.

In response to this, let me say two things. First, I adopted the distinction partly in order to make the point that palliative care's approach to disability is situated at the 'tragedy' end of the spectrum of views associated with the Individual Model. In palliative care, rehabilitation is seen, uncritically, as bringing hope and inspiration, and the Social Model is not something with which professionals in palliative care are familiar. This is evidenced by a recent series of papers on palliative care and disability in the *Journal of Palliative Medicine*, papers which bring the Social Model to the attention of palliative care practitioners for the first time, and which, judging by the editorial in that issue (Chochinov and Stienstra 2006), are regarded as ground-breaking for that very reason.

Second, although the debate has (arguably) moved beyond the polarisation of the Individual and Social models, it has not in fact moved that far. It is acknowledged that disability is a consequence both of individual impairment and social restrictions: 'A social theory of disablement risks incoherence if it cannot make the link... between impairments and the socially-created disadvantages of disablement' (Bickenbach *et al.* 199: 1187). Imrie (2004: 292) agrees, and observes that 'disability is a complex, multi-dimensional phenomenon that cannot easily be understood by recourse to the unequivocal messages of the contrasting models or discourses of disability'. But this is only to say that individual impairment and social disenfranchisement contribute equally to disability, and that it is myopic to ignore either one.

What the study of people whose disability is the consequence of life-limiting illness suggests is something more than this Both/And perspective, which omits what seem to be two crucial features of these patients' experience of cord compression. First, the Both/And perspective (along with the Individual and Social models, which it yokes together) misses the fact that disability, for this group, is mediated by a psychological dimension. It is insufficient to say that bodily impairment and social disadvantage, in combination, 'create' disability. There is a prior question. What, if anything, has been 'created'? Neither the Social Model nor the Individual model questions the *fact* of disability; they merely disagree about what constitutes it, and what explains it. But here is a group of patients who, unarguably, are disabled, but who (in their attitudes towards it) problematise the whole notion of 'having a disability'. They are people who both have and (in their own minds) do not have a disability; and health care professionals cannot simply dismiss the 'not having' part. 'Not having a disability' is an essential aspect of the patients' reality.

The second crucial feature omitted from the Individual and Social models is the extent to which disability is, for cord compression patients, about space. In the other models, space is undifferentiated: there is the disabled individual, and there is the space in which she is situated, and through which she can be mobile. The point at issue is the implicit qualification: 'through which she can be mobile with the help of rehabilitation', or 'through which she can be mobile if an indifferent society makes the necessary arrangements'. But for patients with spinal cord compression, disability is about demarcating space, dividing it up into 'safe' and 'unsafe' regions. As I have already suggested, this concept of 'safety' is not the one the professionals recognise: physical safety. The boundary between the safe and the unsafe marks the point beyond which the patient's identity, her sense of herself as resourceful, resilient and competent, may be compromised. At the same time, and for the same reason, the 'unsafe' region is the space in which the unremitting progress of the disease may be revealed. These are prospects which the patient, not unreasonably, wants to keep at bay, preserving the 'positive illusions' she is intent on maintaining. For the health professionals, that is just part of 'being unrealistic'. For the patients, it is a matter of almost existential concern.

The two facets of disability I have described are naturally linked. The demarcation of space is one way in which the tension between 'having a disability' and 'not having a disability' is managed, one of the psychological devices that problematises the whole idea. But at the same time, holding on to the unresolved ambiguity between 'having' and 'not having' a disability is part of what makes the demarcation of space possible. For if the tension is resolved, and I have a disability, space becomes undifferentiated again, an endless series of obstacles to be negotiated.

12.8 Consequences for rehabilitation

If, for these patients, the notion of 'having a disability' is problematised, then the idea of rehabilitation is problematised, too. This is not for the reasons that rehabilitation is rejected by Social Model theorists - the 'sick joke' played on people whose problem is not impairment but society. Rather, it is because rehabilitation presupposes that the patient recognises, unequivocally, that she has a disability. Patients with spinal cord compression do acknowledge this, but not unequivocally; for they also contrive not to acknowledge it. If health professionals do not understand this, we have seen what the consequences are: either the rehabilitation agenda is pursued by the professional, but rejected by the patient (who sees no need for it); or else the patient's account of herself as competent and resourceful is taken at face value, and no rehabilitation is provided.

The paradoxical conclusion, I think, is that rehabilitation can only be offered on the understanding that it is unnecessary. Or rather – for this formulation is perhaps too melodramatic – on the understanding that it will not compromise the patient's sense of her own competence, and so disrupt the balance between 'having a disability' and 'not having a disability' which the patient is seeking to maintain. This idea is at odds with what the palliative care literature on disability tends to encourage: an emphasis on the patients' helplessness and passivity. It is, in effect, the bit that is worth taking from the Social Model: a questioning of the assumption that the patient is weak and dependent, and an open commitment to the recognition of her competence.

The consequence is that the approach to rehabilitation will have to oblique. It cannot be attempted head-on, so to speak. The images I have here are all opportunistic ones: nudging, waiting, side-stepping, accommodating, a sideways, oblique movement, rather than a direct

assault. One corollary of this line of thought is that 'goal setting' will have to be regarded as dispensable, or at least perpetually deferrable. I suggested earlier that some rehabilitation writers have already expressed caution about goal setting; and I think this study provides further grounds for scepticism. In this respect, however, it cuts across received wisdom. For example, the King's Fund Rehabilitation Review (Nocon and Baldwin 1998) identifies four components that appear to contribute to effective rehabilitation: (i) responsiveness to users' needs and wishes, (ii) multi-disciplinary and inter-agency working, (iii) available when required, (iv) clear rehabilitative purpose and goals. In the case of patients with metastatic spinal cord compression, I have no doubts about the first three. I am seriously questioning the fourth.

I do not think it possible, at this stage, to list comprehensively the conditions under which rehabilitation can successfully be offered to this group of patients. However, I can offer a few pointers:

1. The goals of rehabilitation noted in Chapter 2 – improving function and independence, adjustment to disability, finding fulfilment in social roles – are likely to remain unrealised ideals. However, this does not mean that they should be abandoned; rehabilitation can make a useful contribution to the notion of 'future possibilities'.
2. Beyond strategies to safeguard some basic independence, patients are not particularly engaged with 'learning to live with a disability'. Contradicting patients' aspirations for the future (and their 'positive illusions') risks patients' refusal of rehabilitation.
3. Patients might not actively pursue their goals, but they do articulate preferences and aspirations: 'I want to walk before the year is out.' Therapists need to respond to these in

a way that does not confront patients with limitations that they are not willing to encounter, but that at the same time creates space for patients to make the most of the present.

4. Rehabilitation interventions should contribute to sustaining patients' 'safe spaces' while being alert to the possibility of these spaces becoming confining. Patients should be provided with the resources to maintain their safety – physical and, more particularly, psychological – recognising that there may be situations in which support could usefully be provided to challenge the boundaries of 'what feels safe'.
5. Where patients are exploring their boundaries, rehabilitation can contribute towards engineering small successes which can be built on (such as Anne's supported negotiation of public transport in 2.5.2), rather than patients being left to work it out for themselves (Gill's and Ben's experiences of going shopping in 9.3.1 and 7.2.3.4 respectively).
6. Neither an 'acute care' model nor a 'chronic illness' model works. Some combination of facilitating short-term outcomes while sustaining longer-term ambitions is needed.
7. Therapists should take account of context beyond the individual patient and resist the temptation to categorise patients as 'realistic', 'unrealistic' or 'just that kind of person'.

Perhaps the final section of this chapter can be summarised by saying that, like the patients, health care professionals may have to 'twin-track' if they want to provide rehabilitation to cord compression patients. Instead of attaching the 'unrealistic' label to the patients, they can sustain 'positive illusions', at the same time taking whatever opportunities arise to enhance the patient's day-to-day ability to function in a 'safe' space and, where possible, anticipating – always obliquely – any movement beyond that space in order to prevent the distressing

situations that might otherwise occur. All of this will mean abandoning some of the most deeply entrenched ideas about working with patients who have a disability: patient-centredness, the importance of goal setting, the need for adjustment, and so on. It will not be easy to let some of this go; but, with this group of patients, I think it is essential.

PART V
CONCLUSIONS AND IMPLICATIONS

Chapter 13

Conclusions and implications

This thesis describes a Phase I modeling study (in MRC terms), identifying the mechanisms and outcomes associated with rehabilitation interventions for patients with metastatic spinal cord compression. In this chapter, I provide a summary of its theoretical contribution, and the implications for practice and future research.

This study was primarily a piece of health services research; it was grounded in patients' experience of disability and in the services available to them. The study was funded with the express purpose of improving outcomes for patients. While a range of philosophical, sociological and psychological perspectives have contributed to an understanding of disability and rehabilitation for this patient group, the work has a strong focus on the potential to improve actual practice.

13.1 Theoretical contribution

13.1.1 Mechanisms

The study has identified mechanisms by which outcomes are achieved: in particular, it has identified mechanisms implicated in the fact that, in practice, very little rehabilitation is being provided.

The claim that mechanisms have been identified must be understood as provisional. The study has identified what appear to be mechanisms operating in a small number of cases. Further research, of a kind defined by the MRC framework as Phase II and Phase III, would be required to establish that these mechanisms were in more general operation. The present study is not the sort from which generalisations can readily be made.

The account presented here, if correct, is of particular interest and value because it is at odds with the account which healthcare professionals would provide. It is also of interest in that the literature says a great deal about *what* to do, but says almost nothing about *how* to do it, or what is likely to happen as a consequence. In this study, by contrast, I have attempted to identify mechanisms precisely, showing how patients' orientation to disability interacts with events, conversations and procedures on the ward, and how it elicits a certain response from health care staff, in a way that effectively keeps rehabilitation off the agenda.

13.1.2 Complexity

I have introduced complex adaptive systems (CAS) as a variation on the theme of explanation by reference to mechanisms, contrasting the CAS explanation of the 'not much rehabilitation' outcome with other kinds of explanation (and in particular 'deficiency' explanations). It is a presupposition of this approach that the actions and psychological states of individuals are implicated in – and frequently constitute – social mechanisms, both in terms of what the individual believes and is motivated by, and in terms of the 'structures' to which actions collectively, but unintentionally, give rise. I have incorporated the implications of the CAS analysis into proposals for improving the delivery of rehabilitation to these patients.

13.1.3 Disability

The study has proposed a model for framing spinal cord compression patients' orientation to disability. Patients' responses incorporate two apparently inconsistent attitudes: one which acknowledges disability, and one which fails to do so, striving to keep the 'disability identity' and its perceived consequences at bay. Patients adopt a number of devices to manage the tension between these antithetical, but simultaneously maintained, positions. To

ask whether the Individual Model or the Social Model of disability is the more relevant to this patient group misses the point. Neither incorporates the duality of being 'disabled' and 'not disabled' at the same time, nor the demarcation of space which accompanies this duality. Rehabilitation staff, along with other health professionals, do not recognise the duality, and assume that patients either acknowledge their disability or do not. Accordingly, they regard the patient's 'I'm not disabled' view either as evidence for some degree of denial (which must be countered with a 'reality check') or as justification for not providing intervention. In view of the limitations of the present study, and in particular the necessarily small sample, this model of patients' response to disability clearly requires further testing in order to ascertain its relevance to the general population of patients with metastatic spinal cord compression.

13.1.4 Narrative

A relatively new approach to the analysis of narrative data, drawing on techniques in literary criticism, and focusing on plot, characterisation and narrative style, has been adopted in the study. In research terms, it was used in association with the constant comparative method, borrowed from grounded theory, and provided a further source of categories, properties, and theoretical statements. Potentially, the literary critical approach to narrative analysis has clinical, as well as research, applications. By using these techniques to understand patients' narratives, health care staff can become sensitised to the perlocutionary effect of stories, and correspondingly more self-aware in their response to them.

13.2 Implications for practice

As I noted at the end of Chapter 12, it is not possible, at this stage, to list comprehensively the conditions under which rehabilitation can successfully be offered to this group of

patients. However, there are a number of key concepts that can be specified, and which can form the basis of a 'rehabilitation intervention protocol' for further evaluation as described in section 13.3.1.

13.2.1 Referral

Patients admitted for treatment of metastatic spinal cord compression should be seen as close to the time of admission as possible by both the physiotherapist and the occupational therapist (unless specifically inappropriate; for example, the patient is acutely unwell or imminently dying). Future plans need to be made on the basis of past and present conditions, but the possibility of rapid changes in physical state, emotional outlook and social circumstances should be recognised. Rehabilitation (if required) should not be delayed on the premise that the patient's circumstances are unpredictable and interventions are best left until the future is more certain.

13.2.2 Presentation of rehabilitation to patients

The way in which rehabilitation is placed on the patients' agenda is significant, and nursing and medical staff (particularly consultants) have a considerable role in this. Patients rely on their consultants for key information about future expectations, and the provision of explicit cues regarding the potential contribution of rehabilitation could facilitate its provision. Opportunities should thus be sought for direct contact between senior medical staff and rehabilitation staff (where appropriate, joint consultations with patients). Visible contact with other team members is as crucial as face-to-face contact with the patient. Rehabilitation should be presented in a way that works with, rather than against, the patients' agenda, in effect asking, 'What do you want to achieve and how can I help you to do that?'

13.2.3 Recognising and supporting patients' responses to disability

Staff should recognise the ways in which patients both look for ways to accommodate disability, and also contrive to ignore it. Conceptions of 'safety' should be extended to incorporate more than the patient's physical safety, recognising that, for patients, 'safety' relates to maintaining an environment which avoids a threat to their sense of a competent, worthwhile self. Rather than categorising patients as 'realistic' or 'unrealistic', therapists should sustain patients' 'positive illusions', at the same time taking whatever opportunities arise to enhance the patient's day-to-day ability to function in a 'safe' space and, where possible, anticipating any movement beyond that space in order to prevent the distressing situations that might otherwise occur.

13.2.4 Approaches to rehabilitation

Rehabilitation should not be seen as a structured, ordered, step-by-step process for achieving set goals. Rather, the approach should be oblique: nudging, waiting, side-stepping and accommodating. Goal-setting should be approached with some caution.

13.2.5 Enabling function and independence

Patients are concerned about dependence on others, and look for ways to reorder and restructure daily life so as to continue with desired activities. Compensations for functional limitations are welcomed, and responding to patients' needs in this regard can provide a very useful 'way in' for rehabilitation. Interventions which are helpful are those designed to promote a degree of independence, particularly in so far as these enable patients to remain in the environment in which they feel safe, and support a view of future possibilities.

There are areas in which specific, basic practical advice should be given routinely, particularly with regard to patients' ability to manage incontinence, reduced mobility and fatigue.

13.2.6 Transitions between services

Attention should be paid to patients' transitions between services. Discharge should not be seen as an end-point of interventions. For example, discharge summaries should be standard practice where there is likelihood of patients encountering disability-related issues in the future, and should be sent to the person having the most regular on-going contact with the patient, such as the GP, district nurse or Macmillan nurse. These need to identify the resources that are available to patients if required at a later date, for example, the procedure for referral to specialist palliative care rehabilitation. Where there is a need to refer to other (rehabilitation) services, a specific referral should be made to a named individual, providing that person with a summary of current and likely future difficulties, and an indication of the support expected. With the patient's agreement, there should be active involvement of carers in the rehabilitation process and decision-making for the future.

13.3 Recommendations for future research

13.3.1 Phase II study

I have situated this study within the Medical Research Council's framework for developing and evaluating complex interventions (Medical Research Council 2000*a*). It therefore represents only the first stage in a programme of research, where the natural sequence now leads to the development of an exploratory trial to assess the feasibility of implementing and measuring a defined rehabilitation intervention. If this was successful, one could then move

to the final phase, an RCT with sufficient statistical power. An outline for one possible way forward is sketched below.

13.3.1.1 Aims and objectives

A Phase II study would aim (i) to apply and evaluate a specific, defined rehabilitation intervention developed from the Phase I study with patients with metastatic spinal cord compression; and (ii) to explore and identify the conditions under which this intervention could be delivered and evaluated across a larger population.

Reflecting the principal dimensions of a Phase II study, there would be four main objectives:

- To examine the extent to which it is possible to achieve a change in practice through the intervention proposed.
- To identify the components of the intervention necessary to achieve the outcomes specified.
- To identify valid and reliable outcome measures.
- To consider feasibility issues related to a full-blown trial, particularly those of recruitment.

13.3.1.2 Design outline

One way of achieving these objectives would be through a quasi-experimental, between-participants, pre-test/post-test design (Shadish *et al.* 2002). In the pre-test phase, data would be collected for a specified period prior to the implementation of the intervention. In the test phase, data would be collected on a second cohort of patients, now receiving the intervention, over the same time period.

Data would need to be collected from a range of sources, which could include: (i) process measures, derived from medical records (the audit in Phase I demonstrates that the multi-professional notes on the radiotherapy unit are of unusually high quality); (ii) data from a standardised rehabilitation assessment, such as the Impact on Participation and Autonomy Questionnaire – IPA-E (Sibley *et al.* 2006); and (iii) patient-completed diaries, incorporating tick-box responses to questions about daily activities as well as a subjective, descriptive component (Alaszewski 2006). In addition, during the post-test phase, a detailed record of procedures and systems would be kept, so that the delivery of the intervention could be monitored, and changes made as required.

The intervention would incorporate the recommendations arising out of the Phase I study (as outlined in section 13.2).

13.3.1.3 Potential contribution

The results of such a study could provide a basis for a multi-centre trial, comparing a number of units where the intervention was implemented with ‘control’ centres. This is not to underestimate the challenges inherent in this type of study, but there is precedent for the successful development of research programmes of this sort in rehabilitation, for example in stroke research, dementia care and in chronic fatigue syndrome, as noted in section 3.5.3. The follow-up Phase II study is currently being planned, with a grant application due to be submitted in September 2007 to the Department of Health’s *Research for Patient Benefit* Programme.

13.3.2 Additional studies

13.3.2.1 Outcome measurement

While the Phase II study (above) incorporates an element of the appraisal of outcome measures, this is an area which could benefit from focused attention. Measuring outcomes in palliative care rehabilitation is a long-standing matter for debate, and goal-setting has been proposed as a potentially useful alternative to standardised measures of function (Eva 2006). Given the issues related to goal-setting raised by this study, further research into its utility, conditions and limitations would be valuable.

13.3.2.2 Extending concepts beyond metastatic spinal cord compression

The question arises as to whether this particular model of the patient's response to disability has application beyond patients with metastatic spinal cord compression. This study's successful case-study design could be extended to include palliative care patients with a range of cancer and non-malignant diagnoses, particularly those nearing the end of life. However, it would first be necessary to confirm the relevance of the model to the wider population of cord compression patients (as acknowledged in section 13.1.3), given the limitations of the present study.

13.3.2.3 Rehabilitation staff training

This study has (briefly) raised issues relating to opportunities for training for rehabilitation staff working with patients with metastatic spinal cord compression. There is the potential to develop and evaluate flexible training programmes which incorporate this study's model of patients' response to disability, as well as an understanding of the concept of 'narrative vigilance' in response to patients' stories.

13.3.2.4 Prognostic indicators and rehabilitation referrals

This study has not addressed in any detail the feasibility or acceptability of specialist rehabilitation for patients, particularly for those who are likely to survive for longer than three months. Further work is needed to identify situations in which some type of specialist rehabilitation provision might be indicated. Prognostic indicators, such as those developed by Tokuhashi *et al.* (2005), Eriks *et al.* 2004 and Hacking *et al.* (1993), and incorporating indications of patient preference, could be examined as indicators of patients' potential to benefit from rehabilitation.

13.4 Limitations of the study

The choice of interviews as a means of data collection was, in some respects, pragmatic rather than ideal. An observational study would have enabled a wider range of situations to be studied, and would not have limited the data collected to self-report (as it was in this study). These problems were partially addressed though the interview strategy which explicitly invited comment on emerging ideas from a wide range of people, and by supplementing the case study data with the audit data.

Seven out of the nine patients around whom the case studies were centred survived longer than three months; indeed, five survived longer than six months. With a median survival of 53 days, there is a weighting of case study data towards those with longer life expectancy. The longitudinal nature of data collection compensates for this to some extent, as I was able to compare patients' early reactions to later responses.

There is an undeniable bias in the study in favour of rehabilitation. This arises out of my own professional background as an occupational therapist, and also out of the fact that the study

was funded in anticipation of service improvement. While I am significantly sceptical about rehabilitation – my clinical experience has given me plenty of opportunity to question its utility – I was aware of considerable discomfort at the prospect of suggesting, on the basis of my results, that health care resources would be better spent elsewhere. Such a recommendation would cut across all conventionally accepted policy and practice. On the other hand, this is no reason for not arriving at a radical conclusion, if that is where the evidence is pointing. In fact, I think the evidence justifies my present position – that rehabilitation does have the potential to improve outcomes for patients, but only if delivered in an acceptable way. In reaching this position, I was greatly assisted by debates with the study advisory group members, in particular the two patients and the carer who were part of the group.

13.5 In conclusion

The main interest, but also the main challenge, of this study has been in the combination of diverse theoretical sources and, consequently, the need to consult the literature in more than one field of enquiry. Even in the field of rehabilitation, there is little (if any) cross-referencing between the contributions to the mainstream rehabilitation literature and the contributions to palliative care; any more than there is contact between palliative care and disability studies. Yet research with patients who have metastatic cord compression obliged me to bring these fields together. Beyond the clinical issues, my commitment to identifying mechanisms took me into theoretical areas that I did not at first anticipate – in particular, to complex adaptive systems and the idea of narrative – in an attempt to explain the unexpected outcome I identified. Recognising that the perlocutionary effect of narrative is itself one of the key mechanisms in the production of this outcome was just one example of the way in which

these disparate areas of enquiry converged; and another is the realisation that disability would need to be theorised differently (that is, in a manner conforming to neither the Individual Model nor the Social Model) if the orientation of patients with spinal cord compression towards disability was to be faithfully captured, and if it was to figure in the complex explanation of the 'not much rehabilitation' outcome. It is for these reasons that the study has covered the ground it has, attempting to combine these literatures – oblivious, for the most part, to each other – in a satisfying and persuasive way. Whatever the merits of the present enquiry, undertaking this research has convinced me of the virtues of interdisciplinary work, not merely within health care itself, but between health care and the social sciences and humanities.

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Appendices
