The development and evaluation of a Goal setting and Action Planning framework for use in Palliative Care (G-AP PC)

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Acknowledgements

Declaration

I hereby declare that this thesis embodies the results of my own research and that I am the full author of this thesis, except where otherwise stated.

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Abstract

Background: Palliative care is a support system to help people live actively until they die. Current policy aims to integrate rehabilitation and goal setting as mechanisms to help professionals to support patients to do this, but there is little agreement about what this means in practice. No theory based framework currently exists to help palliative care professionals consistently work with patients to identify and work towards goals. This thesis describes how a framework for goal setting and action planning in palliative care (G-AP PC) was developed and implemented systematically in one hospice.

Research aims:

1. To synthesise published literature regarding goal setting in palliative care settings.

2. To investigate current goal setting practice in one hospice setting.

3. To develop and evaluate a theory and evidence-based goal setting intervention for palliative care settings.

Study design

This study is placed in the 'development and feasibility' phases of the Medical Research Council (MRC) framework for developing and evaluating complex interventions. The intervention (G-AP PC) was systematically developed. Firstly a rigorous investigation of current practice was conducted by synthesising the literature on the subject, and investigating current goal setting practice in one hospice setting. These findings informed the development of a theory-based Goal setting and Action Planning practice framework (G-AP PC) which was then implemented and evaluated in one hospice in-patient unit. Normalization Process Theory (NPT) was used to structure the development and evaluation of the intervention.

Findings:

Goal setting with patients is recognised as important within palliative care, but is poorly conceptualised and lacks a theory and evidence-base for its practice. G-AP PC was successfully developed, implemented and evaluated in one hospice setting. Findings demonstrate that G-AP PC is acceptable and feasible for use by professionals and patients alike. It helped professionals to work as a team; shift their attention from *symptoms/problems/risk* to patient's *goals*; act on what patients wanted to achieve, within short timescales and document patients goals appropriately. Patients reported that use of G-AP PC allowed them to focus on goals that were important to them. There was also evidence that goal setting helped increase patients' motivation and self-efficacy.

Conclusions:

G-AP PC is a feasible and acceptable intervention. The study has demonstrated that the interventions can increase patient centred goal setting and motivates both patients and staff to work towards and achieve patient goals that are not only about controlling symptoms but also about engaging in meaningful activities, enabling patients to live actively until they die.

Chapter 1. Introduction

1.1 Introduction to the thesis

During my career I have worked in the NHS and the third sector in Scotland as a speech and language therapist. For the last 17 years, I worked as a member of two multidisciplinary teams, with adults with acquired communication disabilities in the community. During this time I became aware of the importance and complexities of engaging patients in the goal setting process. I found that the multidisciplinary team worked at their best when they listened to the opinions and priorities of patients and families. This would lead the team to provide input directed towards patient-centred rather than professionally-led goals, which appeared to have a positive impact on the patient's motivation and engagement in the rehabilitation process. As a speech and language therapist, I was often involved in helping people with severe and complex communication difficulties. This added an extra dimension to the challenge of helping people to be heard and involved in making decisions about their own care.

Often, the patients I worked with had deteriorating conditions such as Motor Neurone Disease (MND), Multiple Sclerosis (MS) and Brain tumour. My work with this group of patients has inspired this piece of applied healthcare research, mainly because my colleagues and I found it particularly difficult to set goals with people who were actively dying. As a rehabilitation professional, I felt that setting goals with patients was central to my work. I faced a dilemma: goal setting as I knew it from traditional rehabilitation was about helping people to regain function or adapt to life with disability; in the face of life-threatening illness, I felt that goal setting was just as important, but patients often found it difficult to be 'heard' in the face of professional's opinions. It seemed to me that, when patients were dying, it was vital that professional input should be targeted towards what was most important to patients

and their families, but in practice, this was difficult to do. I use an anonymised example of a patient that I worked with to illustrate this.

A man called John, diagnosed with MND, was referred to the community rehabilitation team. He lived with his wife and ten year old son. Following referral, John's condition rapidly worsened. He had to give up work because of his deteriorating mobility and speech. He needed to use a communication aid as his speech became unintelligible, and shortly after referral, his swallowing deteriorated, so he was referred for a Percutaneous Endoscopic Gastrostomy (PEG) so that he could continue to receive nutrition, in spite of his inability to eat. These changes happened within the space of three months and gradually John's control over his life diminished. There were many professionals involved in John's care, and time was spent at multidisciplinary meetings discussing how to anticipate and deal with problems as they arose. Each professional worked on their own goals to support John, and although everyone working with John was concerned with his welfare, there was little mention of what was important to him and his family. As John's condition deteriorated, it became very difficult for him to make himself heard above the voices of each professional.

Whilst working with John, I was frustrated that, as he was dying, his world was taken over by the agenda of medical, nursing and allied health professionals. He appeared to be on the periphery of decision making. Many of the discussions that professionals had were around managing his symptoms and how best to provide care, rather than what was important to John (for example, spending time with his son, communicating with his family). I felt that if the multidisciplinary team had asked John about his goals, and focused on these, this may have helped him to continue to live actively while he was dying and may have changed the priorities of professionals away from symptom and problem management to helping John to participate in life. After John died, there was a debriefing session with members of the rehabilitation team. Many of us were uneasy about how we had worked with John, and there

was agreement that perhaps if we had been more 'goal focused', we may have been able to support John to do the things that mattered right up until he died. Although we routinely used goal setting in our work with stroke patients, there was no agreed framework or language to enable the multidisciplinary team to do this with patients who were actively dying.

In 2007 I had the opportunity to apply for a part-time research position at Strathcarron Hospice. I submitted a proposal to investigate and develop goal setting in palliative care and was fortunate enough to be successful. From the beginning, I wanted my research to be relevant and useable in clinical practice, and I have endeavoured to do this throughout the project.

1.2 Structure of the thesis

This research is a three stage study designed to inform, develop and evaluate goal setting practice in palliative care. It is well documented that goal setting and rehabilitation are complex interventions (Levack et al. 2006a, Holliday et al. 2005, Wade 2005). The difficulties of evaluating complex interventions in healthcare have been acknowledged by the Medical Research Council (MRC). In 2000 they developed a sequential framework which outlined five step-wise phases involved in the evaluation of complex interventions (MRC 2000). This was updated in 2008, resulting in a more flexible approach to the development and evaluation process, summarised in Figure 1 (based on Craig et al. 2008:8):

Figure 1 Developing and evaluating complex interventions: new guidance

Feasibility/piloting

1. Testing procedures

2. Estimating recruitment/retention

3. Determining sample size

Development

1. Identifying the evidence base

2. Identifying/developing theory

3. Modelling process and outcomes

Evaluation

1. Assessing effectiveness

2. Understanding change process

3. Assessing cost-effectiveness

Implementation

1. Dissemination

2. Surveillance and monitoring

3. Long term follow-up

This applied piece of health research is placed in the *'development and feasibility'* phases of

the MRC's framework for developing and evaluating complex interventions (Craig et al. 2008).

Stages 1 and 2 of this study are placed in the 'development phase' of the MRC framework.

Stage 3 is placed in the 'feasibility/piloting phase'. I have used qualitative research methods

throughout this study, but have used different methods at different stages, depending on the research questions. I have structured the thesis so that methods are described in relation to each stage within each chapter, as outlined below.

- **Chapter two:** I set the scene by providing an overview of rehabilitation, goal setting and its relevance to palliative care;

- **Chapter three**: I describe the structured literature review which I undertook to find out about current goal setting practice and theory in palliative care. I firstly describe the methods used and then discuss the findings and implications for practice;

- **Chapter four:** I present the findings from a case study (where I use observation, interviews and case note analysis) in which I investigated goal setting practice in one hospice;

- **Chapter five:** I describe how I used semi structured interviews with patients to find out about their views and experiences of goal setting in the hospice;

- **Chapter six**: I present the synthesis of the findings from the literature review, the case studies and patient interviews which informed the development of G-AP PC, a goal setting and action planning intervention for use in palliative care. I describe how I worked with a task group of staff to model and refine the intervention. I used Normalization Process Theory (NPT, May 2010) to structure my work with the task group, who provide insights into how the intervention can be implemented in the hospice;

- **Chapter seven:** I describe the implementation and evaluation of the intervention with a team in the hospice. I use NPT to structure analysis of the results;

- **Chapter eight:** I summarise the project as a whole and discuss its relevance to practice and implications for future research.

Chapter 2. Living with dying: the role of rehabilitation in palliative care.

2.1 Introduction

Dame Cicely Saunders, an early pioneer of palliative care in the UK, founded St Christopher's Hospice in 1967. Since then, palliative care has become established as an integral part of mainstream healthcare (Scottish Government 2008, NICE 2004). Saunders' original work was based on the philosophy that patients should be at the centre of care and that they should be supported to live actively until they died, as the following quote illustrates:

> *"You matter because you are you. You matter to the last moment of your life and we will do what we can not only to help you die peacefully but to live until you die"*
> (Saunders 2006:xxiii)

Over the last four decades, palliative care has changed and developed, but its original principles remain the same. The World Health Organisation (WHO) defines palliative care as "*a support system to help patients live as actively as possible until death*" (WHO 2004:44). Rehabilitation, which is well established in general medicine (Scottish Government 2007, WHO 2006-2007, Department of Health 2000), is a relatively new concept in palliative care (Eva and Wee, 2010). It has been identified as a fundamental mechanism for helping people to live actively until they die (NICE 2004, NCPC 2000). In their guidance for improving supportive and palliative care for adults with cancer, the National Institute for Clinical Excellence (NICE) recommend that patients should *"receive an active and planned approach to rehabilitation that involves assessment, goal setting, care planning and evaluation"* (NICE 2004:136). The National Council for Palliative Care (NCPC) also highlight that goal setting is a central component of rehabilitation: "*Always centring around the wishes and aspirations of the patient, and acknowledging all aspects of their well-being, rehabilitation in palliative care sets realistic goals"* (NCPC 2000:3).

In this chapter I set the scene for this research by describing the place that policy sees rehabilitation playing as part of a solution to support an aging population living with increasing levels of chronic illness and disability and describe the role that rehabilitation plays in helping people to 'live while dying'. I then provide an overview of the theoretical underpinnings of rehabilitation and discuss how although rehabilitation processes are seen to have an important place in palliative care, there is little research or scholarship on how it may need to be applied differently in palliative care compared to traditional rehabilitation settings. In the third section I describe recent work which has been carried out to clarify the theoretical underpinnings of rehabilitation. I describe in turn each of the three models which Wade (2005) suggests can be used to help us describe and understand rehabilitation: illness, process and behaviour change models. I discuss the relevance and application of each model in relation to palliative care before I introduce the next steps in this research.

2.2 Rehabilitation: part of the solution to enable people to live actively

The WHO estimates that 10% of the world's population experience a form of disability or impairment. This number is increasing because: a) there is general rise in the world's population; b) people in developed countries are living for longer and c) people are surviving for longer with a range of chronic health conditions (WHO 2006-2007). In response to this challenge, the WHO commissioned a world report on disability and rehabilitation. One of the aims of the report was to ensure that people with disabilities are provided with:

> "*more equal opportunities and rights, and to live with dignity through enhanced health care and rehabilitation services and barrier free environments*" (WHO 2006-2007:2)

Rehabilitation is a central component of health care delivery, as well as a vehicle for helping people to play an active role in managing their own health. It is described as:

> *"A process aiming to restore personal autonomy to those aspects of daily life considered most relevant by patients or service users, and their family carers"*
> (Scottish Government 2007:14)

UK health policy has acknowledged that patients should be at the centre of a healthcare system that focuses on the promotion of peoples' independence and self-care (Scottish Government 2007, Department of Health 2000), thus enabling them to take an active role in the management of their own health. Rehabilitation is seen as a key way to achieve this (Scottish Government 2007, Department of Health 2000). It is also seen as central to the shift in focus from hospital to community based services, with the aim of promoting patients' independence for as long as possible (Department of Health 2001), supported to manage their own health where possible and increasingly involved as partners in their care (Scottish Government 2007). Involving 'patients as partners' is particularly emphasised in 'Co-ordinated, Integrated and Fit for Purpose' (Scottish Government 2007), a delivery framework for adult healthcare in Scotland, which proposes that rehabilitation, with its emphasis on self-management and patient centred care, should be viewed as central to modern healthcare.

2.3 Rehabilitation and palliative care

Palliative care aims to support people to live as actively as possible until death (World Health Organisation 2007), but in reality this can be a complex and contradictory business. The challenge of working with patients in the face of deteriorating function is highlighted as a tension for both professionals and patients (Jacques and Hasselkus 2004, Bye 1998). Professionals endeavour to strike a balance between supporting patients to do *'the things that matter and continuing life'* (Jacques and Hasselkus 2004:48) in the face of unpredictable deterioration. Patients struggle to maintain a sense of their identity as capable, problem solving individuals within a world of shrinking possibilities (Eva and Paley et al. 2009).

Current palliative care health policy proposes that rehabilitation is a useful process to help people cope with living while dying (NICE 2004, NCPC 2000). It has been specifically identified as a method of improving a patient's quality of life by:

'maximising their ability to function, to promote their independence and to help them to adapt to their condition' (National Cancer Action Team 2009:11)

Although rehabilitation is seen as important, it is suggested that patients' rehabilitation needs are *'poorly identified'* (Eva and Wee, 2010:161) in palliative care settings. This is partly due to a lack of understanding and clarity around the role rehabilitation can play in palliative care (Schleinich et al. 2008) and partly because of a lack of robust research evidence to demonstrate its value (or otherwise),(Eva and Wee, 2010). In addition, it is not clear how, or if, the process of rehabilitation might differ from rehabilitation in other settings where it has been established for longer (for example, the classic rehabilitation setting of spinal cord injury). In the 1980's, Dietz (1981) tried to address this. He argued that rehabilitation processes for people with cancer, which is often characterised by deterioration and unpredictability, needed to be adapted. He suggested that the goals of cancer rehabilitation could be categorised as: preventative; restorative; supportive or palliative. However, since then, little work has been done to identify theoretical models to underpin the rehabilitation process in cancer or palliative care. In contrast, over the last ten years, attention has been paid to developing theoretical underpinnings of rehabilitation in more traditional settings. In the next section I outline these models and discuss the specific challenges of applying them to palliative care.

2.4 Theoretical underpinnings of rehabilitation

Until recently, the process of rehabilitation has been described as *'somewhat theoretically undernourished'* (Siegert et al. 2005:1494)*.* Several authors have acknowledged that the term 'rehabilitation' is poorly defined and there is little guidance on its delivery or composition

(Playford et al. 2009, Wade 2009, Davis 2006, Wade 2005, Wade and de Jong 2000, Wressle et al. 1999) partly because it encompasses such a range of possible interventions, delivered by a number of different professionals in a variety of settings (Wade 2005). The WHO (2004:49) defines rehabilitation as:

> '*A proactive and goal-orientated activity to restore function and/or to maximise remaining function to bring about the highest possible level of independence, physically, psychologically, socially and economically*'.

Wade (2005) suggests that three integrated theoretical models are needed to help us describe and understand the rehabilitation process:

- An *illness model,* which provides a framework for thinking about illness and disability;

- A *process model,* which describes the process of rehabilitation;

- A *behaviour change model,* which explains the mechanisms by which people change their behaviour.

Figure 2 shows a conceptual diagram which represents the way in which the three models interact. The **illness model** (Number 1) helps professionals understand illness and its impact on the individuals they are working with. The **process model** (Number 2) helps professionals identify the individual components of the rehabilitation process and how they are pieced together. The **behaviour change** model (Number 3) provides possible explanations about the mechanisms by which patients and professionals are motivated to change their behaviour, which is a key component of rehabilitation. I will now describe each model and identify areas where work is needed to develop our understanding of the rehabilitation process in palliative care.

Figure 2 Interaction of models
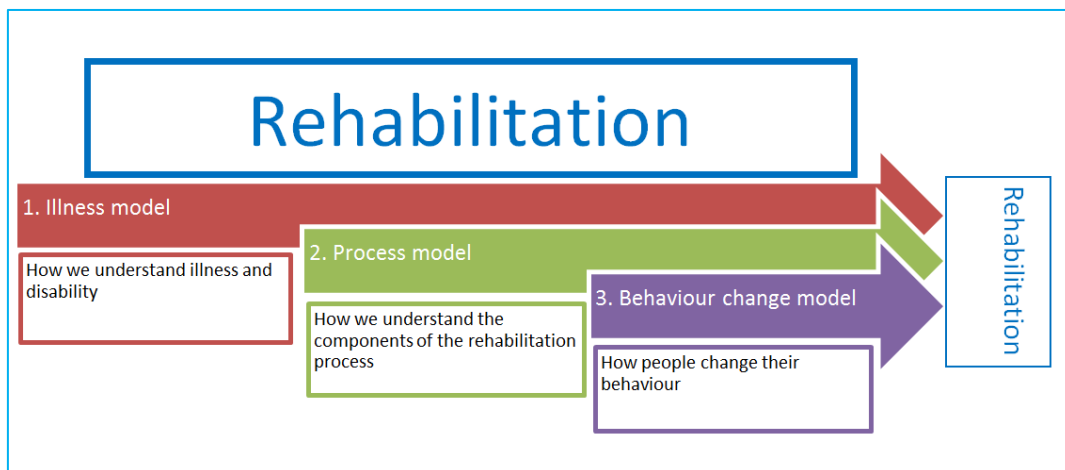
2.4.1 Illness model

The WHO International Classification of Functioning, Disability and Health (ICF) (WHO 2001) provides a framework which aims to provide an international, standard language for describing and measuring health and disability. Since its introduction in 2001, it has gradually become internationally recognised as a useful framework for describing and underpinning the rehabilitation process (Davis 2006, Barnes and Ward 2004, Bornman 2004, Waddell and Burton 2004). The ICF was developed from an earlier framework, the International Classification of Impairment, Disability and Handicap' (ICIDH), which was first published in 1980 (WHO 1980). Here I describe both frameworks because it is important to know how and why the ICF (the newer framework) evolved, particularly in relation to societal attitudes towards disability and in relation to understanding the impact of disability on a person's life.

The original framework (ICIDH) described the consequences of health conditions at three levels (Table 1).

Table 1 ICIDH framework levels (based on Bornman 2004:185)

Impairment	Any loss or abnormality of psychological, physiological or anatomical structure or function (*disturbances at organ level*).
Disability	The consequences of impairment in terms of functional performance and activity by the individual (*disturbances at the level of the person*).
Handicap	A disadvantage experienced by a given individual, resulting from an impairment or a disability that limits or prevents the fulfillment of a role that is normal (depending on age, sex and social and cultural practice) for that individual. The term handicap thus reflects interaction with, and adaptation to, the individual's surroundings (*disturbances at the level of society*).

The original ICIDH framework focused on the consequences of illness, which were understood to impact on each other in a linear progression (Figure 3):

Figure 3 ICIDH Framework
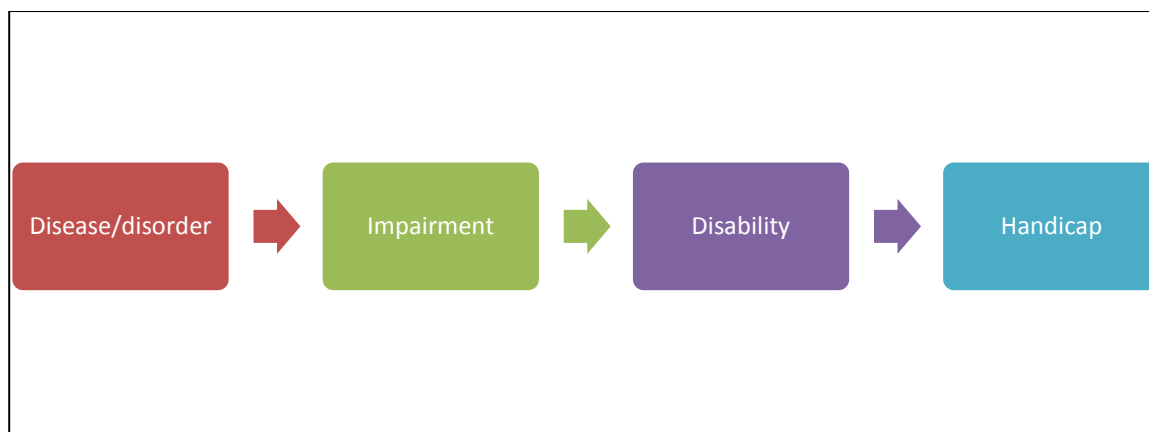
For example:

> *Mrs H, a person with Motor Neurone Disease (**disease/disorder**), has severe dysarthria (**impairment**). This results in her having difficulty making herself understood (**disability**) and consequently, she is unable to take part in conversations or to contribute towards discussions where decisions are made (**handicap**).*

This ICIDH provided healthcare professionals with a structure for targeting their rehabilitation interventions. For instance, a speech and language therapist might target therapy at the level of **impairment** (providing exercises for Mrs H to carry out in order to maintain speech intelligibility); **disability** (providing alternative methods of communication to enable Mrs H to make herself understood) or **handicap** (providing training for those in Mrs H's environment so that she is given more opportunities and time to contribute to discussions). Although widely acknowledged as a useful framework, the ICIDH had some limitations and was criticised, particularly by disability activists who make a distinction between a 'social' and a 'medical' model of disability:

- From a 'medical model' perspective, disability is regarded as a disease state which results in a person having an impairment which requires some kind of medical treatment (Waddell and Burton 2004).

- From a 'social model' perspective, disability is regarded as a limitation imposed by a society that discriminates against them in terms of attitudes and physical barriers (Barnes and Ward 2004).

The ICIDH was widely criticised as representing disability from a 'medical model' viewpoint. It was seen as discriminatory, a means of classifying and labelling people with disabilities, resulting in a form of oppression (Ustun et al. 2003). It was also criticised for over simplifying the concept of disability. The linear progression implied that the consequences of illness are straight forward and factors such as the person's environment, their experience of illness or other personal factors were not taken into account (Bornman 2004, Ustun et al. 2003, Johnston and Pollard 2001).

In response to the wide criticism of the ICIDH, the World Health Organisation developed the International Classification of Functioning Disability and Health (abbreviated to ICF, WHO 2001), an updated framework for describing a person's *functioning, disability* and *health*. This

framework has reframed the concepts of 'disability' and 'handicap' with the more positive concepts of 'activity' and 'participation'. This is based on a bio-psychosocial model, rather than a medical or social one, and takes into account the person's biological, psychological and social circumstances (Engel 1980). It also enables consideration of environmental and personal factors, as outlined below:

Figure 4 WHO ICF Framework

Interaction of Concepts

Health Condition (disorder/disease)

Body function&structure (Impairment) ⟷ Activities (Limitation) ⟷ Participation (Restriction)

Environmental Factors   Personal Factors
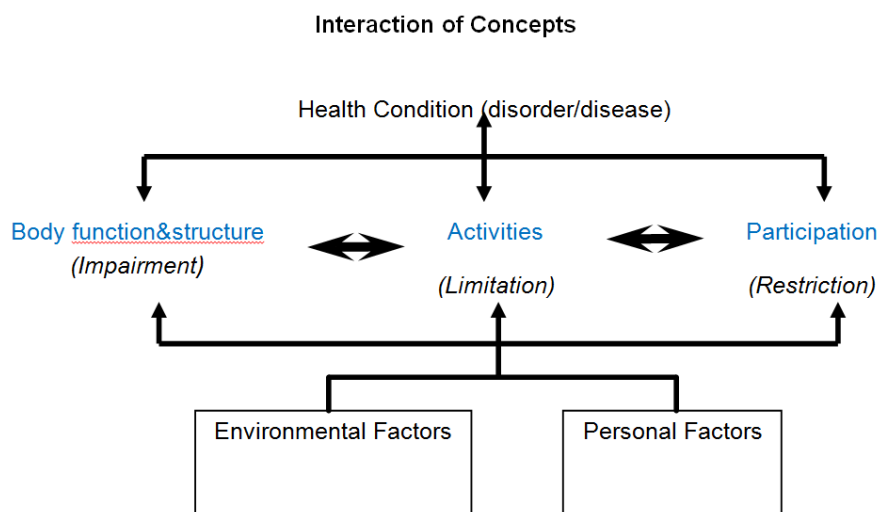
(WHO 2001:18)

If we revisit the example of Mrs H, it is possible to see how use of the ICF enriches possible rehabilitation interventions by the speech and language therapist and results in a more holistic approach.

> *Mrs H, a person with Motor Neurone Disease (**Health condition**), has severe dysarthria (**impairment**). This results in her having difficulty making herself understood (**activity**) and consequently, she is unable to take part in conversations or to contribute towards discussions where decisions are made (**participation**). She lives on her own (**environmental factor**) and feels strongly about remaining at home for as long as possible. She is also keen to maintain communication through speech rather than use an alternative method such as a high-tech communication aid (**personal factor**).*

Using the WHO ICF, the therapist can take into account personal and environmental factors when discussing rehabilitation goals. For example, given that Mrs H lives on her own, it may be important for her to have a method of contacting carers and relatives when she needs help. This intervention would be targeted at the level of Mrs H's environment, for example, providing suitable equipment, as well as training staff and family. Given that Mrs H also wants to maintain her speech intelligibility for as long as possible, the therapist might provide input at the level of impairment, giving advice on breath control, positioning and fatigue management. Given that speech intelligibility is likely to deteriorate, this could be done whilst exploring acceptable solutions for communication through other methods (input focused at the level of activity and participation).

The ICF provides a framework which helps the healthcare professional take a holistic view of the patient. This allows them to consider the impact of illness and disability in relation to activities that the person wishes to participate in, within the context of their environment and personal factors. This promotes discussion with the patient about areas they want to work on, thus lending itself to the goal setting process, which is central to rehabilitation. Using the ICF, rehabilitation goals can be set at the levels of impairment, activity, participation, or the environment. Personal factors such as an individual's preferences and coping style can also considered. Knowing which level interventions are targeted helps professionals to choose appropriate outcome measures, thus allowing them to measure the effectiveness or otherwise of their input. In the example given above, appropriate measures for the speech intelligibility goal would be using standardised dysarthria assessments before and after treatment. The goal targeted at the level of the environment would be more likely to be measured through quality of life measurements.

Although the ICF has become embedded in rehabilitation practice, it is not without criticism, particularly because it does not take into account issues relating to a person's quality of life or

the stage of their illness (Raghavendra et al. 2007, Wade 2007, Wade and Halligan 2003). Others have highlighted that it lacks sufficient detail in relation to enabling different professional groups to describe specific health conditions and also lacks conceptual clarity for describing disability (Bruyère et al. 2005). In addition to this, the language used in the ICF has been said to make it inaccessible to patients (Bornman 2004) and as a result it tends to be used from the point of view of professionals rather than the patient (Wade and Halligan 2003). Although the concepts of activity and participation are recognised as positive ways of describing the impact of disability, in practice, professionals can find it difficult to distinguish between the two, and this can result in confusion about where the professional should target their intervention (Raghavendra et al. 2007).

Relevance to palliative care

In palliative care, the healthcare team work together with patients and families to address their physical, psychological and spiritual needs (WHO 2004). This involves a team approach, with patients at the centre of care (WHO 2007). In many ways, the approach to care is similar to that of rehabilitation. Wade (2005:814) suggests that the goals of *rehabilitation* are to:

- Optimise the patient's social participation;

- Maximise the patient's well-being;

- Minimise relative's stress and distress.

These goals can be mapped to *palliative care*, which seeks to:

- Offer a support system to help patients live as actively as possible until death *(optimising social participation)*;

- Integrate the psychological and spiritual aspects of patient care *(maximise patient's well-being)*;

- Offer a support system to help the family cope during the patient's illness and in their own bereavement *(minimise relative's stress).*

Given that rehabilitation and palliative care share similar goals, it might be assumed that the same illness models could underpin both approaches, and that the WHO ICF would be particularly well placed to underpin rehabilitation in palliative care. However, until recently, little attention has been paid to the application of the ICF in palliative care rehabilitation. A recent retrospective chart review of the utilisation of physical therapy in a palliative care unit suggested that the main concept underpinning rehabilitation in palliative care was function, with an emphasis on impairment rather than activity and participation (Javier and Montagnini 2011). Whilst a rehabilitation approach to palliative care has been advocated in the UK, the key documents which promote it do not mention the ICF (NCPC 2006, NICE 2004, NCPC 2000). However, there are some areas in palliative care where ICF has been mentioned: cancer rehabilitation and degenerative neurological conditions (Helbostad et al. 2009, Gilchrist et al. 2009, Ness 2006, Cieza et al. 2004, Ward and Robertson 2003). Gilchrist et al. (2009) describe how ICF can be used to guide outcome measurement in oncology rehabilitation and emphasise the importance of professionals knowing where their intervention is targeted if they are to choose appropriate outcome measures. Ward and Robertson (2003) describe the application of ICF as a model to underpin rehabilitation in Parkinson's disease as well as its role in evaluating the effectiveness of such services. In this context, the ICF provides clarity for the whole team and helps professionals consider a combination of impairment based treatments (such as medication for pain and insomnia or treatments aimed at improving mobility or speech intelligibility) alongside input aimed at extending a person's level of activity and social participation (such as getting in and out of the car or using the telephone).

In summary, despite its limitations, the ICF provides a useful framework and a common language for rehabilitation professionals; it has contributed to an increased understanding and scrutiny in relation to where professionals target their interventions and how services are organised. Although not commonly used yet in palliative care, it has the potential to provide a foundation and language for understanding health and disability in relation to this setting.

However, an illness model is only one of three models that can be used to explain and describe rehabilitation. I now describe the process of rehabilitation, as Wade (2005) suggests, as a 'process model'.

2.4.2 Process model

Wade (2005) proposes that a model to explain the *process* of rehabilitation should outline what the *goals* of rehabilitation are and how it is *organised*. With the ICF framework in mind, Wade suggests that the goals of rehabilitation are to capitalise on an individual's participation in activities, by '*maximising a patient's behavioural repertoire; in other words by giving them the skills and equipment needed to minimize the limitation on those activities they need or wish to undertake.'* (Wade 2005:814). Several attempts have been made to map out the actual process of rehabilitation (Wade 2005, Gravell 2002, Scottish Intercollegiate Guidelines Network 2002, Steiner et al. 2002, Stucki and Sangha 1996) and there is broad agreement that it is an iterative cycle comprising: *assessment*, *goal setting*, *intervention* and *evaluation* (Figure 5).

Figure 5 The rehabilitation process
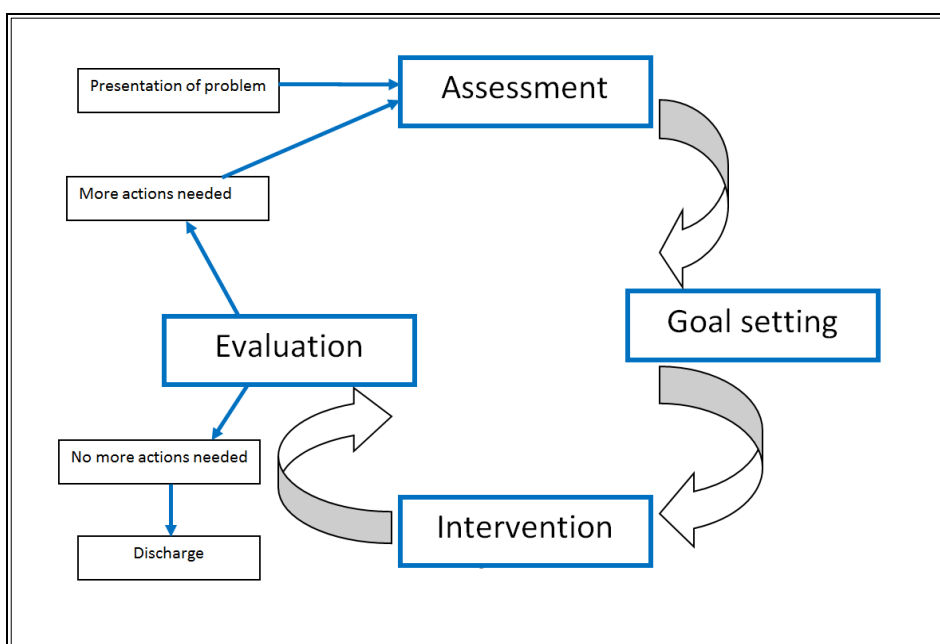
Although Figure 5 summarises what is widely agreed to be the process of rehabilitation, it is perhaps an over-simplification of what is a fundamentally complex process. Each phase relies on the multidisciplinary team working together bringing their individual professional expertise, particularly to the assessment phase. The *intervention phase* comprises data collection (from the assessment and goal setting phases) and the provision of support and treatment, often targeted at the levels of activity and participation (Davis 2006, Wade 2005). At this stage, interventions aim to encourage patients to *"take greater control of their own condition management with focused rehabilitation goals"* (Scottish Executive 2007:44). Following intervention, patients are reassessed and may be discharged (if their goals have been achieved) or new goals are identified, and so the cycle continues.

Relevance to palliative care

The iterative cycle of rehabilitation described above can and has been applied to rehabilitation in palliative care (NCPC 2000). However, given that patients health conditions are often changing at unpredictable rates, the time scales between stages are likely to be different compared to more usual rehabilitation settings. There is likely to be a continuous movement backwards and forwards between each stage, as a person's situation changes. This is alluded to in 'Fulfilling Lives', which states that:

> *"The process of assessment should be continuous, and respond quickly to the changing picture of the patient's life."* (NCPC 2000:8)

One of the problems with rehabilitation in the palliative care setting is that patient's needs are not always recognised and that rehabilitation services are not always *'readily available'* (Cheville 2009:62). In attempt to address this, care pathways for rehabilitation in different types of cancer have been developed by the National Cancer Peer Review Programme in England (National Cancer Action Team 2009). This guidance includes models which describe levels of support and assessment which should exist for rehabilitation in cancer care at

different stages of the disease (from diagnosis and care planning; treatment; post treatment; monitoring and survivorship; palliative care to end of life). The guidance highlights issues that professionals should focus on rather than the rehabilitation process itself, and little attention is paid to the complexity of the rehabilitation process. For example, in the rehabilitation care pathway for Brain and Central Nervous System cancer (National Cancer Action Team 2009), within the palliative and end of life care sections, areas of importance include: cognitive and psychological factors; communication; exercise and physical well-being; equipment provision; fatigue; information/support; mobility; nutrition; pain management; work, leisure and activities of daily living. The guidance presents as a 'to do' list rather than a presentation of the process of rehabilitation. This perhaps reflects that rehabilitation in palliative care is still in its infancy and practitioners and researchers are not yet asking the *'how to'* questions about the process, but are still focusing on the *'what is rehabilitation'* question. This is an area that requires development if rehabilitation in palliative care is to become more than a recipe or list of items which professionals need to 'do', without thinking about how they engage patients in the process and promote their active participation.

Goal setting as part of the rehabilitation process:

There is agreement that patient centred goal setting is a key component of the rehabilitation process (Playford et al. 2009, Wade 2005, Barnes and Ward 2004, Gravell 2002, Scottish Intercollegiate Guidelines Network 2002, Steiner et al. 2002). However, it is recognised as the most challenging and problematic part of the process, as it relies on collaboration between the multidisciplinary team, the patient and their family (Levack et al. 2006a, Siegert and Taylor 2004, Bradley and Bogardus et al. 1999). A recent conference identified areas of consensus and controversy around goal setting in rehabilitation (Playford et al. 2009). Areas of consensus were: that goal setting is a central component of the rehabilitation process; the need to establish a theoretical base for goal setting; that different patient groups *'may demand different models'* (Playford et al. 2009:343); and a need for further research to

identify the components of the goal setting process. Areas of controversy focused on the evaluation of goal achievement, whether or not goals should be achievable or ambitious, and the challenges of achieving patient-centred goal setting.

In spite of an emphasis in the literature about the importance of goal setting within rehabilitation, there is wide variation as to how it is carried out, its purpose and what it actually means (Levack et al. 2006a). Levack et al. (2006a:740) state that "*little agreement exists regarding the best way to undertake goal planning"*. They also highlight that a range of terms are used by professionals to describe 'goal setting' (for example, goal, objective, aim, care planning) and suggest that the process by which goals are set with individuals varies considerably between settings and practitioners. It is recognised that a clear theoretical underpinning for the *process* of goal setting needs to be identified. Without a clear process, goal setting can be marked by *"frustration, difficulty and perceived failure"* (Siegert and Taylor 2004:1175).

There appear to be two ways of approaching goal setting in rehabilitation. The first is to engage the patient in setting meaningful targets (goals), which they will be motivated to work towards so as to achieve a desired end. Here, underlying theory is most developed, at least within traditional rehabilitation (Scobbie, et al. 2011, Playford et al. 2009, Scobbie et al. 2009, Holliday et al. 2005, Siegert and Taylor 2004). I will discuss this in more detail under the heading of 'behaviour change models'. The other approach focuses on the use of goal setting as a method for measuring the outcomes of rehabilitation interventions, as described below.

Goal setting and outcome measurement:

Explicit goal setting methods such as Goal Attainment Scaling, the Canadian Occupational Performance Measure (COPM) and writing SMART goals are examples of approaches which incorporate outcome measurement into goal setting. The concept of SMART goals was introduced to goal setting in industry in the early 1980s (Doran 1981) and has since been

applied to rehabilitation (Barnes 2004). The acronym SMART originally stood for Specific, Measurable, Assignable, Realistic and Time-related, but since then, the initials have been associated with a wide range of different terms, some with much altered meanings (Wade 2009). Originally, SMART goals were associated with Locke and Latham's Goal Setting Theory (Locke and Latham 2002) with the focus on ensuring that goals were sufficiently specific to motivate people to achieve their goals. However, the emphasis has gradually moved towards outcome measurement, with the 'measurable' element of 'SMART' being regarded as crucial for ascertaining whether or not goals are achieved. As a result, professionals have become preoccupied with goals that are realistic, achievable and measureable and in some cases, this has led to the focus of goals shifting from being patient centred to more professionally focused (Barnard et al. 2010).

In her study which involved conversational analysis of goal setting interactions between professionals and patients, Barnard (2010) found that professionals modified patient's goals if they felt they were unachievable. They also reworded goals as they wrote them down to ensure that the impact of their rehabilitation interventions could be *measured*. Thus, the health professional's belief that goals should first and foremost be measurable and realistic, appears to have detracted from the partnership and patient centred aspects of goal setting, which some have argued is a central component of rehabilitation (Rosewilliam et al. 2011, Barnes and Ward 2004, Siegert and Taylor 2004, Scottish Intercollegiate Guidelines Network 2002).

Goal Attainment Scaling (GAS), which originated in the field of mental health (Malec 1999), has been applied to rehabilitation settings and is suggested as a feasible method of goal setting (Turner-Stokes 2009, Bouwens et al., 2009, Bovend'Eerdt et al. 2009). The method recognises that goals may be fully or partially achieved and involves the following steps:

1. Goal identification (patients and professionals discuss and identify goals)

2. Goal weightings (how important each goal is to the patient)

3. Expected outcomes of goals; this involves negotiation between the professional and patient about desired and likely outcomes following treatment. Outcome levels are rated as: 'better than expected' (+1); 'much better than expected' (+2); 'less than expected' (-1) and 'much less than expected' (-2)

4. A scoring baseline is defined in relation to the agreed goal (that is, where does the patient feel they are in relation to the agreed goal: 0,-1 or -2)

5. Outcome scores for each goal are rated.

The process is best explained through use of an example. Mr T has severe communication difficulties due to dysarthria following a stroke:

1. Identification of goals:

   a. 'to be able to communicate with family and friends using speech'

   b. 'to be able to use the telephone to talk to my daughter in Bournemouth'

2. Weighting of goals (in relation to importance)

   a. Mr T may weight both goals above as equally important, in which case they would be assigned a value of 1.

3. Expected outcomes are defined. Outcome levels are rated as: 'better than expected' (+1); 'much better than expected (+2); less than expected (-1) and much less than expected (-2)

   a. Goal 1 - 'to be able to communicate with family and friends using speech'

      i. +2 'family and friends will understand my speech 90% of the time'

      ii. +1 'family and friends will understand my speech 70% of the time'

      iii. -1 'family and friends will understand my speech 50% of the time'

      iv. -2 'family and friends will understand my speech 25% of the time'

b. Goal 2 - 'to be able to use the telephone to talk to my daughter in Bournemouth'

   i. +2 'I will be able to phone my daughter and talk to her without any help'

   ii. +1 'I will need help with dialling the phone number, but will manage to make myself understood on the phone to my daughter'

   iii. -1 'I will need someone with me to help me out when I call my daughter, in case she doesn't understand what I'm saying'

   iv. -2 'I can only speak to my daughter with help and about specific topics.'

4. A scoring baseline is defined in relation to the agreed goal (this is done through discussion with the patient, for example, Mr T may feel at the beginning of input that he is -2 for each goal)

5. Outcome scores for each goal are rated (scores are assigned as part of discussion between the professional and patient at the end of an episode of input and goal achievement can be tracked through the score achieved).

GAS has been used as a method of goal setting in a variety of rehabilitation settings (Bouwens et al. 2009, Hurn et al. 2006, Schlosser 2004). Its focus is on outcome measurement rather than the process of negotiating patient centred goals which impact on a patient's motivation and behaviour. GAS has been shown to be a reliable and valid outcome measurement in rehabilitation (Hurn et al. 2006), but has also been criticised because of its subjectivity and complexity, which makes it difficult to use, especially with patients who have cognitive and/or communication impairments (Bouwens et al. 2009). Although GAS provides rehabilitation professionals with a method of measuring goal achievement, it does not provide a theoretically informed framework for professionals to use by which to engage patients in setting rehabilitation goals. It is also problematic in terms of its application to rehabilitation in

palliative care, as the focus is very much on whether or not goals are achieved, which may not always be possible in a palliative care context.

The COPM (Law et al. 1990) is a standardised instrument, developed in Canada, which is used as a goal setting and outcome measurement tool by occupational therapists and multidisciplinary rehabilitation teams internationally. It provides a formal method of setting goals with patients, who are asked to identify activities which are important to them, categorised under self-care, productivity or leisure issues. Patients are asked to rate the activities in terms of importance (1= not important – 10 = very important) before rating their own performance and satisfaction on a scale of one to ten (1 = not able/not satisfied – 10 = able to perform extremely well/extremely satisfied). From this, priorities for intervention can be identified. Following intervention, patients re-rate their goals in relation to importance, performance and satisfaction, giving a measurement of the effect of therapy corresponding to the original goals.

Again, this is best explained through use of an example. Take Mr T. He had identified communication with family and friends as an important issue under leisure, rating it as 9 for importance. He rates his performance as 3 and satisfaction with his performance as 4. The issue of communication with family and friends can be discussed in the context of other areas that Mr T has identified as important, and decisions are made about which goals Mr T wants to work on, thus setting the agenda for rehabilitation. Goals can then be reviewed and re-scored after an agreed period of input.

The COPM has been used effectively in a range of contexts (Colquhoun et al. 2012, Enemark and Carlsson 2012, Gustafsson et al. 2012, Carswell et al. 2004, Watterson et al. 2004) and has been shown to help professionals work in a more patient centred way (Chen et al. 2002). The structure of the process leads professionals to ask patients about issues which are important to them, thus making the goal setting process more patient led (Gustafsson et al. 2012).

Although it originates from occupational therapy, the COPM has been used successfully by multidisciplinary teams (Wressle et al. 2003). However, the terminology used within the framework is based on language used by occupational therapists. It is based on the Canadian Model of Occupational Performance, a person centred model which looks at the relationship between the person, their occupation and their environment (Townsend and Polatajko 1997, Law et al. 1990). It might be inaccessible for people from other professional groups. However, it does provide a theory based structure for engaging patients in the goal setting process and has been shown to be a valid, reliable and responsive tool for outcome measurement which is now used in a variety of clinical settings (Carswell et al. 2004). Although this is the case, the COPM focuses mainly on goal identification *(what do you want to work on?)* and measurement of goal achievement *(how did you do?)*. It does not provide any guidance on the action and coping planning phases of the goal setting process *(how will we go about achieving your goal?)*, which are now recognised as important components of the goal setting process, particularly in relation to supporting behaviour change in patients (Scobbie et al. 2009).

Relevance to palliative care

In palliative care, goal setting is not exclusively linked to rehabilitation. It is used more broadly as a mechanism for guiding multidisciplinary working and ensuring that decision making is patient led (Needham and Newbury 2004, Gum and Snyder 2002, Lunt and Jenkins 1983). It is also referred to as a way to help patients find meaning within the context of life threatening illness (Jacques and Hasselkus 2004). I discuss these broader applications of goal setting in palliative care in section 3.1.

The use of goal setting as a method of measuring the impact of rehabilitation interventions has been explored in palliative care. One practice-based study (Needham and Newbury 2004) audited the use of goal setting as an outcome measure. Goals were set with patients on admission, and goal achievement at the end of input was noted. Within the paper, no detail is

given about how goals were identified with patients, although one of the criteria within the audit was that goals *'should be achieved wherever possible/realistic'* (Needham and Newbury 2004:446), suggesting that SMART goals were being used. Not surprisingly, the study demonstrated a high level of goal achievement (either fully or partially) from the perspective of the patient, the family and the professional. This highlights one of the problems inherent in using goal setting as a method of measuring outcomes. If professionals limit goals only to those which are achievable, as they did in Needham's study, then they are more than likely to be achieved.

GAS has been used to measure outcomes during in-patient rehabilitation for patients with Multiple Sclerosis (Khan 2008). In Khan's study, use of GAS focussed on patients who were *"living at home, were active and mobile in the community"* (Khan 2008:653), so were not palliative care patients. However, there is an on-going programme of work at the Dame Cicely Saunders Institute which aims to develop and evaluate patient centred outcome measures for use in rehabilitation and palliative care settings. They are currently promoting more consistent use of GAS and GAS-Light (a simplified version of GAS) with a range of people who have long term neurological conditions. This research in its early stages and currently it is not clear if GAS can be used with patients who are in the later stages of MS (Khan 2008).

The use of COPM has been explored in palliative care. Watterson et al. (Watterson et al. 2004) conducted a retrospective chart review to investigate which types of goals were important to patients in a cancer rehabilitation centre. The chart review focused on the problem identification, rating and goal setting stages of the COPM rather than the outcome measurement aspect of it. It was found that COPM could be used successfully to help patients identify goals and that these were predominantly based around self-care. This study suggests that COPM can and has been applied to palliative care settings, although no data has been provided about its use as an outcome measurement tool.

I discuss the use of both COPM and SMART goals in relation to palliative care in more detail in chapter 3.

2.4.3 Behaviour change models

Wade (Wade 2005) proposes that behaviour change models should be considered in relation to rehabilitation. However he does not elaborate on this, except to say that behaviour change *'must underpin most if not all rehabilitation treatments'* (Wade 2005:812)*.* Goal setting has been identified as a central mechanism for underpinning behaviour change in rehabilitation (Playford et al. 2009, Levack et al. 2006a, Levack, et al. 2006b, Barnes and Ward 2004). In April 2009, an entire edition of the journal Clinical Rehabilitation was dedicated to the subject of goal setting applied in rehabilitation practice. This was significant as it signalled recognition of a) the importance of goal setting as part of the rehabilitation process and b) the complexity of the goal setting process. In their consensus report, Playford et al. (2009) concluded that although some progress has been made in developing theory to underpin goal setting, current models and theories provide *'only incomplete explanation of how goals can be or should be applied to clinical rehabilitation.'* (Playford et al. 2009:337).

Levack et al. (2006b) conducted a systematic review of the literature, aiming to determine the effectiveness of goal planning in rehabilitation. They were unable to draw generalizable conclusions about the effectiveness or otherwise of goal planning for several reasons: the included studies lacked consistency around definitions of goal setting and rehabilitation; and methodological limitations such as poor baseline measurement, description of patients and definitions of 'usual practice' made it difficult to ascertain whether or not goal planning had an effect on outcomes. They also make it clear that goal setting is used for different purposes in rehabilitation (both for outcome measurement and as a mechanism for behaviour change). This should be taken into consideration when evaluating studies.

Several authors have recognised the lack of underpinning theory in relation to goal setting as part of behaviour change, and this is has been identified as an area which requires further work (Rosewilliam et al. 2011, Wade 2009, Wade 2005, Siegert and Taylor 2004). Scobbie et al. (2009) have made the most significant advances in this area with a programme of work which aims to identify and develop theory based goal setting in rehabilitation. As a first step, they conducted a review of the literature which aimed to identify and apply psychological theory to goal-setting in rehabilitation. They used robust, explicit and systematic methods to search the literature for papers which proposed the use of specific theories of behaviour change in relation to goal setting. They identified 24 papers that met their inclusion criteria and found that a total of five theories were commonly used to underpin the process of goal setting in rehabilitation. These were: (i) Social Cognitive Theory, (ii) Goal Setting Theory, (iii) Health Action Process Approach, (iv) Proactive Coping Theory and (v) Self-regulatory Model of Illness Behaviour. Each theory was appraised and compared on the basis of *'key constructs, clinical utility and empirical evidence'* (Scobbie et al. 2009:329).

The key constructs within each theory are outlined below (Table 2).

Table 2 Key constructs from behaviour change theories

Theory	Key constructs
Social Cognitive Theory (Bandura 1997)	Self-efficacy Outcome expectancies
Goal Setting Theory(Locke and Latham 2002)	Goal attributes: specificity and difficulty influence goal related performance Appraisal Feedback
Health Action Process Approach (Schwarzer 1992)	Action planning Coping planning

	Self-efficacy Outcome expectancies
Proactive Coping Theory (Aspinwall and Taylor 1997)	Action planning
Self-Regulatory Model Of Illness Behaviour (Levanthal, described in Myers and Midence 1998)	Illness representations Coping response (action planning) Appraisal

There is overlap between the key constructs from each of the five theories, and, having appraised the evidence from the papers included in their review, Scobbie et al. (2009) concluded that Proactive Coping Theory and the Self–regulatory Model of Illness Behaviour did not add anything which was clinically useful or significantly different from the other theories. Although people's health beliefs and illness representations might be expected to influence how people cope and respond to illness, in the two included studies, this appeared to make no difference to people's adherence to either taking medication or creating action plans. Scobbie at al (2009) identified three core theories of behaviour change which were relevant to goal-setting in rehabilitation: Social Cognitive Theory; Goal-setting Theory and Health Action Process Approach. The final three core theories comprise seven key constructs: Self-efficacy; Outcome expectancies; Goal attributes (difficulty and specificity); Action planning; Coping planning; Appraisal and Feedback (Table 4). In the next section I describe each of these theories, and outline the key constructs included in each one.

a. Social Cognitive Theory (Bandura 1997)

Two key constructs within Social Cognitive Theory (Bandura 1997) are self-efficacy and outcome expectancies. Bandura proposes that people's beliefs about what they can achieve have a strong influence on their behaviour. Someone with low self-efficacy will lack

confidence in his or her ability to achieve a goal, which will impact on their motivation to work towards it, possibly resulting in avoidance of goal related behaviours altogether. For example, following a stroke, a patient might set themselves a goal of walking to the local shops. Their confidence in being able to achieve this goal may be low. They might feel more confident about achieving a goal such as walking to the bathroom and would therefore be more motivated to start working towards this. Bandura (1997) explains outcome expectancies as beliefs that certain behaviours will lead to desirable outcomes. In practice, this means that in order to be motivating, goals should be relevant to the person, with a perceived benefit for them. In the example above, achieving the goal of being able to walk to the bathroom will result in increased independence and privacy for the patient. Self-efficacy and outcome expectancies lead to increased motivation to work towards goals and, if they are achieved, lead to mastery experiences, which in turn increase self-confidence and motivation.

b. Goal Setting Theory (Locke and Latham 2002)

Goal Setting Theory originated in industry in the 1980's, where it was used to motivate employees to be more productive. It is based on the premise that if a person consciously decides to work towards a goal, this effects their subsequent actions. Many studies have found that people try harder to achieve goals if they believe they are difficult and they will be less motivated to work towards goals which they perceive as too 'easy' (Locke and Latham 2002). Goal related behaviour is also enhanced if goals are clearly specified, so specific, difficult goals are more motivating than general 'do your best' goals. For example a specific goal such as being able to walk to the bathroom will be more motivating and tangible to a patient than a general goal to 'improve mobility'. In Goal Setting Theory, the importance of feedback on performance is also emphasised. People use information gained from progress in relation to their goals to make decisions about future goals.

c. Health Action Process Approach (Schwarzer 1992)

The Health Action Process Approach (HAPA) recognises that often there is a gap between what people intend to do and what they actually do in practice. In HAPA, Schwarzer (1992) postulates that health-related behaviour change involves two stages: motivation (deciding to make a change/goal setting) and volition (which involves planning, initiating and maintaining change). The first stage is closely linked with self-efficacy and outcome expectancies. The second relates to self-regulation and involves action planning and coping planning. In an action plan, the steps towards initiating a goal-related behaviour are explicitly marked out. In a coping plan, potential problems and barriers to goal achievement are identified and proactive plans are made so that problems encountered can be coped with. An example of an action and coping plan is provided in Table 3:

Table 3 Example of an action and coping plan

Action plan:	I will go swimming during my lunch break twice a week.
Potential problems:	I may feel too hungry at lunch time. I might not feel like going swimming.
Coping plan:	Take a banana and eat it at 11am. Arrange to go swimming with a friend – meet them at the swimming pool, then there is no excuse.

By making a pro-active coping plan, the gap between intentions and behaviours is reduced. Goals, action and coping plans can then be reviewed in light of progress.

2.4.4 Goal setting and Action Planning framework (G-AP)

Scobbie et al. (2011) used causal modelling to develop a theory-based Goal setting and Action Planning framework (G-AP) for use in rehabilitation settings. Having identified the relevant theories (described above), Scobbie et al. developed a theory based goal setting model for use by a multidisciplinary rehabilitation team. They consulted with a team of nine

rehabilitation professionals (of which I was a member), who contributed to the model development through discussion and then applied it to a convenience sample of six patients. The model was then refined, resulting in a practice framework which could be described and used by the rehabilitation team. The resulting framework (G-AP) comprised four 'intervention points', which could be mapped to specific theoretical constructs, which made 'sense' to clinicians and appeared to work in practice, as outlined in Figure 6.

Figure 6 G-AP Framework
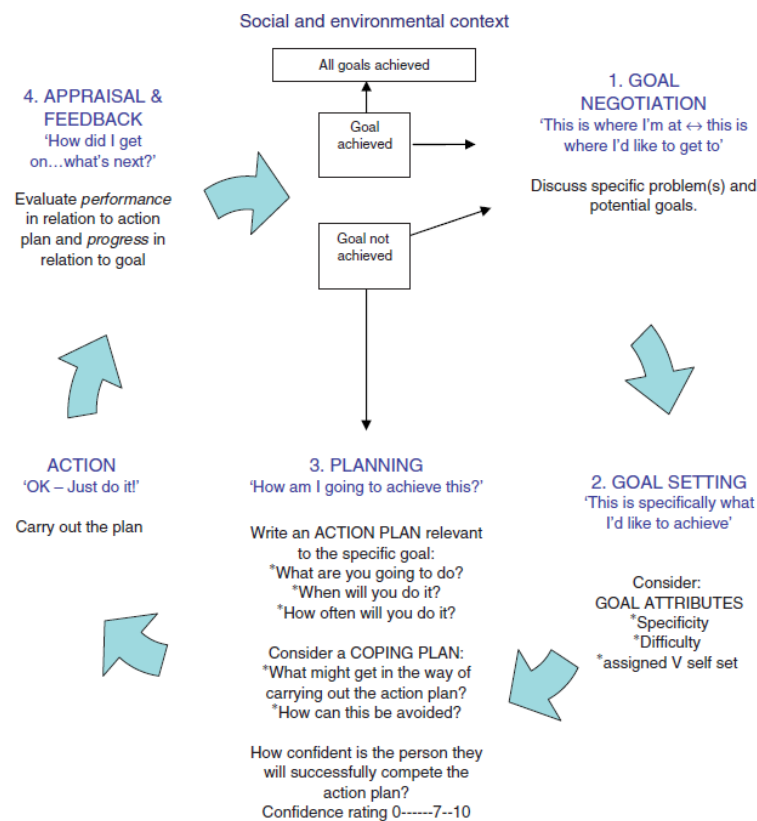
(Scobbie et al. 2011:447)

The key constructs for maximising behaviour change for each stage of the process were identified and are summarised in Table 4.

Table 4 Key constructs underpinning each stage of G-AP

Stage	Construct
Stage 1 (Goal negotiation)	Self-efficacy Outcome expectancies
Stage 2 (Goal setting)	Goal attributes (specificity and difficulty)
Stage 3 (Action and coping plan)	Action planning Coping planning Self-efficacy
Stage 4 (Appraisal and feedback)	Appraisal Feedback

This framework has been used in one community rehabilitation team (Scobbie et al. 2011), and the acceptability and feasibility of this theory based framework is now being tested in a wider range of stroke rehabilitation teams. I was directly involved in the development of G-AP, and I knew as a clinician that it worked in practice, and appeared to help the multidisciplinary team to work together as a team (although I was aware that this had not been tested empirically). As a clinician, I could understand and apply the theories upon which it was built.

Relevance to palliative care

The G-AP framework described above was researched and developed for use in stroke rehabilitation and its application to palliative care may be limited. However, both policy and scholarship agree on the importance of rehabilitation in palliative care and, as I have outlined, our understanding of the theoretical basis for rehabilitation in palliative care is poorly developed. Given that it is agreed that goal setting provides the scaffolding on which rehabilitation interventions are built (Playford et al. 2009, Levack et al. 2006a, Levack et al. 2006b, Barnes, Ward 2004), G-AP may provide a useful starting point for helping us to

understand the theoretical underpinnings of goal setting in the context of palliative care. However, because the disease trajectory in palliative care is different to that of stroke rehabilitation (traditional rehabilitation pre-supposes the potential for recovery and improvement, whilst palliative care assumes a deteriorating and unpredictable trajectory) there are likely to be differences relating to definitions, purposes and theoretical underpinnings of goal setting.

The next steps to develop our understanding of goal setting in palliative care are to a) carry out a review of the literature on goal setting in palliative care (Chapter 3) including relevant theories that may help us understand the process; and b) carry out a study to investigate current goal setting practice in one palliative care setting (Chapters 4 and 5).

STAGE 1: LITERATURE REVIEW

Chapter 3: Goal setting in palliative care: a structured literature review.

3.1 Introduction:

In chapter two I outlined the importance of rehabilitation and goal setting as components of contemporary palliative care. Although they have been specifically acknowledged in policy as key elements of palliative care, until recently, little attention has been paid to how this translates into practice. In their report on the role of rehabilitation in helping people with cancer to live actively after diagnosis and treatment, the National Cancer Action Team highlight the importance of rehabilitation at all stages of cancer care. They suggest that rehabilitation should include: *"timely access to appropriate elements of rehabilitation based on accurate holistic needs assessment, and shared goal setting with the patient"* (National Cancer Action Team 2013:7). Although goal setting is highlighted as a key component of cancer rehabilitation, there is no explanation about how this should be delivered or agreement about which theories should underpin the process.

In palliative care, goal setting is not only associated with rehabilitation; it has also been suggested to have an impact upon patient centred care (Old and Swagerty 2007, Fins 2006) and multidisciplinary team working (The National Council for Palliative Care 2000). It has also been linked to helping people gain mastery over their illness (Taylor 1983), maintain a sense of hope; (Buckley and Herth 2004); and enhance resilience (Monroe and Oliviere 2007). The relevance and reach of goal setting in palliative care appears to extend beyond the confines of rehabilitation, and it may be understood and used in practice in different ways and for different purposes. Goal setting is recognised in policy as an important component of palliative care, but little work appears to have been done to define or understand it. As a first

step to understanding the meaning and purpose of goal setting in palliative care, I conducted a literature review which aimed to investigate:

1. What is the range and quality of the published literature on patient-centred goal setting in palliative care?

2. What are the main themes contained within this literature in relation to patient centred goal setting?

3. What is the conceptual or theoretical basis underpinning goal setting in palliative care?

In this chapter, I describe the methods used to carry out the literature review and discuss the findings.

3.2 Methods

To determine whether or not a systematic literature review of goal setting in palliative care had already been done, I conducted a preliminary search of the literature. I searched the Cochrane Database of Systematic Reviews, the Database of Abstracts of Reviews of Effects (DARE) and the Joanna Briggs Institute in November 2010 using the search terms 'goal setting' and 'palliative care'. This search confirmed that a systematic review had not been carried out in this topic area and suggested that very little good quality empirical research exists in this area. For this reason, I hypothesised that a systematic review of only experimental studies was unlikely to identify many useful papers. Instead, I took a broader approach, allowing for other empirical research using a range of research designs, as well as more conceptual literature to be considered. I followed systematic and transparent procedures for carrying out a structured review (Petticrew and Roberts 2006, Arksey and O'Malley 2005) and was guided by Thomas et al. (2004) and Hawker et al. who describe a method of *'reviewing disparate data systematically'* (Hawker 2002:1287). The process followed involved five steps, outlined below:

1. Identification of inclusion criteria;

2. Search for relevant studies;

3. Critical appraisal;

4. Charting the data;

5. Collating, summarising and reporting results.

(Based on Arskey and O'Malley 2005:8/9 and Hawker et al. 2002:1286)

In this way I endeavoured to ensure that, as far as possible, a systematic and rigorous approach was taken and that all the relevant literature was identified, critically appraised and synthesised. I now describe the methods used to achieve this before I discuss the findings.

3.2.1 Identification of inclusion criteria

This was an iterative process during which I refined inclusion criteria following my initial searches. For example, the WHO definition of palliative care is*: "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness"* (WHO: http://www.who.int/cancer/palliative/definition/en/). This is a very broad definition, and resulted in large numbers of papers being retrieved, many of which were concerned with the management of chronic, long term health conditions or the management of early stage, curable cancer. For example, papers were retrieved about people in the early stages of Chronic Obstructive Pulmonary Disease (COPD) and about women who had survived breast cancer. Following discussion with my supervisors, we decided to only include papers concerned with patients with advanced, progressive, life threatening disease, as this study focuses on goal setting with patients who are admitted to the hospice with advanced disease and limited life expectancy. Papers were included if they focused on patients with advanced, progressive life threatening illness or if they had 'terminal care' in the title or abstract. Use of the term 'goal setting' resulted in retrieval of large numbers of papers about preferred treatment options and advanced care planning so I refined the definition of

goal setting to focus on goals that were patient centred and based around activity. The rationale for this decision was that I was primarily interested in goal setting in the context of rehabilitation in palliative care (in relation to living as actively as possible) rather than future treatment options and preferences about place of death.

The final search terms and inclusion/exclusion criteria that we agreed are outlined in Figures 7 and 8. Papers were included if they met all the inclusion criteria outlined in Figure 8. No restrictions were placed on study design or paper type.

Figure 7 Structured literature review: Search terms used

"goal setting" with synonyms "Rehabilit*" (using truncation in order to pick up words such as rehabilitate); "goal planning"; "Care planning"; "Goal attainment" ; "Goal achievement"

Combined with:

"palliative care" (using 'adj' operators in order to pick up phrases such as palliative patients, care of the terminally ill) with synonyms "terminal care"; "hospice care"; "end of life" and "life threatening illness"

Figure 8 Structured literature review: inclusion and exclusion criteria

Inclusion criteria

(i) Papers which focused on patient centred goal setting (specifically, goals based around activity);

(ii) Papers based in or about palliative care for patients with advanced, progressive life threatening disease;

(iii) Papers which were conceptual, opinion, practice-based or used quantitative, qualitative, mixed research methods or were literature reviews and

(iv) papers published in a peer review journal

Exclusion criteria:

Papers which were:

 a) not written in English and;

b) published prior to 1970 (because the field of palliative care has only been established within healthcare over the last 40 years (Clark 2007).

3.2.2 Searching for relevant papers

Searches were carried out between November 2010 and January 2011 using MEDLINE, PSYCHINFO, EMBASE, CINAHL, ASSIA and Google Scholar databases. Titles and abstracts of the papers were retrieved, screened and duplicates were deleted. Obviously irrelevant papers were excluded at this stage. In order to ensure that studies were not missed and the process of screening papers was rigorous, systematic and consistent (Petticrew and Roberts 2006), 10% of the rejected papers were checked by one of my supervisors. Further papers were located by hand searching reference lists of included papers.

The results of the search are shown in Figure 9.

Figure 9 Results of the literature search

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┌─────────────────────────────────┐
│   3205 papers retrieved from    │
│      electronic databases:      │
│                                 │
│   •  578 MEDLINE                │
│   •  354 PSYCHINFO              │
│   •  748 EMBASE                 │
│   •  322 CINAHL                 │
│   •  153 ASSIA                  │
│   •  1050 Google scholar        │
└─────────────────────────────────┘
                │              ┌──────────────────────┐
                │──────────────│  Duplicates removed   │
                │              │                      │
                ▼              │      n = 2186        │
┌─────────────────────────────┐ └──────────────────────┘
│  1019 articles screened by  │
│       one reviewer          │
└─────────────────────────────┘
                │              ┌──────────────────────┐
                │──────────────│ Rejected after initial│
                │              │      appraisal        │
                ▼              │                      │
┌─────────────────────────────┐ │       n = 897        │
│                             │ └──────────────────────┘
│    Leaving 122 articles     │ ┌──────────────────────┐
│                             │ │ Rejected after full  │
│                             │ │    papers read       │
└─────────────────────────────┘ │ (10% of these checked │
┌────────────────────┐  │       │   by a supervisor)   │
│ Papers retrieved   │──┤───────│                      │
│ from reference     │  │       │      n = 108         │
│ lists              │  │       └──────────────────────┘
│      n = 2         │  │
└────────────────────┘  ▼
        ┌─────────────────────────────┐
        │      Kept: n= 16            │
        └─────────────────────────────┘
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3.2.3 Quality appraisal

The search strategy was broad in terms of methodologies included, and as a result, a range of research papers as well as opinion, conceptual and practice based papers were identified. I carried out quality appraisal in two steps. Firstly, I categorised included papers according to type. This was done using Kolehmainen at al's categorisation flow chart, which was modified to include 'literature review' as a separate category (Kolehmainen et al. 2010:49) (Figure 10).

Figure 10 Structured literature review: categorisation flow chart

(Based on Kolehmainen at a 2010)

1. Is there a description of research design and research methods?

Yes

No

2(a) What type of research methods were used?

2 (b) Is the paper a systematic review of the literature?

3 (a) Does the paper present conceptual ideas in a form of a 'whole', which includes discussion about possible relationships between concepts and the 'whole'?

3 (b) Is it a description of an audit or a specific project embedded in real

3 (c) Does the paper list ideas, suggestions or recommendations without explicit consideration to potential relationships or to the 'whole'?

Quantitative research

n = 4

Mixed – methods

n = 1

Yes

Qualitative research **n = 3**

Literature review

n = 1

Conceptual paper **n = 3**

Practice-based project/audit **n = 3**

Opinion paper

n = 1

Once papers had been categorised, I quality appraised each of the research papers. Given that I was appraising papers which used a variety of research methods, this was particularly challenging. I wanted to capture the broad quality of each paper, as well as its applicability or relevance to this study, (i.e. did it shed light on how goal setting is understood and used in palliative care). In order to do this, I used a quality appraisal tool, developed by Duncan et al. (Duncan and Murray 2012) which enabled me to grade each study by the quality of sampling, data collection and analysis. Each paper was also graded according to its applicability to the study. My supervisors and I were aware that this type of quality appraisal is subjective, so we minimised the risk of bias using the following process:

1. Quality appraisal was carried out by myself and a supervisor, who graded each paper separately.

2. Results were compared and any differences were discussed. If possible, consensus was reached.

3. If consensus could not be reached, my second supervisor adjudicated.

Criteria for quality appraisal and applicability are summarised in Table 5.

Table 5 Structured literature review: quality appraisal criteria (based on Duncan and Murray 2012)

Description of type of sampling method used in each paper	Description of data collection and analysis	Data Quality	Applicability
Convenience/Purposeful/ Random/Theoretical	**++ (Good**: Description is clear and contains sufficient detail allowing ease of precise repetition)	**Different sources used:** Data collected at more than one time-point, or via multiple standardised questionnaires.	**Highly Applicable**: Content fits well to current study
	+ (Some: Description is clear but further required to aid clarity/allow precise replication)	**Allows complexity:** Data is rich enough to allow deeper analysis than description/frequency information, or allows the comparison between groups or different participants	**Applicable:** Some elements fit with the current study
	- (Partly: Insufficient description of method or inappropriate method used for study aims; precise replication based on published information would not be possible)	**Simple:** Data is mainly descriptive (whether collected qualitatively via structured means or via quantitative questionnaires)	**Limited applicability:** Only relevant to the setting descried in the paper

Non research papers were graded according to their applicability to the research questions, using the criteria in Table 5.

Summaries of research and non-research papers are provided in Tables 6 and 7 respectively. In each table a column is provided outlining the theoretical underpinning or concepts discussed in each paper.

Table 6 Structured literature review: summary of research papers

Author, year and country	Aim of paper	Study type	Theoretical underpinning/ concepts discussed	Sampling method	Description of data		Data Quality	Applicability	Overall rating
					Collec tion	Analy sis			
Benzein and Saveman, 1998, Sweden	To describe nurses' perception of hope among cancer patients in palliative care	Qualitative study – telephone interviews with nurses.	Concept of hope (nursing perspective)	Purposeful	+	+	Simple	Applicable	Low
Bye, 1998, Australia	To examine the perspectives of occupational therapists working in palliative care, to investigate a potential contradiction between occupational therapy principles and assumptions and needs of people with terminal illness	Qualitative study – using interviews and observations	Affirming life: Preparing for death	Purposeful	++	+	Allows complexity	Highly applicable	High
Czar, 1987, USA	To compare two goal setting processes - Mutual Goal setting (MGS) and Nurse-Determined Goal setting (NDGS), to find out if MGS results in a more positive behavioural change in the presence of a life	Quasi-experimental study.	Behaviour change through goal setting	Convenience	++	+	Allows complexity	Highly applicable	High

Author, year and country	Aim of paper	Study type	Theoretical underpinning/ concepts discussed	Sampling method	Description of data		Data Quality	Applicability	Overall rating
					Collec tion	Analy sis			
	threatening illness and if the stress experienced by the individual influences the person's behaviour change.								
Herth 1995, USA	To identify and compare the use of hope-engendering interventions employed by hospice and home health care nurses in their care of terminally ill clients.	Survey	Concept of hope (nursing perspective)	Convenience	++	+	Simple	Applicable	Medium
Jacques and Hasselkus 2004, USA	To gain an understanding of occupation as it is created and experienced by people who are dying.	Qualitative – ethnographic study (participant observation, interviews and document review)	Occupation at the end of life	Convenience	++	+	Simple	Applicable	Medium
Kaldjian et al. 2009, USA	To identify and recommend the most commonly articulated goals of care from the literature.	Structured literature review	Unclear	N/A	-	-	N/A	Limited applicability	Low

Author, year and country	Aim of paper	Study type	Theoretical underpinning/ concepts discussed	Sampling method	Description of data		Data Quality	Applicability	Overall rating
					Collection	Analysis			
Lunt and Jenkins, 1983, UK	To develop a method for co-ordinated goal setting in terminal care.	Retrospective chart review	Unclear	Convenience	+	+	Simple	Highly applicable	Medium
Schleinich et al. 2008, Canada	To develop and pilot test a questionnaire to identify palliative patients' priorities for rehabilitation	Mixed methods – Questionnaire including closed and open questions	Canadian Model of Occupational Performance	Convenience	++	++	Allows complexity	Limited applicability	High
Watterson et al., 2004, UK	To investigate occupational performance goals identified as being important by patients in a cancer rehabilitation centre, using the Canadian Occupational Performance Measure.	Retrospective chart review	Canadian Model of Occupational Performance	Convenience	++	+	Simple	Applicable	Medium

Table 7 Structured literature review: summary of non-research papers

Author, year and country	Aim of paper	Type of paper	Theoretical underpinning/concepts discussed	Applicability
Abrahm et al. 2008, USA	To illustrate how rehabilitation and goal setting can help patients cope with transitions at the end of life	Practice based case study	Unclear	Limited applicability
Della Santina and Berstein 2004, USA	To provide a framework for whole patient assessment and goal planning	Conceptual	Multi-dimensional models of suffering	Applicable
Gum and Snyder 2002, USA	To explore hope theory in relation to how people cope with terminal illness	Conceptual	Hope theory (psychological perspective)	Highly applicable
Kasvven-Gonzalez et al. 2010, USA	To illustrate how quality of life can be improved through rehabilitation at the end of life	Practice based	Unclear	Applicable
Leung et al. 2009, Canada	To present a conceptual model that differentiates expectations from hope	Conceptual	Hope theory (psychological perspective)	Applicable
Needham and Newbury 2004, UK	To audit the use of goal setting as a measure of outcome in an inpatient palliative care unit	Practice based	Unclear	Highly applicable
Weissman et al. 2010, UK	To give practical examples of how to set goals with patients at the end of life	Opinion	Unclear	Limited applicability

3.2.4 Charting the data

Following quality appraisal and initial data extraction, I used Framework analysis (Framework) (Ritchie and Lewis 2003, Ritchie and Spencer 1994,) to structure data analysis. Since it was first developed, it has been widely used as a method of data analysis within social and health related research, mainly with data collected by qualitative interview or focus group discussion. I chose Framework as a method of analysis for the review of the papers identified from this search because it would provide me with *"systematic and visible stages to the analysis process"* (Lacey and Luff 2001:9) which could be traced back, providing clarity about how results have come about and from which data. Although the key stages of the process are mapped out, Framework also allowed me some flexibility, providing a method of organising and displaying the data, in this case relevant sections extracted from included papers in the review, but still allowing meanings to develop and connections to be made during the analysis process.

The key stages of Framework are outlined below:

Stage 1: Familiarisation

Stage 2: Identifying a thematic framework

Stage 3: Indexing

Stage 4: Charting

Stage 5: Mapping and interpretation

(Lacey and Luff 2001:11)

I read each paper in-depth (Stage 1) and began to highlight recurrent and relevant topics. From this I compiled a list of topics and sub-topics which I compared with my original literature review questions, which were to identify themes from the literature and to find out

which, if any theories underpin goal setting in palliative care. At this stage, I kept topic labels descriptive and closely linked to the original text (Figure 11).

Figure 11 Initial index

1. Hope and goal setting are linked	2. Process of goal setting	3. A structured framework can be helpful	4. Barriers
1.1 Goal setting engenders hope 1.2 Goals give purpose 1.3 Hope/Quality of Life and goal setting are linked 1.4 Hope changes as illness progresses 1.5 Goal achievement helps motivation	2.1 Goal setting is made up of a series of steps 2.2 Patients/family should be involved 2.3 Key questions can guide the goal setting process 2.4 Patients can identify goals 2.5 Goals should be reviewed 2.6 Inflection points can be identified to help with the review process 2.7 Process is as important as the outcome 2.8 Collaborative goal setting helps behaviour change 2.9 Goal setting is different to the nursing process 2.10 Goals should be set by the whole team 2.11 Communication between the professional and patient is an important part of goal setting	3.1 COPM is a useful tool 3.2 Goal attainment can be conceptualised in a model 3.3 Few systematic methods exist	4.1 COPM can be confusing 4.2 Review of goals can be difficult to do 4.3 Practical constraints make goal setting difficult 4.4 Goal setting varies depending on the facilitator 4.5 Patient centred goal setting is difficult to do 4.6 Goals can be from different points of views 4.7 Balancing risk
5. Types of goals	6. What goal setting is	7. What goals should be	8. People adapt as illness progresses
5.1 Self-care goals are more frequently identified than productivity and leisure goals 5.2 Goals can be diverse 5.3 Goals can be categorised 5.4 Different categories of goals correlate to purpose in life	6.1 Goal setting is part of palliative care 6.2 Goal setting in palliative care is different to goal setting in psychiatry and learning disability and neuro-rehab 6.3 Goal setting is an important part of occupational therapy at the end of life	7.1 Goals should be short term and realistic 7.2 Goals should be meaningful to patients 7.3 Goals should be well defined 7.4 Goals should be documented 7.5 Goals should be collaborative	8.1 People's priorities/ goals change 8.2 Goal setting is part of affirming life and preparing for death
9. What goal setting does			
9.1 May help decision making patient led 9.2 Can help maintain quality of life 9.3 Goal setting empowers patients 9.4 Gives patients a sense of control			

My supervisors and I discussed the first iteration of the coding framework in relation to the papers and the aims of the literature review. Themes were revised several times until consensus was reached that they covered all aspects of what was included in the papers. Figure 12 shows the final coding framework which was used to index the data.

Figure 12 Final coding index

1. What goal setting is	2. Who can set goals and for what purpose	3. Goals should be	4. What goal setting does
1.1 Important 1.2 Collaborative 1.3 Part of a process	2.1 Can be used with most patients 2.2 Can be used for different purposes	3.1 Made up of a series of steps 3.2 Realistic 3.3 Short term 3.4 Patient centred 3.5 Personal to the patient 3.6 Structured methods help the process 3.7 Goals can be categorised	4.1 Helps multidisciplinary working 4.2 Goals bring meaning 4.3 Empowers patients 4.4 Gives patients a sense of control
5. Goals change over time	**6. Goal setting is different in palliative care**	**7. Barriers**	**8.Theories underpin goal setting**
5.1 Patients redefine their goals as illness progresses 5.2 Goals should be reviewed and adapted	6.1 Patients are deteriorating 6.2 Goal setting is part of affirming life and preparing for death	7.1 Few structured methods exist 7.2 Practical constraints 7.3 Communication between professional and patient 7.4 Balancing risk 7.5 Different points of view	8.1 Hope and goal setting are linked 8.2 Collaborative goal setting helps behaviour change 8.3 Hope theory can underpin goal setting 8.4 Goal setting increases motivation 8.5 Adaptation to illness

I used the coding framework in Figure 12 to code relevant data from each paper. I then abstracted direct quotes from each paper under individual themes and summarised them onto data charts. An excerpt from one of the data charts is given in Table 8.

Table 8 Excerpt from data chart 'goals change over time'

Paper	5.1 Patients redefine their goals as illness progresses	5.2 Goals should be reviewed and adapted
Needham and Newbury (2004)	P.445 'patients' individual wishes may not only differ from their families' and professionals', but can also change over time.' P.449-450 'Given the complexity of the patients' needs and the often rapidly changing condition of patients admitted for specialist palliative care, however, the goals sometimes changed during the patients stay.'	
Della Santina and Bernstein (2004)	P. 616 'Generally, early in the course of disease, the goals are focused on diagnostic tests and therapeutic interventions aimed at cure or life prolongation. As illness becomes more advanced, patient and family preferences and perspectives often evolve to focus more on comfort, quality of life and support for the family. The timing of this shift depends on the particular individual.'	P.597 'because the goals often change over time as illness progress, goal planning should be viewed as a dynamic process that is revisited continuously by health care providers, particularly at certain inflection points.'

3.2.5 Collating, summarising and reporting results

By organising data onto charts I was able to make comparisons between papers across each theme. This gave me the opportunity to look at the data as a whole so that I could begin to describe it and generate findings. By going back to the original aims of the literature review, I was able to group the eight codes from the final coding framework into three overarching themes:

1. How the papers present the topic of goal setting in palliative care *(What goal setting is; who can set goals and for what purpose, what goals should be, what goal setting does)*;

2. The challenges of delivering goal setting in palliative care *(Goals change over time; goal setting is different in palliative care and barriers)*;

3. Theories that underpin goal setting in palliative care.

In the next section I provide a summary of findings from the literature review and discuss the implications and relevance of these in relation to the overall project.

3.3 Findings

This review aimed to answer the following questions:

A. What is the range and quality of the published literature on patient-centred goal setting in palliative care?

B. What are the main themes contained within this literature in relation to patient centred goal setting?

C. What is the conceptual or theoretical basis underpinning goal setting in palliative care?

3.3.1 What is the range and quality of the published literature on patient-centred goal setting in palliative care?

My comprehensive approach to searching the literature meant I retrieved both research and non-research papers. However, as a result of the more focused criteria for including papers, a relatively small number of papers were included in the final review (Table 9).

Table 9 Summary of research and non- research papers by type

| Research papers | | | | Non-research papers | | |
(N = 9)				(N = 7)		
Quantitative	Qualitative	Mixed methods	Literature review	Conceptual	Practice based/audit	Opinion
4	3	1	1	3	3	1

Just over half of the included papers reported on empirical research studies. Quality appraisal was carried out on these papers and is summarised in Table 6 (see section 3.2.3). Papers were

rated according to sampling methods, data collection, analysis and quality as well as their applicability or relevance to this study. Two studies were rated as 'high' on both quality and applicability. One of these (Bye 1998) was a qualitative study which examined the perspectives of occupational therapists working in palliative care. The other (Czar 1987) was a quasi-experimental study which compared two different methods of goal setting used by nurses. Another study (Schleinich et al. 2008) was rated as high quality but had limited applicability because it was testing the reliability of a patient questionnaire, which focused on the role of therapists in palliative care, rather than specifically focusing on patient centred goal setting. The remaining studies were of medium or low quality and resulted in very descriptive data which was only applicable to a particular setting or situation. The results of the quality appraisal process confirmed that little good quality research has been carried out in this area. However, the papers which have been identified merit further analysis because the aim of this literature review is not only to find out the quality of research in this area but also to build an understanding of how goal setting in palliative care is currently understood. Therefore in the next section I present the findings from the analysis of all the papers.

3.3.2 What are the main themes contained within this literature?

As stated in section 3.2.5, analysis of the included papers resulted in three main themes:

1. How the papers present the topic of goal setting in palliative care *(What goal setting is; who can set goals and for what purpose, what goals should be, what goal setting does)*;

2. The challenges of delivering goal setting in palliative care *(Goals change over time; goal setting is different in palliative care and barriers)*;

3. Theories that underpin goal setting in palliative care.

In this section, I discuss the first two themes. The third will be discussed in section 3.3.3 as it relates to the third aim of the literature review.

i). How the papers present the topic of goal setting in palliative care

a. What goal setting is

Goal setting was clearly recognised as an important part of patient-centred palliative care (Weissman et al. 2010, Kaldjian et al. 2009, Abrahm et al. 2008, Lunt 1987) but there was no established definition of goal setting in the reviewed papers. However, there was agreement that it involved collaboration between patients, families and the multidisciplinary team (Kasven-Gonzalez et al. 2010, Schleinich et al. 2008, Czar 1987, Lunt and Jenkins 1983). One author regarded the *process* as equally important as the *outcome*:

> *'The quality of the therapist-client interaction during the goal setting process was as important as actually achieving goals.'* (Bye 1998:12)

The example above and others (Schleinich et al. 2008, Lunt, Jenkins 1983) recognise that the process of goal setting is a complex one which relies on good partnerships between staff and patients. There was a suggestion that goal setting is made up of various stages which need to be carefully orchestrated, taking into account issues such as patient's preferences and deterioration. Weissman et al. (2010) described a family meeting where goals were discussed, and summarised the complexities inherent in the goal setting process:

> *'Understanding exactly what the patient's goals are and understanding the clinical scenario are important for appropriately guided treatment.'* (Weissman et al. 2010:939)

The papers covered a range of challenges in relation to setting goals with patients in palliative care. These will be discussed in more detail in section 3.3.2(ii).

b. Who can set goals and for what purpose

Four papers described studies where an explicit method of goal setting was used in practice (Needham and Newbury 2004, Watterson et al. 2004, Czar 1987, Lunt and Jenkins 1983).

These found that, apart from those who were imminently dying, goals could be successfully set with most patients (Needham and Newbury 2004, Lunt and Jenkins 1983). The papers covered goal setting in various palliative care settings, where it was used for several purposes. One practice-based study (Needham and Newbury 2004) audited the use of goal setting as an outcome measure. Goals were set with patients on admission to an in-patient unit in a hospice and goal achievement at the end of input was noted. The study demonstrated a high level of goal achievement (either fully or partially) from the perspective of the patient, the family and the professional. Needham and Newbury (2004) and Lunt and Jenkins (1983) acknowledge that it can be difficult to maintain a patient led goal focus over time, due to practical and operational constraints such as time, professional's priorities and reluctance on the part of some professionals to talk about goals (Needham and Newbury 2004). Kasven-Gonzalez et al. (2010) and Weissman et al. (2010) highlight the importance of the documentation of goals as a method of enhancing collaboration between members of the multidisciplinary team, although the practicalities of doing this were not described. The included papers acknowledged that although goal setting can be used with a wide range of patients in different settings and for different purposes, it is not a straightforward process. The reasons for this are discussed in more detail in section 3.3.2(ii).

c. What goals should be

Three papers described goal setting as a process involving a series of small steps such as problem identification and prioritisation (Della Santina and Bernstein 2004, Bye 1998, Czar 1987), and goals themselves were described in a number of ways, ranging from *'explicit, attainable and short term'* (Lunt and Jenkins 1983:495) to being about *'comfort, living longer and support for family'* (Kaldjian et al. 2009:502). Many of the included papers proposed that goals should be realistic (Kasven-Gonzalez et al. 2010, Leung et al. 2009, Needham and Newbury 2004, Gum and Snyder 2002, Czar 1987, Lunt and Jenkins 1983) but others suggested that the *process* of setting and working towards goals was as important as actually

achieving goals (Gum and Snyder 2002, Bye 1998) and that it did not always matter if goals were achieved (Bye 1998). Leung et al. (2009) highlighted that goals should be short term and specific enough so that progress in relation to goal achievement could be monitored. She highlighted the importance of giving patients feedback about their performance in relation to their goals, suggesting that this could help patients to adjust their goals if they became unachievable.

Several papers (Needham and Newbury 2004, Watterson et al. 2004, Gum and Snyder 2002, Bye 1998) advocated that goals should be patient centred and that the process should involve a partnership between the professional, the patient and their family. There was agreement that goals should be personal to patients themselves, and that this might lead to the identification of highly individual goals which were of significance to particular patients (Jacques and Hasselkus 2004, Watterson et al. 2004, Gum and Snyder 2002, Bye 1998, Lunt and Jenkins 1983).

Reliably eliciting goals from patients and families was recognised as challenging, and several authors attempted to address this (Weissman et al. 2010, Abrahm et al. 2008, Della Santina and Bernstein 2004, Watterson et al. 2004, Czar 1987, Lunt and Jenkins 1983). Della Santina and Bernstein (2004) proposed a patient assessment tool, the 'Needs at End-of-life Screening Tool' (NEST) which provides a framework for guiding patient assessment and goal setting. However, this has not been tried and tested in practice and does not appear to have any theoretical basis. A retrospective chart review investigated the use of an established tool, the COPM, as a possible method of eliciting and documenting patient centred goals (Watterson et al. 2004). This demonstrated that goals can be elicited and categorised, and in the context of the study, patients predominantly chose goals related to self-care. It is suggested that the COPM may be helpful for guiding the goal setting process but because the study was a case

note review, there is no information about how use of the COPM affected professional's ability to engage with patients in the goal setting process.

Other papers (Kaldjian et al. 2009, Schleinichet al. 2008, Jacques and Hasselkus 2004, Bye 1998, Lunt and Jenkins 1983) proposed that goal categories were a useful way of framing goal setting, although there was wide variety in the categories used. For example, Lunt and Jenkins (1983:501) provided 'goal content categories' which were made up of problem lists such as: *'pain, nausea and vomiting, breathlessness'* etc. Jacques and Hasselkus (2004:48) provided domains of occupation which could be used to guide goal setting: *'continuing life'; 'preparation for death'; 'waiting'; 'death and after death'*. Whilst many papers acknowledged that goal setting should be underpinned by a theoretical model (Leung et al. 2009, Jacques and Hasselkus 2004, Watterson et al. 2004, Gum and Snyder 2002, Bye 1998, Czar 1987) , there was no consensus about the origins or nature of this model.

d. What goal setting does

Three papers (Needham and Newbury 2004, Gum and Snyder 2002, Lunt and Jenkins 1983) suggested goal setting as a mechanism for guiding multidisciplinary working and ensuring that decision making was patient led. Five papers proposed that goal setting gave people hope (Leung et al. 2009, Needham and Newbury 2004, Gum and Snyder 2002, Benzein and Saveman 1998, Herth 1995), and three that it brought meaning (Kasven-Gonzalez et al. 2010, Leung et al. 2009, Jacques and Hasselkus 2004). This was illustrated in one good quality ethnographic study which gave examples of goals set by patients which brought meaning to their lives, for instance:

> *'Daniel described two important and meaningful goals that he wanted to meet before the end of his life – to travel to a friend's graduation and to have time with his estranged daughter. Yet Daniel also told me that he tried to live "one day at a time."'* (Jacques and Hasselkus 2004:51)

Whilst papers recognised that goal setting in palliative care might enhance quality of life (Jacques and Hasselkus 2004, Benzein and Saveman 1998) and possibly enable people to *'live*

as actively as possible before death' (World Health Organisation 2004:44), there was no empirical evidence to support this in any of the papers, apart from Jacques (Jacques and Hasselkus 2004), as mentioned above.

Ten of the included papers (Kasven-Gonzalez et al. 2010, Kaldjian et al. 2009, Leung et al. 2009, Della Santina and Bernstein 2004, Needham and Newbury 2004, Watterson et al. 2004, Gum and Snyder 2002, Bye 1998, Herth 1995, Lunt and Jenkins 1983) highlighted that patients adapt their goals as illness progresses. Gum and Snyder (2002) suggested that people could maintain unrealistic hopes on one level whilst simultaneously working on more tangible, realistic goals. It was suggested that this could be an important coping strategy for some people:

> *"we have argued that the manner in which dying individuals identify and pursue goals influences how they cope. We believe that people who focus their goal pursuits on rewarding, attainable goals, as well as continuing to pursue a cure for their illness if so desired, are likely to cope successfully with dying."* (p892)

Three papers suggested that setting and achieving goals gives patients a sense of control and helps them to feel empowered (Kasven-Gonzalez et al. 2010, Leung et al. 2009, Gum and Snyder 2002). Two of these papers (Leung et al. 2009, Gum and Snyder 2002) were theoretical in nature and did not provide empirical evidence that this was the case. However, unlike other papers, they were based on established theories such as Goal Setting and Hope Theory.

In summary, the papers confirmed that goal setting is perceived as an important part of palliative care which can be used with patients in their last year of life. The papers provide examples of goal setting being used for a number of purposes, ranging from outcome measurement to enhancing patient centred care and collaboration between multidisciplinary team members. It is also regarded as an important method of helping people to find meaning, adapt and cope with life threatening illness.

ii). The challenges of delivering goal setting in palliative care:

a) Goals change over time

Many of the included papers made it clear that goal setting in palliative care is not a linear process and that patients often redefine their goals as illness progresses (Kasven-Gonzalez et al. 2010, Kaldjian et al. 2009, Leung et al. 2009, Della Santina and Bernstein 2004, Needham and Newbury 2004, Gum and Snyder 2002, Bye 1998, Herth 1995). Della Santina and Bernstein (2004) highlighted that patient's attitudes towards goals were likely to change according to the stage of their illness, but also recognised that this might be a highly individual response:

> 'Generally, early in the course of disease, the goals are focused on diagnostic tests and therapeutic interventions aimed at curing or life prolongation. As illness becomes more advanced, patient and family preferences and perspectives often evolve to focus more on quality of life and support for the family. The timing of this shift depends on the particular individual.' (p616)

Other papers also agreed that goals were likely to change throughout the course of illness (Jacques and Hasselkus 2004, Gum and Snyder 2002, Herth 1995, Lunt and Jenkins 1983), with the focus often moving from goals about physical independence to goals about leaving a legacy (Leung et al. 2009, Della Santina and Bernstein 2004, Bye 1998). The importance of regularly reviewing and adapting goals as a way of ensuring that patient's changing goals were acknowledged and supported was highlighted in several papers (Watterson et al. 2004, Lunt and Jenkins 1983, Della Santina and Bernstein 2004, Gum and Snyder 2002). However, whilst important, regular review of goals was acknowledged to be difficult to achieve due to practical constraints such as the ward routine and changes in a patient's condition (Needham and Newbury 2004, Lunt and Jenkins 1983).

b) *Goal setting is different in palliative care*

Despite the apparent relevance of goal setting in palliative care, the included papers emphasised that health professionals are faced with a number of challenges when trying to set goals with patients in this context. Jacques and Hasselkus (2004) and Gum and Snyder (2002) emphasised that all experiences are altered in the presence of death and dying, and as a result recommended that goals should be highly individualised and patient centred. Personal factors such as patient's coping strategies, age, mood and preferences were identified as factors that affect goal setting (Bye 1998, Lunt and Jenkins 1983).

Although goal setting appears to have been quite widely imported into palliative care settings, it does not seem to be directly transferable to palliative care without modification. Traditional rehabilitation pre-supposes the potential for recovery and improvement, whilst palliative care assumes a deteriorating and unpredictable trajectory. Lunt (1983) suggested that goal setting techniques which were developed in other settings (such as learning disability and psychiatry) may not be *'immediately transferable to terminal care, because they were based on a skill building approach which seemed inappropriate for people whose health and abilities are rapidly deteriorating'* (p496). This statement alludes to the fact that palliative care professionals face a particular challenge when trying to set goals with patients and that the goal setting process may need to be altered in this context. This is reiterated in other papers which state that patients' goals can rapidly change and may have to be adapted and scaled down as illness progresses (Kasven-Gonzalez et al. 2010, Kaldjian et al. 2009, Della Santina and Bernstein 2004, Needham and Newbury 2004, Herth 1995).

The issue of deterioration and unpredictability has been addressed to some extent by Jacques and Hasselkus (2004) and Bye (1998), who acknowledge that patients and professionals are engaged in the complex and sometimes contradictory activity of living while dying. This fits well with the WHO definition of palliative care, of living as actively as possible until death

(WHO 2004). However, neither paper addresses the practicalities of how professionals should go about setting goals with patients in routine practice.

c) Barriers

Whilst there is agreement in the papers that goal setting involves collaboration between patients, their family and professionals, two papers suggest that it can be difficult for professionals to work with patients who have unrealistic goals (Della Santina and Bernstein 2004, Needham and Newbury 2004) and that goals should be negotiated until they *are* realistic (Kaldjian et al. 2009, Della Santina and Bernstein 2004, Needham and Newbury 2004). There is recognition that patients, their families and the multidisciplinary team may have conflicting views regarding goals (Schleinich et al. 2008, Della Santina and Bernstein 2004, Needham and Newbury 2004). Needham and Newbury (2004) provided clear examples of the differences in emphasis between professionals, patients and families. Professionals often took a problem or symptom based approach and seemed to be more aware of potential risks, which were often a barrier in supporting patients to work towards their goals; whilst patients and families tended to focus on specific goals about what they wanted to 'do' (Needham and Newbury 2004).

It is highlighted that few structured methods of goal setting currently exist in palliative care (Schleinich et al. 2008) and in the identified papers, attempts were made to explore or develop more structured approaches to guide the process (Kaldjian et al. 2009, Schleinich et al. 2008, Della Santina and Bernstein 2004, Needham and Newbury 2004, Watterson et al. 2004, Czar 1987, Lunt and Jenkins 1983). One study explored whether or not the COPM could be used as a method of eliciting patient-centred goals (Watterson et al. 2004). This is the only paper which tested an already established, theory based goal setting method, but the emphasis was on the *types* of goals which patients identified, rather than the *process* of setting goals, and whether this was appropriate in palliative care.

Lunt and Jenkins (1983) explored the use of goal setting in an in-patient palliative care unit, and found that, although initially staff were committed to setting goals with patients, after the study had finished, the use of goal setting could not be sustained due to practical constraints such as the ward routine and other tasks which took higher priority. Lunt also found that individual staff members varied in their ability to set goals with patients, suggesting that there was a need for staff training in this area. Schleinich et al (2008) also acknowledged that the goal setting process is a complex one which is not straight forward:

'Identifying patient goals and priorities is fraught with difficulty' (p822)

In summary, the literature highlights some of the challenges that professionals face when setting goals with patients in palliative care settings. It is striking that these are also common to goal setting and traditional rehabilitation: the tension of balancing different points of view, whether or not goals should be realistic and methods of eliciting goals from patients. One unsurprising difference between goal setting in palliative care and traditional rehabilitation is the challenge of working with people who are deteriorating and how professionals balance helping people to live whilst they are dying. Currently there are no definitive answers about how this challenge is met; however, the literature points us to areas for development, for example, developing and evaluating different methods of goal elicitation (Della Santina and Bernstein 2004, Watterson et al. 2004) as well as developing our understanding of theory to underpin the goal setting process in palliative care (Leung et al. 2009, Gum and Snyder 2002). In the next section I summarise findings from the literature, focusing on theories which appear to underpin goal setting in palliative care.

3.3.3 What is the conceptual or theoretical basis underpinning goal setting in palliative care?

Goal setting appears to have been widely imported from traditional rehabilitation without modification into palliative care settings. This is evidenced by the predominant belief that goals should be **S**pecific, **M**easureable, **A**chievable, **R**elevant and **T**ime limited (SMART)

(Kasven-Gonzalez et al. 2010, Leung et al. 2009, Needham and Newbury 2004, Gum and Snyder 2002, Czar 1987, Lunt and Jenkins 1983), a concept which originated in industry but is now widely accepted as a standard for goal setting in traditional rehabilitation (Barnes and Ward 2004). There are two additional theoretical underpinnings which appear to be specific to goal setting in palliative care; theories of hope and how people cope with living whilst dying.

The very act of setting goals within palliative care settings is recognised as a way to instil hope in people (Needham and Newbury 2004, Herth 1995) and this increased sense of purpose alone may help patients cope better with the challenging situations they face. Importantly, such goals do not always have to be realistic, as is often perceived to be the case in traditional rehabilitation settings (Barnes and Ward 2004). People enjoy working towards goals, even if they may never be achieved (Benzein and Saveman 1998, Bye 1998). A patient set goal (perhaps perceived as unrealistic by their healthcare professionals) may help the person understand what is – and is not – manageable, and scale back accordingly (Kaldjian et al. 2009, Leung et al. 2009, Gum and Snyder 2002, Herth 1995). For example, patients may develop alternative pathways to goals only after they have tried and experienced the limitations that their illness places on them (Gum and Snyder 2002).

The concept of hope is repeatedly mentioned in relation to goal setting in palliative care (Kasven-Gonzalez et al. 2010, Leung et al. 2009, Needham and Newbury 2004, Gum and Snyder 2002, Benzein and Saveman 1998, Herth 1995). Whilst hope is described in the nursing literature as *'complex, multidimensional and dynamic'* (Herth 1995:31), it is more clearly articulated in the psychological literature. Gum and Snyder (2002) define it as *'positive expectations for goal attainment or as beliefs about possibilities for the future'* (p884). They provide a theoretical model (originally developed by Snyder, 2002) which seeks to explain how people with life threatening illness work towards goals and how this links with hope.

Snyder's model of hope (Snyder 2002) emphasises the importance of setting *specific* rather than *vague* goals so that goal achievement can be monitored. Goal review is emphasised as important, because even when goals are no longer achievable, mourning the loss of unattainable goals is an important aspect of adapting to illness (Leung et al. 2009, Gum and Snyder 2002). Reminders of previous achievements and positive self-talk are also mechanisms which can motivate patients to seek alternative pathways to achieve existing goals or set and work towards new ones (Leung et al. 2009, Gum and Snyder 2002). Snyder suggests that a person's level of hopefulness can affect how they respond to illness and proposes that individuals who are 'high-hope' will cope better than those who are 'low-hope'. The model suggests that professionals can support patients to pursue their goals by developing ways or strategies to *achieve* goals (pathways thinking) and by anticipating potential problems and how they *might be overcome* (agency thinking). Leung et al (Leung et al. 2009) also present a conceptual model of hope. They distinguish between 'hopes' (what *could* happen) and 'expectations' (what *will* happen) and propose a conceptual model to help professionals strike a balance between *"encouraging reasonable hope and creating unrealistic expectations of health outcomes"* (Leung et al. 2009:348). They refer to Synder's Hope theory (Snyder 2002) in their model and suggest that goal setting and goal pursuit impact on a patient's ability to adapt to illness. Unsuccessful goal pursuit is regarded as an opportunity to foster a person's resilience through the development of new goals or hopes following reflection on whether goals are achieved. Goals can then be altered accordingly. Hope Theory (Snyder 2002) has the potential to offer professionals working in palliative care a theoretical explanation of how goal setting and hope are linked and perhaps challenges the widely held belief that goals should be always be realistic. However, to date, this theory has not been tested empirically.

Two papers focused on occupation at the end of life (Jacques and Hasselkus 2004, Bye 1998). Both of these acknowledged that professionals often simultaneously support patients to prepare for death whilst helping them to deal with the practicalities of living. Bye proposed a

conceptual framework for *"Affirming life: Preparing for death"* (Bye 1998:8) and Jacques and Hasselkus (2004) highlighted the importance of *"doing the things that matter: continuing life"* (p.48), which is based on Bye's work. Goal setting is proposed as central to both frameworks and provides professionals with a tangible way of supporting patients to connect with life, *'beyond illness'* (Bye 1998:19). For example, Bye (1998) emphasises the importance of patients setting and working towards goals that focus on helping them to connect with life rather than only focusing on independence and getting back to 'normal'. This suggests that in palliative care, goals are not only about rehabilitation, but can also be linked to doing things that are meaningful within a changed reality, where death is imminent.

Both Hope Theory and theories of how people cope with living whilst dying provide a structure which may help professionals address some of the barriers to goal setting which have been identified in the literature. The importance of theory has been highlighted by the MRC in their guidance on developing and evaluating complex interventions in healthcare, which states that:

> "a *good theoretical understanding is needed of how the intervention causes change, so that weak links in the causal chain can be identified and strengthened*" (Craig et al. 2008:7).

The theories (Hope Theory and Affirming life: Preparing for death) identified in this literature review provide a strong starting point from which to begin to build more coherent, theory based approaches to goal setting in palliative care which could be tested in practice.

3.4 Discussion:

In this structured literature review I have identified, appraised and synthesised the published literature on patient-centred goal setting in palliative care. My search strategy retrieved sixteen papers which varied in quality and type. I have described how the papers present the

topic of goal setting, identified the challenges of delivering goal setting in palliative care and theories which are thought to underpin the process.

3.4.1 Key findings

The papers which I identified demonstrate that, in agreement with current policy, goal setting is an important and relevant part of palliative care. In spite of this, there is no established definition of goal setting and it appears to be used for a number of purposes in different ways. There is agreement that goal setting is complex and often the actual process is at least as important as the outcome. Over half of the papers included in discussed the potential use of a structured method of goal setting (Weissman et al. 2010, Kaldjian et al. 2009, Abrahm et al. 2008, Schleinich et al. 2008, Della Santina and Bernstein 2004, Watterson et al. 2004, Gum and Snyder 2002, Czar 1987), which suggests that there is an interest in developing more robust, consistent ways of approaching goal setting in palliative care. However, to date, little work has been carried out in developing and testing theory based approaches to goal setting in palliative care. This is in contrast to other areas of rehabilitation (for example, stroke rehabilitation) where theoretically informed goal setting frameworks are being developed and appraised (Scobbie et al. 2011, Barnard et al. 2010, Scobbie et al. 2009, Playford et al. 2009, Levack et al. 2006b)

One of the main challenges for patients and professionals working in palliative care is that they are dealing with deteriorating and unpredictable disease trajectories. This is widely acknowledged in the literature, and the identified theories/frameworks from this literature review: Hope Theory (Gum and Snyder 2002) and Affirming life: Preparing for death (Bye 1998), may provide professionals with explanations and logic to help them become more consistent in their approach to goal setting. For example, Leung et al. (2009) and Gum and Snyder (2002) both highlight that providing feedback plays an important role in helping patients to adapt to their deteriorating health. Giving patients opportunities to try to achieve goals gives them information so that they can adapt their goals, mourn the loss of goals or

plan alternative routes to achieve them. Making this theoretical component explicit in a goal setting intervention may help professionals to support patients as they adapt to illness.

3.4.2 Limitations

In carrying out this literature review I have made every effort to ensure that the process has been rigorous, transparent and replicable. Whilst the search strategy was comprehensive, I cannot be certain that all relevant articles were retrieved. Furthermore, I did not search the grey literature where it is possible that other relevant papers could have been found.

The search strategy retrieved very few data-based papers and as a result my approach to analysis was qualitative. I am aware that whilst I was systematic, rigorous and transparent in my approach, there is a level of subjectivity which cannot be removed. As such, other researchers may have drawn out different themes from the data extracted from the papers.

3.4.3 Summary

In order to deliver effective goal setting in palliative care, two important issues require to be addressed. The first is pragmatic: how does a healthcare professional deliver goal setting when dealing with the deteriorating and unpredictable nature of patients' health? The second is more theoretical: which theories are relevant and useful and how might they be used to enable the optimal and consistent delivery of goal setting in palliative care?

The literature review does not provide a clear answer to the first question. Although many of the papers described goal setting practice, their focus was on the types of goals which patients wanted to achieve rather than on the process of goal setting itself. Potential solutions to dealing with the unpredictability of patients' health trajectory are to review patient's goals more frequently, and /or set shorter term goals; but the included literature had no consensus on how this should be done in practice. Further work is needed to clarify the best way to approach goal setting in palliative care.

The answer to the second question seems to be clearer. The concept of hope is repeatedly mentioned in relation to goal setting in palliative care (Kasven-Gonzalez et al. 2010, Leung et al. 2009, Needham and Newbury 2004, Gum and Snyder 2002, Bye 1998, Herth 1995). The very act of setting goals within palliative care settings is recognised as a way to instil hope in people, and this increased sense of purpose alone may help people to cope better with the challenging situations they face. Importantly, such goals do not always have to be realistic, as is often perceived to be the case in traditional rehabilitation settings (Barnes, Ward 2004). People enjoy working towards goals, even if they may never be achieved (Needham and Newbury 2004). A patient set goal (perhaps perceived as unrealistic by their healthcare professionals) may help the person understand what is – and is not – manageable, and scale back accordingly (Leung, Silvius et al. 2009, Gum and Snyder 2002).

In addition to this, Bye's framework of how people cope with life threatening illness (Bye 1998), may be helpful. She proposes that healthcare professionals should simultaneously support people to 'affirm life' whilst helping them prepare for death. This fits well with the WHO definition of palliative care, of living as actively as possible until death, and provides professionals with a framework for balancing living actively whilst dying, which are both important aspects of palliative care.

3.4.4 Conclusions

In this literature review we have seen that, although regarded as important, there is little agreement on what goal setting is, what it does or how it should be delivered. The theories identified from this literature review are different to those already identified in the stroke rehabilitation literature (see chapter 2.4). This supports the conclusion that goal setting in palliative care is different to goal setting in more traditional rehabilitation specialities. Although we may be able to build on developments which have been initiated with other

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patient groups, structured approaches to goal setting in palliative care are likely to be unique to this setting.

Further analysis of how professionals set goals with patients in practice will deepen our understanding of goal setting in palliative care and may clarify the relevance of particular theories which might be useful in developing more robust methods of approaching goal setting in this context. I explore this in chapters 4 and 5 where I describe the second stage of this research.

STAGE 2: INVESTIGATION OF CURRENT PRACTICE IN ONE HOSPICE SETTING

Chapter 4: A study of how goal setting is delivered in one palliative care unit

4.1 Introduction:

In chapter three I discussed the findings of a structured literature review on goal setting in palliative care. This showed that although rehabilitation and goal setting are mechanisms for helping people to live actively until they die, there is little agreement about the best way to go about setting goals with patients in palliative care. There is evidence to suggest that people working in palliative care face a particular set of challenges when trying to set goals with people, partly because the disease trajectory is one of deterioration rather than improvement (Jacques and Hasselkus 2004, Lunt and Jenkins 1983). In order to understand how goal setting is delivered in practice in palliative care, I undertook a mixed methods study incorporating case study design (Yin 2009, Yin 1994), in one palliative care setting. The aim was to investigate palliative care practitioners' understanding and their practice in one hospice environment and try to bring to the fore the key components and underlying mechanisms of goal setting as part of day-to-day practice. In this chapter I describe the setting, the research design and report on the findings.

4.2 Setting

This research is based in a 24 bedded hospice which delivers specialist palliative care to people living in central Scotland. The areas covered are both rural and urban. The hospice delivers its services in three distinct ways:

Day Care: patients attend the hospice day care unit usually one day a week. Here the focus is on social interaction and recreational activities. Patients also have the opportunity for medical assessment and review;

Home Care: this is a domiciliary service provided by nursing and medical staff who visit patients in their own homes. The focus tends to be on symptom management and problem solving with patients;

The Ward: patients come to the ward for four main reasons; therapeutic assessment, symptom control, maximising potential and end of life care.

Referral rates vary, but in 2011/2012, a total of 1086 referrals were made to the hospice service as a whole. Of these, 423 were admissions to the ward, and 179 of these patients were discharged home. A typical pathway for this group of patients is outlined in Figure 13:

Figure 13 Typical patient pathway at the hospice

1.
- Patient identified by GP, home care nurse or hospital palliative care team as requiring inpatient care.

2.
- Discussion takes place with patient and family about possible aims of admission. Referral form completed.

3.
- Decision made about admission based on priority (clinical or care environmet) and dependency workload issues on the ward.

4.
- Patient is admitted to the ward and booked in by nursing and medical staff.

5.
- Patient is reviewed on a daily basis and discharged if appropiate, or remains in the hospice for end of life care.

Once patients are admitted to the ward, they are reviewed on a daily basis by nursing and medical staff. A physiotherapist, occupational therapist, social workers, chaplains and complementary therapists also have sessional input. Formal multidisciplinary staff meetings are held on a weekly basis when discussion takes place about treatment, progress and discharge.

4.3 Study aims and research questions

The aim of this phase of the research was to identify the key components and underlying mechanisms of the goal setting process in a single hospice setting. Specific research questions were:

1. How is goal setting delivered in practice to patients who are admitted to the hospice for symptom control, maximising potential or therapeutic assessment?

2. What are multidisciplinary staff team members' experiences and perceptions of goal setting as an intervention for patients who are admitted to the hospice for symptom control, maximising potential or therapeutic assessment?

Research question one is designed to provide a description of goal setting in the hospice. The second question provides an opportunity to explore possible explanations as to why goal setting looks as it does within this setting. I focused on patients who were most likely to receive and benefit from rehabilitation, where I hypothesised that explicit goal setting was most likely to occur. I based the study on goal setting in the in-patient service rather than day-care or community as in-patients receive services from the whole multidisciplinary hospice team. Day-care and community patients receive input from hospice staff as well as community staff who are not employed by the hospice (for example, the local community rehabilitation team).

4.4 Research Design:

Given that little is known about the elements which make up the goal setting process in the context of palliative care, I felt that it was important to choose a research design that would allow me to explore the process within the context in which it happens. Case study design is recognised as a valuable approach for studying *"broad, complex questions….to be addressed in complex circumstances"* (Keen and Packwood 1995:445). According to Yin (2009), case study design is an empirical enquiry that:

> *"investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident."* (p13)

It is particularly suited to research focusing on 'why' or 'how' questions in a setting where the researcher has *"little control over events"* (Yin 2009:19). I wanted to find out how professionals set goals in the hospice as well as what they thought about goal setting in this context. In order to do this, I needed to be able to collect different types of data which could later be compared (for example, I wanted to be able to make comparisons between what people did in practice and what they said they did). In order to do this, I used multiple methods within a case study design.

The cases which were studied were *professionals* who work with patients to help them make decisions and set goals. I decided to focus on professionals rather than patients as:

1. Professional staff were likely to have an understanding of the importance and complexity of goal setting through awareness of current guidelines (Scottish Government 2007, NICE 2004, NCPC 2000) and were therefore most likely to be able to speak about it and demonstrate it. In contrast, I hypothesised that patients were less likely to have this detailed knowledge and would therefore be less likely to be able to demonstrate goal setting during observations;

2. Professional staff who work with patients are most likely to involve and lead patients through some form of goal setting or joint decision making in the hospice. I hypothesised that professionals would be most likely to be able to predict when they would set goals with or make decisions with patients, thus allowing me to observe them at appropriate times;

3. Focusing on the work of the same professional on different occasions with different patients would allow me to make comparisons and begin to explore which factors affect the process of goal setting;

4. Selecting a sample of a range of different professionals would allow me to make comparisons about goal setting across and between different professional groups, although I acknowledge that given the small sample, making generalisations about professional groups will not be possible.

Prior to starting the study, an advisory group of professionals from the hospice was set up. The group was made up of four members of the senior management team, representing medical and nursing staff. The group met on a quarterly basis and provided me with advice and feedback throughout the project which was very helpful, particularly during the research design phase. There were no service users on the advisory group because, due to life threatening illness, consistent membership by patients over time would have been difficult, if not impossible to achieve. Instead I attended and presented at a meeting of the local palliative care Patient and Public Involvement (PPI) group and sought advice from them during the development of the goal setting intervention, prior to the implementation study (see Chapter 6, section 3.2).

4.4.1 Sample for case studies

I recruited professionals between March and November 2009. In order to be able to make comparisons about the goal setting process between different professionals, a purposive sample representing the distribution of professional groups who worked at the hospice was recruited: two doctors, five nurses, one physiotherapist, one occupational therapist and one social worker (Table 10). Where there were several members of a staff group, staff were firstly selected by drawing names out of a hat and then invited to take part in the study. Other members of staff (physiotherapist and occupational therapist) were approached individually and asked whether or not they would like to take part. A total of 15 professionals were given information about the study. Of these, 12 consented to take part. However, because of one person's annual leave and another's shift patterns, it was not possible to include two of them in the study, so a total of 10 professionals participated. In the end, two doctors, five nurses, one physiotherapist, one occupational therapist and one social worker took part in the case studies (Table 10).

Table 10 Professionals included as case studies

Professional group	Numbers of staff	Recruited	Actual participants
Doctor	9	3	2
Qualified Nursing staff (Grade 5 and above):	8 (Home care) 37 (Ward)	2 (Home care) 4 (Ward)	2 (Home care) 3 (Ward)
Physiotherapist	1	1	1
Occupational Therapist	1	1	1
Social worker	2	1	1

4.4.2 Methods

This study was concerned with examining both the behaviours (research question 1) *and* perceptions of professionals (research question 2) with regard to goal setting, which is why I used a multiple methods research design (Patton 2002). The following methods were used to gather information about the goal setting process for each professional recruited on to the study: *observations, documentary analysis of patient notes* and *individual staff interviews.* These are illustrated in Figure 14.

Figure 14 Summary of methods used for each case
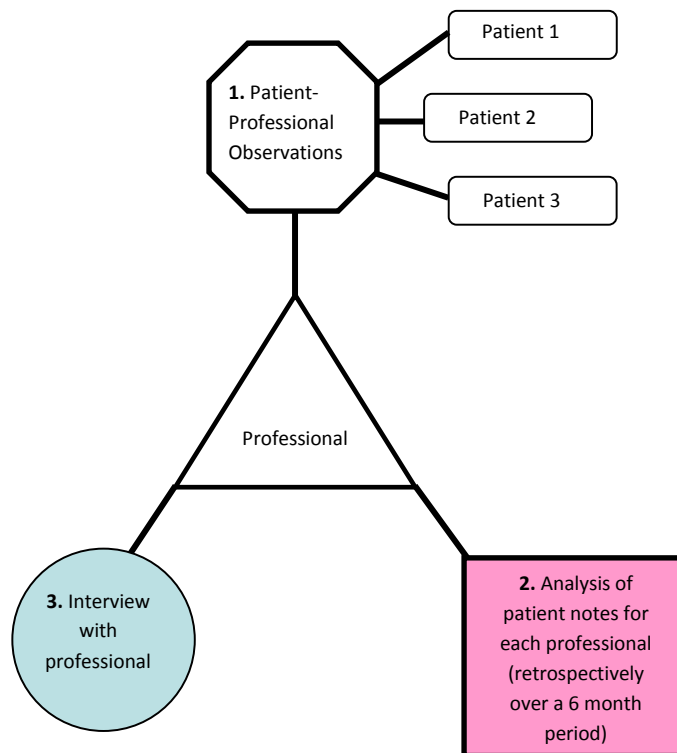
Specifically, this study investigated how goal setting was delivered to patients who were admitted to the inpatient palliative care facility for symptom control, maximising potential[1] or

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[1] Maximising potential in this context means patients who are referred to the hospice for rehabilitation with a view to returning home.

therapeutic assessment[2]. These are terms used within the hospice, which broadly mean, patients who are admitted for some form of rehabilitation (which in this context means input to support them to live as actively as they can).

I will now explain why each method was incorporated into the study and how this was done. Ethical considerations will also be discussed.

4.4.3 Observations

Observation was incorporated into the study design because I wanted to find out how goal setting happened in the hospice as part of day to day practice. Observational data provides *"a first-hand account of witnessed behaviours or events"* (Watson and Whyte 2006:383) and is recognised as an effective method of collecting data, especially when the focus is on finding out about the *behaviours* of people rather than their *perceptions* (Kumar 2005). I decided to use non-participant observation rather than participant observation because I wanted to look at the *behaviours* of those involved in setting goals with patients during particular interactions (Patton 2002). I felt it was important that individuals (patients and professionals) had a clear understanding of my role as a non-participant observer and I wanted to be able to take detailed field notes during interactions. I would not have been able to do this if I had taken on a participatory role during observations. Also, because I was observing interactions, my direct involvement as a participant in discussions may have influenced how the professional worked with the patient.

Patton (Patton 2002) provides a useful summary of what should be observed and written about in observational field notes. Although different terminology is used, the summary is similar to those found in other books which describe observational data collection (Todres and Holloway 2006). Using these resources, I made up a checklist to ensure that I would

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[2] Therapeutic assessment in this context means patients who are referred to the hospice for a period of assessment or symptom control.

remember to notice and document all aspects of what was happening during the interactions I observed. As a practicing clinician, accustomed to gathering, interpreting and making decisions from observations very quickly, I had to make a conscious effort to be an observer rather than an interpreter or problem solver. The headings below provided me with the crucial scaffolding I needed to structure my observations (Figure 15).

Figure 15 Headings used to structure observations

Setting: Physical environment (temperature, atmosphere, layout, decor, lighting); time of day.

Communication: Language/terminology used, how things were said. Non-verbal communication (use of touch, intonation, silence); how people were dressed.

Human and Social environment: How did behaviours and responses change during the interaction? What was said? How were sessions introduced? What signalled the end of a session and how was this linked to future plans? How did respondents react?

Prior to beginning data collection for my project, I read anonymised field notes which had been written by another qualitative researcher (Kelly 2007). I then carried out some 'practice observations' using the headings in Figure 15 as a guide in order to develop my observational skills. I was given continual feedback from my supervisors about the quality of my observational notes throughout the project. This was an important aspect of ensuring that my observations were detailed and accurate. An extract from one set of observations can be seen in Appendix 1.

I observed each professional working with three different patients. Professionals were given information sheets to hand out to patients, who could then ask to speak to me if they had any questions about the study. When patients agreed to be observed and had signed the consent forms, I arranged to observe the professionals at a time and location which suited them. I was

always aware that my presence may have affected how participants behaved during sessions and therefore, whenever I carried out observations, I tried to be as inconspicuous as possible, usually sitting on the periphery of the interaction, depending on the preferences of the patient and professional. I had a small notebook where I took notes during the interactions. Prior to each session, I explained to the patients and professionals that I would be taking notes and usually they were happy to ignore me once their discussions were underway. There were occasions when participants tried to draw me into their conversation. When this happened I tried not to become involved, reminding them that I was there as an observer rather than participant. The sessions that I observed varied in length (from half an hour to over an hour), depending on the type of interaction chosen (for example, some were admission interviews, which tended to take up to an hour. Others were specific sessions with allied health professionals or nursing interventions. These tended to be shorter). Once each observational session was complete, I typed up my field notes as soon as I could. Sometimes it was not possible to type up my notes right away, so I made use of a digital recorder which I used to record my thoughts and feelings after I had carried out observations. I found that this was a really useful strategy as, although my field notes were detailed, if too much time elapsed between carrying out the observation and writing it up, I could forget some aspects of the sessions. I quickly learned the importance of allowing plenty of time for writing up my notes right after each session.

4.4.4 Semi-structured interviews with staff

Although observation is a useful method of capturing what happens in a situation and provides insights into how people behave in specific situations, it is not possible to observe everything, particularly people's intentions and how they feel and think about things (Patton 2002). Use of interviews allowed me to find out about the goal setting process from the professional's perspective and to gain an insight into their beliefs and understandings of goal

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setting (Green 2005). I used semi-structured interviews as opposed to informal conversational interviews or standardised interviews because I wanted to be able to make comparisons between data collected from different interviews (Tod 2006). Use of an interview topic guide allowed me to ask each professional the same broad questions, eliciting data which could be compared at a later date. Because I interviewed a range of different professionals, I needed some degree of flexibility so that I could rephrase my questions if necessary and follow up and probe if I wished to explore anything in greater detail (Mason 2002). Use of very structured interviews would have limited my scope for this level of flexibility.

Each professional who took part in the study was interviewed once in order to find out their perceptions of goal setting as an intervention for patients who were admitted to the hospice for symptom control, maximising potential or therapeutic assessment. Because people become more aware of how they think and feel about the issues that they are being asked to reflect on (Patton 2002) the interview could affect the behaviour and attitudes of the professionals involved. For this reason, I interviewed each of them once *after* I had completed the three observations. The topic guide (Appendix 2) covered: *what goal setting means; how goal setting is carried out and documented; possible benefits and challenges to setting goals with patients.*

Interviews were digitally recorded and I transcribed each verbatim to allow me to become very familiar with the data. Following each interview, I wrote up field notes which included information about the environment as well as a descriptive overview of the professional involved, including their professional background and level of experience. I also spent time reflecting on my own performance as an interviewer in discussion with my supervisors in order to continually improve my interviewing techniques.

4.4.5 Analysis of patient notes

Patton (2002) states that the use of documents as data provides a *"behind-the scenes look"* at aspects of a programme being studied. Case note analysis provided insight into what professionals felt was important enough to document and how they wrote about and thus conceptualised goal setting within the broad confines of case note writing practices. Although it gave me insight beyond observation and interviews, the analysis was challenging. For example, there was variation in how complete case notes were and how much detail was provided. The format used was inconsistent which made it difficult and time consuming to navigate around the notes to find entries which were relevant to goal setting. I was aware that the decisions I took on what to include and leave out were crucial to help me to make consistent judgements. I developed a decision making table (Appendix 3) about what might be classified as a goal in the notes.

I piloted my original data extraction form (Appendix 4) on ten sets of notes. From this, it became clear that I would need to write down more information so that my decision making could be traced back and justified, thus enhancing consistency. I made up a second data extraction form (Appendix 5) and also developed and used the decision making table which I referred to when making judgements about the notes. I collected two types of information from each set of notes: general information relating to goal setting (written by any professional on admission and discharge) and specific entries written by the professionals taking part in the study, relating to goals.

All case notes of patients who were admitted to the ward over a six month period for symptom control, maximising potential or therapeutic assessment were included. In order to reduce the likelihood of staff changing how they documented goals as a result of the research process, the sample was chosen from a six month period in the year prior to the research study commencing. This also ensured that, as far as possible, those professionals who were

included in the study would have written in the notes (this was to take into account staff turnover). All case notes from the six month period were included as at least one of the professionals included in the study had written in each set of notes. The sample included a total of 69 sets of case notes which were written by all members of the multidisciplinary team throughout the patient's involvement with the hospice. During the case note analysis phase of the study, two sets of notes were unavailable, so a total of 67 sets of notes were analysed.

4.4.6 Ethical considerations

Ethical approval was granted by the University of Stirling (Appendix 6) and East of Scotland NHS research committees (REC Reference number: 08/S0501/98, Appendix 7). During the process of obtaining ethical approval, I considered a number of ethical issues. Given the small numbers within groups of staff at the hospice (see section 4.4.1), it was possible that some members of staff would be identifiable from the data, despite all the precautions taken. Potential participants were given the opportunity to discuss this issue in detail with me, and I made staff aware that their anonymity could not be guaranteed in the final report. Following discussion, staff stated that they were happy to participate in the study. To try and reduce the likelihood of staff being identifiable, each professional was allocated a pseudonym. When giving examples from the data, I will refer to all non-nursing and non-medical staff as AHPs and will use pseudonyms for all participants.

As described in section 4.4.3, prior to carrying out observations, each patient was asked for their permission. Staff carrying out the consultations gave patients the information sheets (Appendix 8) and any questions that arose were answered either by the member of staff or myself. It was made clear that patients could refuse to give their permission and that they could change their minds at any time. Patients were given at least 24 hours to consider whether or not they wanted to take part in the study. During the study, four patients who had initially agreed to be observed later declined to take part.

A major ethical issue in this study related to the case note analysis because I was looking at notes without the explicit consent of the patients involved. The Medical Research Council states that "*normally researchers must ensure they have each person's explicit consent to obtain, hold, and use personal information*" (Medical Research Council 2000:9). However, they also state that "*Researchers must also have procedures in place to minimise the risk of causing distress to the people they contact in the course of their research*" (Medical Research Council 2000:9). Many of the people whose notes were analysed during the course of this study had died. I felt that contacting relatives to gain permission to look at the notes of their deceased relative would be likely to cause unnecessary distress and for this reason, explicit consent to analyse patient notes was not sought. The University of Stirling and NHS research and ethics committees were satisfied that this was the right decision, and did not question it during the ethical approval process.

4.5 Analytical approach

The purpose of the case studies was to provide a description of goal setting practice in one hospice setting and to begin to provide explanations about why it happened as it did. I took a descriptive approach to the analysis of individual cases in the first instance and then built explanations as I made comparisons between and within cases. As a first step, I built up an overall picture of each case. This included providing demographic information and a summary of what each professional said, did and documented. I used Framework Analysis (Ritchie and Lewis 2003, Ritchie and Spencer 1994) to organise and analyse the data (see Chapter 3.2.4). This provided me with a method that had *'distinct though interconnected stages'* (Lathlean 2006:424) which could be checked to ensure validity and minimise personal bias in my analysis. It also allowed me to develop meanings and connections during the analysis process. The key stages of Framework have been outlined in Chapter 3 (section 3.2.4), but are provided below as a reminder:

Stage 1: Familiarisation

Stage 2: Identifying a thematic framework

Stage 3: Indexing

Stage 4: Charting

Stage 5: Mapping and interpretation

(Lacey and Luff 2001:11)

Case note analyses for each professional, transcripts and field notes were read and re-read before initial coding was carried out (Stage 1). I then began to highlight recurrent topics and made up an initial thematic framework (Stage 2). The process of initial coding was iterative, and I began by making a series of mind maps to summarise my initial themes. An example is provided in Figure 16.

Figure 16 Mind map showing initial thematic framework
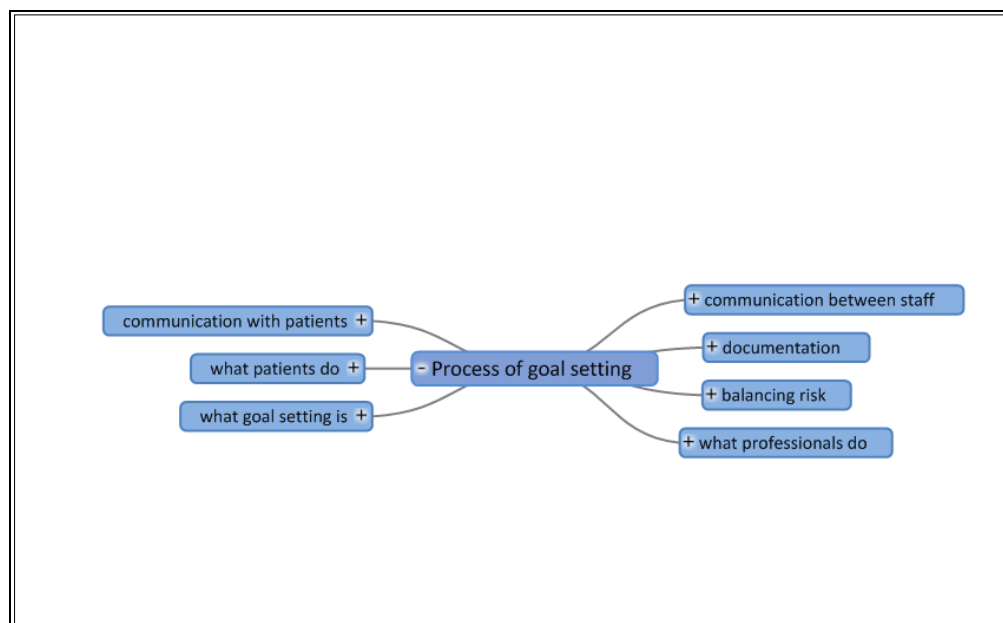
I discussed the initial coding framework, transcripts and field notes with my supervisors and we revisited the literature and original research questions. The process eventually led to three broad themes which could be applied to the case study data. These are shown in Table 11.

Table 11 Thematic framework

1. **What goal setting is**	2. **Challenges/what affects goal setting**	3. **Emerging theory/ conceptual underpinning**
1.1 Goal setting is important	2.1 Risk	3.1 Adaptation
1.2 Current goal setting practice: SMART, patient centred, ordinary things	2.2 Patient experiences/preferences	3.2 Hope
1.3 Process (communication, negotiation)	2.3 Organisational	3.3 Not acknowledging the problem
1.4 What professionals do (assessment, advice, reality check, sorting out practicalities)	2.4 Deterioration	3.4 Giving patients control
	2.5 Communication	
	2.6 Different points of view	

Once we had agreed on the thematic framework (Table 11), I coded a third of all the transcripts and field notes using NVivo software (QSR International Pty Ltd. 2008). These were cross-checked against the field notes and transcripts by my supervisors to ensure that the process of coding was consistent and rigorous. I then coded all the remaining data. Charts were created so that the data could be looked at as a whole, allowing for thematic comparisons to be made between and within cases. Direct quotes from the data were put into the charts so that the original meaning could be retained and checked within the transcripts and field notes. Once data had been organised thematically, I was able to identify patterns and associations between cases and to make comparisons between what people said, what they did in practice, as well as how they documented goals.

The following example comes from notes taken during my analysis:

> Under the theme 'emerging theory/conceptual underpinning', Case three (Charlotte, a
>
> nurse) made no reference during **interviews** to what she was trying to do at any

*abstract level. However, in practice (during **observations)**, it was clear that she helped patients to adapt to their situation by suggesting alternative ways to achieve goals (such as taking a taxi instead of driving). She also supported patients by helping them to reflect on their achievements and encouraged them to do the things that mattered. In the **case notes**, Charlotte refered to the tension that patients face as they try to maintain hope whilst being realistic about the time they have left. Although Charlotte did not explicitly refer to it in the interview, what she did in practice could be seen to underpin hope and thus be mapped to Hope Theory (Gum and Snyder 2002) and Affirming life: Preparing for death (Bye 1998), as discussed in chapter 3.3.3.*

This is one example of how I used Framework to build a picture of each case and begin to generate insights into how goal setting is understood and used in practice within the hospice. In the example above, there is a difference between what Charlotte *said* and *did*. I was able to look at each chart and search for other professionals whose practice appeared to be consistent with underlying theory. I then looked at the characteristics of these professionals and began to look for explanations as to why this was happening. I compared the data from the transcripts and field notes with data from the case notes.

In the next section I report on the results of the analysis. I firstly provide a description of each 'case' and then report on the more detailed analysis which involved within and across case comparison, resulting in more detailed analysis of the themes which were identified. Following this, I will discuss implications of the findings, relating them to existing theoretical models of rehabilitation.

4.6 Findings

A total of ten individual interviews and twenty eight separate observations were carried out (two professionals were only observed twice because of difficulties coordinating my time with that of the professionals and patients). Sixty seven sets of notes were analysed (these had

been contributed to by at least one of the ten professionals). Characteristics of the case note sample is summarised in Table 12.

Table 12 Characteristics of case note sample (n = 69)

Age		Diagnosis		Length of stay in hospice		Discharge information			
Range	*Average*	*Cancer*	*Non-malignant life limiting disease*	*Range*	*Average*	*Home*	*Hospital*	*Nursing home*	*Patient died*
28 - 90	38.46 years	53	16	0 – 106 days	18 days	56	6	4	3

4.6.1 Description of each case

I now provide short summaries of what each professional said about the process of goal setting, what they did in practice and how they documented goals, organised under the three themes discussed in section 4.5 (Table 11). The aim of this overview is to provide an impression of how each professional dealt with goal setting in practice, rather than a detailed analysis of what each professional said, did and wrote about. I firstly provide brief summaries of each professional and then use excerpts from observational, interview and case note data to demonstrate that I have attended to all the available data (Table 13). The purpose of presenting each case on a table is to allow within and across case comparisons to be made. (Yin 2009) I present a more detailed analysis in relation to each theme in section 4.6.2 onwards.

Alison is an AHP who has worked in palliative care for over 20 years. She believes that goal setting is an important aspect of palliative care that gives patients a sense of hope and achievement. She believes that the process is an implicit one involving identification of problems and helping patients to discover their limitations. In practice, Alison spends time identifying problems with patients and balancing risk. She rarely documents specific, patient centred goals, tending to focus on problems or more general goals.

Becky is a doctor with between 5 and 10 years of experience working in palliative care. She believes that goal setting is an important part of palliative care that is relevant for everyone. Becky believes that the process of goal setting is an implicit one involving a process of negotiation and reality checking. In practice she documents goals but also identifies problems with patients.

Charlotte is a nurse who has worked in palliative care for over 20 years. She acknowledges that goal setting can sometimes be challenging because of differing points of view and clinical deterioration. She believes that the goal setting process is an implicit one, and acknowledges that documentation could be improved. In practice, Charlotte asks patients what they are managing to do and actively encourages patients to balance living whilst dying. In the case notes, she focuses on problems and symptoms.

Debbie is a doctor who has worked in palliative care for less than five years. She believes that goal setting is an important part of palliative care, and that it is a process of negotiation. She feels that documentation could be more explicit. In practice, Debbie finds out about patient's problems, but also asks patients what they want to be able to do. She also discusses action plans with patients. She documents some goals in the case notes and tries to help patients to adapt.

Elaine is a nurse with between 5 and 10 years of experience working in palliative care. She talks about goal setting as a process of negotiation between professionals and patients. She believes that goals should be realistic and that it can be particularly challenging if patients are unrealistic or if their condition deteriorates. In practice, Elaine encourages patients to adapt as their condition changes, and tends to focus on symptoms, problems and balancing risk. In the case notes, she focuses on symptoms and problems.

Frances is an AHP with between 5 and 10 years of experience working in palliative care. She believes that the process of goal setting is an implicit one that involves a process of negotiation. She feels that goals should be realistic and finds it challenging when patients have unrealistic goals. In practice, Frances asks patients what they want to achieve, but also identifies problems. She encourages patients to adapt to their changing situations and plan for the future, after they have died. In the case notes, she focuses on balancing risk as well as providing equipment and discharge planning.

Katie is an AHP who has worked in palliative care for less than five years. She believes that goal setting is important and that goals give patients a sense of achievement and control. She feels that the documentation could be improved and believes that, in the hospice, other professionals tend to focus on problems and symptoms rather than goals. In practice, Katie asks patients what they would like to do and encourages them to prepare for the future, focusing on what patients can do rather than symptoms and problems. However, this is not reflected in what Katie writes in the case notes, which report on practical tasks which she has done, rather than patient's goals.

Hazel is a nurse who has between 5 and 10 years of experience working in palliative care. She believes that the goal setting process is an implicit one. She believes that goals should be achievable and that it can be challenging when patients and professionals have different points of view or if patients are unrealistic. In practice, Hazel tries to find out about patients' points of view and focuses on their achievements. In the case notes, Hazel writes about problems and balancing risk.

Iris is a nurse with between 5 and 10 years of experience working in palliative care. She believes that goal setting is an important part of palliative care that gives patients a sense of hope. She believes that it is always possible to set goals with patients but that sometimes,

professionals focus on care rather than goals. In practice, Iris focuses on practical nursing tasks and balancing risk. This is also reflected in what she writes in the case notes.

Janet is a nurse with between 5 and 10 years of experience working in palliative care. She believes that goal setting is an important part of palliative care and that goals and hope are linked. She believes that goal setting provides a focus for patients and professionals and can give patients a sense of achievement. In practice, Janet asks patients about goals and works with them to make short term action plans. She acknowledges uncertainty and helps patients to adapt their goals or ways of achieving them. In the case notes, Janet writes about risk and what patients can manage rather than focusing solely on problems and symptoms.

Table 13 Summaries of what each professional said, did and documented

Professional	What is goal setting	What affects goal setting	Emerging theory
Alison - WHAT SHE SAYS	**Believes that goal setting is important :** *'Well I think in Palliative care it's very important to let patients goal set'* **Goals should be achievable and made up of a series of small steps:** *'Let's see what we can do today and build on that. What we can do to help you to achieve that particular goal.'* **The process of goal setting is about helping patients discover limitations and identify problems:** *'To bring them along and do a small stair assessment and it lets them see*	**Balancing risk:** *'so we need to be very sure that what we're allowing patients to do is safe for them, and sometimes it maybe risk's involved'* **Feels that illness, practical problems, and mood can affect goals:** *'sometimes it may be that they're feeling a wee bit low in mood and they haven't been out of the hospice, and you can see that the fact that they're in their room or, aren't using the facilities so well.'*	**Talks about goals giving patients hope and something to work towards:** *'I think it gives them a form of hope and I think it gives them something to do urr, to aim for each day rather than waken up in the morning and just feel that this is me again. Another day.'* **Believes that achieving goals leads to more goals, increases patient's confidence and gives them control:** *'I think it's important if they have a small goal that they achieve what they can and it gives them a purpose and it lets them live with the illness rather*

Professional	What is goal setting	What affects goal setting	Emerging theory
	either how impossible it is or how breathless that makes them feel.' **The process is implicit rather than explicit:** *"I think it's something that we don't state 'goal setting', we don't tend to use the word. I think we do say the 'patient would like to' or 'has a wish to do'"*		*than just lie and wait for it to take over – more and I think patients are sometimes are surprised at what they do achieve.* **Goals may need to be adapted:** *'if the goals are a little bit unrealistic, we can often encourage patients to come back a pace and say well maybe today we'll deal with today and right now and not worry about urrr next week'*

Professional	What is goal setting	What affects goal setting	Emerging theory
Alison - WHAT SHE DOES	**Helps patients discover limitations for themselves:** *Alison demonstrates what she wants Sarah to do – she goes up the stairs and explains that she can put a stool at the top so Sarah can have a rest if she needs one.* **Focuses on problems:** *'She acknowledges that Sarah wants to go home, and says that she wants to look at "what's difficult".'*	**Checks medical risks:** *'She also states that they can't do any exercises for the leg until they know how it's going to be treated, although she can still do the 'exercises with the board'* **Is aware of different people's points of view (family, patient, professional):** *'After the session, Alison is keen to discuss it with me. She talks about the tension between her assessment of Sarah's abilities and Sarah's view of what she can manage. Alison explains that Sarah wants to go home but that she*	**Helps patients adapt by showing them what they can and cannot manage:** *'Prior to my observation, Alison briefly chats to me about the purpose of the session – The lady (Sarah age 65) wants to go home. Alison is concerned about how Sarah will manage the stairs if she goes home, and wants to explore this in today's session.'*

Professional	What is goal setting	What affects goal setting	Emerging theory
		isn't sure that this is realistic. She also mentions that Sarah's son wants Sarah to stay in the hospice rather than go home' **Does not always listen to patient's problem solving ideas:** *'Betty has stated that managing the stairs is not really a problem, because of the adaptations that they have already made (they have either a down stairs toilet or a commode – I am not sure which), Alison, does not explore this any further.'*	

Professional	What is goal setting	What affects goal setting	Emerging theory
Alison - WHAT SHE DOCUMENTS	**Focuses on her interventions and risk assessment rather than specific goals:** *Case note 5: 'maximising potential, manage oedema'* *Case note 12: "hoist would be safest. Patient is OK with this"* **Documents one specific goal (getting home for Christmas):** *Case note 38 'wants home for Christmas day visit. Would have difficulty getting in/out of car. Disabled taxi would be safest option. Nurses aware.'*	**Writes about the problems of patients accepting their limitations and listening to advice:** *Case note 57: 'I feel patient does things her way and often does not wish more professionals to be involved.'*	**Documents how patients are adapting to deterioration:** *Case note 48: 'Agreeing to have urinal at home to ↓ times he has to do stairs'*

Professional	What is goal setting	What affects goal setting	Emerging theory
Becky - WHAT SHE SAYS	**Believes that goal setting is important:** *'I think it's hugely relevant.'* **Believes that goals can always be set:** *'Wouldn't set goals? Pause. No. I think – I think you can always – identify goals with patients'* **The process is an implicit one:** *'Yes, I don't think it's just – err 'what d'you want to do, what d'you want to aim for' – err I think it's much more interwoven than that'* **Goals should be achievable and made up of a series of small steps**: *'So I think with the goals – there's this kind of too-ing and fro-ing*	**People may have different opinions:** *'but I think we also have to remember that the patient's family might have goals which may or may not be the same as the patient. And I think also as health professionals, we too have goals within a palliative care setting um. And I think the challenge is to – see how they overlap'* **Professionals have a duty to explain risks:** *'we have a duty to explain the risks, but I think as long as we've done that and it's an informed decision that they're making then – yeah, uh huh. I think that despite reservations, people do go away and come*	**Goal setting gives patients control and a sense of achievement:** *'The sense of achievement. – Was important – a sense that – still being in control, because I think initially the team's reaction was you know – it's not gonna work, it's not going to happen. – and I think that feeling of – yeah, I can and I've got a bit more autonomy back and I can make – I'm participating in – in decisions.'*

Professional	What is goal setting	What affects goal setting	Emerging theory
	– a kind of checking – is it achievable, is it not achievable. What do we need to make it achievable.' **They should be patient centred:** *'I think the patient themselves, are at the centre of it.'* **Goal setting is about finding out what's important to the patient:** *'Just a very open question –'what can we do for you?' Or 'What's important for you?''* **It is a process of negotiation and should be regularly reviewed:** *'So, it's - it's a too-ing and fro- ing – it might involve negotiation – or modifying what the goals are, depending*	*back.'* **Communication about goals between the team is important:** *'Yes. I think it's communication within the health professional teams – I think if someone picks up on something – it may be that they're wanting to go somewhere. There will be a discussion in the team about whether it can happen um.'*	

Professional	What is goal setting	What affects goal setting	Emerging theory
	on the situation.'		
Becky - WHAT SHE DOES	**Identifies problems with patients:** *'Becky directs the conversation back to Bill – "what else have you been having trouble with that we can help you with?"* **Checks how much patient's understand about their situation:** *'Becky interrupts: "can I go back a bit – and find out about your understanding of the illness".'*	**Balancing limitations of illness with what patients can actually do:** *'Pete then explains that he had gone up the steps with the physiotherapist. He says that he was "tired at the top. Then I understood". Becky says that "the suggestion's been that at home you would live on one level".* **Does not always pick up on goals which patient's talk about:** *'Pete replies: "I've got my greenhouse. I paid £745.00 for it six months ago. I would need to walk away and leave it". Pete talks about the waste of having*	

Professional	What is goal setting	What affects goal setting	Emerging theory
		a greenhouse lying doing nothing. Becky acknowledges that gardening is important but does not pick up on how this goal might be addressed.'	
Becky - WHAT SHE DOCUMENTS	**Writes about implicit goals:** *Case note 5: 'doesn't like large number of tablets'* **Documents goals:** *Case note 21: 'wanting to go home for hogmanay "as a surprise" for his wife I have expressed concerns how he would manage – fell at Christmas and returned early as struggling. – Appears frailer than last week. Suggest we review nearer the time.'*	**Writes about differing perspectives between patient, family and professional:** *Case note 18: 'still being assessed. Family expecting him to be 'built up' for home. Need to address their expectations – likely to deteriorate soon'.* **Writes about deterioration and how patient adapts:** *Case note 34: 'very keen for home and accepting of limitations/modifications to*	**Writes about the balance between maintaining hope and realism:** *Case note 45: Talking about goals – has seen his son get his driving licence. Hoping to see other son get through finals – gently challenged this but still hoping.'*

Professional	What is goal setting	What affects goal setting	Emerging theory
	Writes about symptoms and problems: *Case note 50: ''pain better. Wound management ongoing.*	*lifestyle to facilitate this.'*	
Charlotte - WHAT SHE SAYS	**The process is implicit:** *'Yeah, and I think that's - that's, well, it's more than vaguely goal setting. It's not – it's not a kind of –it's not a written thing and it's not a step by step thing – it's quite an informal thing. But the goal setting's there.'* **It involves a process of negotiation and finding out what patient's understand about their illness:** *'I would kind of go –round about and you know, try and – get them – to*	**Patient's cognition, fatigue and symptoms can affect goal setting:** *'I've got a man who's got a wee bit of confusion – short term memory isn't good – and he has a facial cancer. And um – all he wants is not to have this pain. – and he doesn't have a lot of capacity in other ways. And I haven't even tried to – set goals with him in that sense – but I've done it with his daughter.'* **Documentation of goals could be more**	

Professional	What is goal setting	What affects goal setting	Emerging theory
	understand how realistic would that be – *according to disease, of according to what's* *been happening in the last few weeks – ask* *them questions back.'*	**explicit:** *'we all have the same documentation* *that we need to fill out, but yeah, we do it in* *different ways with a different emphasis –* *would say. And – we actually did a* *neurological checklist for patients coming in* *and C and L and I devised something and we* *realised now it's not very good – but it was at* *least a help.'*	
Charlotte - WHAT SHE DOES	**Asks what patients have been doing/managing and how they are coping:** *Charlotte changes the subject, asking "have you done the boat at all this week? (I assume that they are referring to a model boat). Paul*	**Acknowledges the challenges of working alongside other organisations:** *As we walk back to the car, Charlotte tells me how frustrated she feels. She had spent a lot of time training the carers to carry out passive*	**Tries to help patients balance living with dying. Gives positive feedback on achievements:** *Charlotte comments "you're obviously coping with the pain", saying that the pain is not stopping her from doing*

Professional	What is goal setting	What affects goal setting	Emerging theory
	says that you "need a steady hand". He then talks about how his arm held him back from tying up the clematis as he could only move his arm "so far". **And:** *Charlotte asks: "how are you feeling within yourself?"*	*exercises with Rita and has also gone over the importance of positioning as a method of helping top control Rita's pain. She does not feel that the carers have been following her advice.*	*things, such as the decorating.* **Encourages patients to adapt and do things in different ways:** *Charlotte wonders if wearing the sling would help with this type of thing? Paul says that it "gives support but you cannae get the reach" and says that between he and Kate they managed to get the job done. Charlotte reinforces to Paul how well he is adapting.* **Provides feedback to patients about doing things to 'keep going':** *Carol then talks about how she is "doing things to keep me going". Charlotte agrees*

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Professional	What is goal setting	What affects goal setting	Emerging theory
			that she is doing this – and reminds Carol of how ill she was before.
Charlotte - WHAT SHE DOCUMENTS	**Writes about problems and symptom management:** *Case 41: 'Speech: weak and tired. Mood: very low. Fatigue +++.'*	**Writes about the challenge of patients having different points of view to professionals:** *Case 9: 'wife feels that she is coping well with caring for T……wants him to die at home if possible. Because "he is stable"(!) Thinks he may live for years'.*	

Professional	What is goal setting	What affects goal setting	Emerging theory
Debbie - WHAT SHE SAYS	**Believes that goal setting is important:** *'It's really important – urr – in a hospice setting.'* **Goal setting gives people a focus.:** *'it gives both the staff and the patient a kind of focus so that we all know what we're working towards.'* **The process involves negotiation and compromise:** *'trying to get them to realise where they are in their disease. And – trying to get them to look at what they're actually managing at the moment and how much of that they would manage – say at home or in another environment. And then it's trying to*	**Working with other agencies can be challenging:** *'There was also the wider set up by the community team – the district nurses and the GP and em the community OT were all not em on board really with trying to either get her home with long term care or nursing home.'* **Deterioration and symptoms can affect goal setting:** *'you're constantly assessing goals because you've often told the nurses well we were planning - this patient had been planned for home but they've not been well today and now they need a hoist to transfer –or so we're*	

Professional	What is goal setting	What affects goal setting	Emerging theory
	get a compromise between what might be achievable in a short visit home or what's achievable on discharge home.' **Goals should be short term and may need to be adapted as things change:** *'It's easier to discuss err shorter term goals to begin and then once we get a better understanding of the patient themselves and the illness and what their needs are. Then it's easier to discuss longer term goals, once you know them a bit better.'*	*constantly reassessing the goals.'* **Documentation could be more explicit, which might help communication between team members:** *'usually there's some documentation about what's been discussed with the patient in terms of what we're aiming for in terms of the goal em and then there's often communication from different team members, like the physio, the OT and social worker as to where we are in achieving that goal – but it can sometimes I guess it can be throughout the notes it can be quite*	

Professional	What is goal setting	What affects goal setting	Emerging theory
		difficult to – to find at times.' **Patients and professionals can have different points of view:** *'quite often the family's idea of what the patient might manage and the patient's idea and the doctor's idea – is all very different. So it's trying again to come to – some sort of compromise.'* **Goal setting can be difficult if patients are unrealistic:** *'if we're looking towards home or if we're trying to find out how realistic the person's goals are. And maybe even – not destroy them – but err try and - you know – try and see if we can – if we – if we're maybe*	

Professional	What is goal setting	What affects goal setting	Emerging theory
		looking – if the patient's goals too – too difficult or too unrealistic and we're maybe trying to create a goal that's in between.'	
Debbie - WHAT SHE DOES	**Finds out about patient's problems and symptoms:** *'Debbie immediately starts the conversation saying she wants to "get a feeling for what's been most problematic".* **Asks patients what they would like to 'do':** *'Debbie asks Evelyn what type of things she would like to do. Evelyn says she would like to be able to go out but she is "too tired to go out".'*	**Acknowledges with patient that their illness gets in the way of goal achievement:** *'Debbie talks about Hannah's tiredness. She says that this might not go away as her liver is not working very well. She says that they may need to find ways "to help you cope with it".'*	**Discusses action plans:** *'Debbie goes back to talking about what the hospice will need to do to get Hannah home: "we need to get an idea of what sort of help you need" and says that she will need assessment from the physio and OT.'* **Gives the patient control. Helps them to adapt:** *Debbie talks about the next steps for Hannah: "the main aims had been to get home – is that still the case?" Hannah agrees*

Professional	What is goal setting	What affects goal setting	Emerging theory
			that yes, this is still what she is aiming for: "that's why I wasn't averse to coming in here. Things don't happen with a magic wand. There's lots to do". *Debbie agrees, saying* "we'll need to look at your mobility and see what supports are needed" *(to get you home).*
Debbie - WHAT SHE DOCUMENTS	**Documents general goals:** *In admission document (case 15): 'To give his wife a rest. To find out what's causing his pain'.* **And more specific ones:** *Case 21: 'Managed stairs. Burning in feet still a problem. Not sure when he's doing his Christmas shopping!*	**Writes about risks:** *Case 22: 'Fall during night when she tried to get up by herself and lost balance.......Mrs G adamant she is going home.* Relates symptoms to activity limitations. *Case 34: 'only gets pain during washing but is*	

Professional	What is goal setting	What affects goal setting	Emerging theory
	Pupils OK. Keen for home tomorrow until Sat. Plan – arrange discharge/pass meds. Discuss with social work to help with shopping'.	*now using sevridol prior to care which helps'.* **Relates symptoms to activity limitations:** *Case 34: 'only gets pain during washing but is now using sevridol prior to care which helps'.*	
Elaine - WHAT SHE SAYS	**Goal setting gives a focus:** *'but I think with palliative care patients you know – because if you don't set goals, then which direction are you going in? So – and the patient – most patients like a plan of action.'* **It is a process of negotiation between patients and professionals:** *'You can try – gently try to say - lets come back a bit here, and – you know, try and get them to see.*	**Patient's preferences and illness affects goal setting:** *'That situation didn't go very well because, as we predicted, her condition deteriorated very rapidly – in a short space of time – we managed to get her on the waiting list – at the end of one week, with a view to getting admission at the beginning of the following week – but we missed the boat.'* **It is difficult to set goals with patients who**	**A tension exists between giving people hope and realism:** *And - in so many words, who are we to say – to take their hope away – you can try and be realistic with them. They might not want to hear that – so, do you go along with them and support them? Or do you go completely against what they're hoping and maybe not get back in – in the door.*

Professional	What is goal setting	What affects goal setting	Emerging theory
	Kind of where they're at physically - And try and get them to acknowledge – no, I'm not as good as I was. But that's very, very difficult. It's a fine – a fine line.' **Goals should be realistic:** *'But I think as well that we have to be realistic.'* **You can always set goals:** *'and even that visit where they're very unwell or poorly, they might not even be able to communicate with you – you're still saying - we want to achieve the goal of comfort and control of symptoms. And that the family feel well supported.'* **Tries to help patient plan ahead and**	**are unrealistic:** *'I think as I said, the challenges are with - you know, a patient that really doesn't want to – accept their illness – I think it's very, very difficult.'*	**Patients do not always acknowledge problems:** *'I think the patient deep down knew that he was deteriorating but because he'd been such an independent man – that he felt that he – he's quite stubborn as well and he thought we could do this – he thought he could still do this for himself.'* **Goals give patients control:** *'but he's alert and orientated enough to make decisions about what he wants – em and that's where I feel that he can still have that element of control.* *That we're still listening. We're not just*

Professional	What is goal setting	What affects goal setting	Emerging theory
	anticipate problems: *'maybe in the initial visit if I think the patient may be complex, then I'll maybe test the water and say – if we can't achieve these things at home – would you consider in the future – or I'm letting you know what's available in the future. So I've already sewn the seed with them and they can think about it.'*		*seeing that person as debilitated, frail, lying in a bed and can't think for himself. When actually he can – so it's giving him those choices.'* **Goals can be about everyday life or leaving a legacy:** *'I've had younger patients maybe with grandchildren that they want to do memory boxes with and – it's about - providing time to discuss that – what they want to put in that – maybe other family members to help them – so that's a goal to achieve.'* And *'then we'll try everything to get their*

Professional		What is goal setting	What affects goal setting	Emerging theory
				symptoms under control – and make them feel, you know – um – just brighter in themselves and that they've got quality to err enjoy that party – or - it might be the last thing that they do – but that's what they want to achieve.'
DOES	Elaine - WHAT SHE	**Focuses on problems and symptoms:** *She then asks some more probing questions, trying to find out what the main problems are: "so, dizziness is still a problem from time to time, but head aches in the morning? – when you waken up?"*	**Checks risks:** *Elaine asks "any more falls?" Helen says that no, she hasn't fallen again. She thinks the zimmer is helping her, although sometimes she walks away and leaves it.*	**Encourages patients to adapt:** *Elaine reassures her saying "you were pacing yourself. Working within your limitations. You were listening".*

Professional		What is goal setting	What affects goal setting	Emerging theory
SHE DOCUMENTS	Elaine - WHAT SHE DOCUMENTS	**Focuses on problems and symptoms rather than goals:** *Case 34: 'Pain, Lymphedema, wound care, respiratory issues, nausea, financial issues and psychological issues.'*		
	Frances - WHAT SHE SAYS	**Goal setting is implicit:** *'Because I think we do it automatically but don't necessarily think of it in terms of 'we are goal setting'* **Goal setting involves finding out what people want to achieve:** *'It's purely about things that people want to achieve.'* **Goals are often about ordinary things:** *I think that their main goals when they come in here tend to be like getting rid of the*	**There is sometimes a gap between what patient's say they want to do and what they actually do:** *'And you've gone to them to try and they are saying the words, they want to do this, but when you actually go to them and try to get in and get started and suggesting that they get things brought in from home they just keep prevaricating and putting it off and putting it off and putting it*	**Goals give patient's hope and a sense of achievement:** *'And I feel that when she was in here she lost everything and with working, everybody worked really well with her and gave her back that autonomy and that control and that gave her the courage to take back other things'*

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Professional	What is goal setting	What affects goal setting	Emerging theory
	symptoms, getting their mobility back, getting back home and they tend to be the main ones, so for myself I tend to focus more on that side of things and occasionally you'll have people who'll have the goal of .. "I want to make something or write letters", or some things that are a bit out of the usual. **Goals can be about leaving a legacy:** *'she also left a wonderful legacy of lots of lists and instructions and things so that her husband could cope with Christmas and start of school again and birthdays and all sorts of things.'*	*off.'* **Patient's goals can change:** *'Where the patients goals have changed.'* **Time pressure – people can be discharged too quickly:** *'It does tend to be that when the symptoms are under control, we get them home because we have more patients waiting to come in.'* **Documentation could be improved:** *'So I think if it was documented and it's clearly there that these are the patients' goals. Then anyone can help to achieve them or achieve any part of them.'*	**Goal setting can help people adapt as illness progresses:** *'Yes, because it focuses them as well. Just to keep them in mind and sometimes to look at them and think "well I am working on this and I've achieved that and that's me kind of a third of the way towards that goal and now I need to look at…" '*

Professional	What is goal setting	What affects goal setting	Emerging theory
		Patients can be unrealistic: *'the only time when I don't do it, is when I have someone who is so unrealistic and they actually have to been shown that they cannot achieve that.'* **Patients and professionals may have different points of view:** *'So what I would say is that quite often we have a bit of conflict where relatives - and because it's not that they don't want them out, they don't want them to achieve that goal, but actually they are terrified and also the amount of input that a patient can sometimes expect from family is far, far more than they can ever commit to.'*	

Professional	What is goal setting	What affects goal setting	Emerging theory
Frances - WHAT SHE DOES	**Focuses on everyday tasks, equipment and the environment:** *She explains what her role is, saying she is here to help John with everyday tasks such as getting in and out of the car, washing and dressing.* **Identifies problems and suggests solutions:** *Frances asks Eric if there is "anything else at home that is difficult?"* **And:** *Frances explains that direct debits and phone banking can be a good way to deal with finances.*	**Focuses on risks:** *Frances then says "rugs?" Tony says that he does have rugs. Frances says "sometimes it's easier to lift the rug. There's less risk of you tripping." Tony says "if I've got to take it up, I'll take it up. It's not an issue."*	**Makes suggestions about how patients can adapt:** *"How do you feel about a wheelchair for outdoor use?" Tony says that he will "just have to accept it".*

Professional	What is goal setting	What affects goal setting	Emerging theory
	Encourages patients to do things for themselves: *She says that she would "like to see what you can do for yourself in terms of washing and dressing".* **Asks patients what they want to do. Asks patients about their hobbies:** *Frances asks "what other things do you like to do? You obviously like the computer?"*		

Professional		What is goal setting	What affects goal setting	Emerging theory
Frances - WHAT SHE DOCUMENTS		**Writes about organising equipment and discharge planning rather than goals:** *Case 42: I will consider pros and cons of both houses over weekend and make decision on Monday. Care equipment will be decided then.'*	**Focuses on risk:** Case 69: *'patient has his own method of using equipment and is not always safe.'*	
Katie - WHAT SHE SAYS		*Goal setting is important:* 'It's hugely important – yeah' *Goals can be set with everyone:* Can you think of anyone you wouldn't set goals with? 'No. I can't. Pause. Um. No (laughs). I don't know – it might be easy to say with somebody at the end of life, but that's not	**Balancing risk:** *'so, for example, with discharge planning – the main difference that comes up is that staff think that the patient is –at too much of a high risk to live at home.'* **Deterioration:** *'Sometimes there's been a situation where the goals haven't been um completed or fulfilled - Because – um – the*	**Goals give patients a sense of control and achievement and raises patient's self-esteem and sense of self:** *'It's about helping them to feel that they're still participating, that they're still in control. That they have the right to make decisions. That they're still living, they're not dead – so - so kind of embrace that where we can. Um – so – living*

Professional	What is goal setting	What affects goal setting	Emerging theory
	true. You know, I've worked with people who just wanted to write their will – and they were dying.' ***Goals should focus on what the patient can do:*** *'We focus on the 'I cans' so - this is the part of your life that you have power and control over.'*	*person has died –part way through it.'* **Focus on dying and symptom control can be easier than focusing on goals:** *'I think that symptoms is perhaps a bit easier – and maybe a bit more – it's more comfortable for staff because it's got a beginning and an end'* **Patients and professionals may have different points of view:** *'but they feel that they have to cause maybe there's family pressures or because they keep getting the message from medical staff that they'll be unsafe – so in that situation'*	*until you're dead comes in – that whole idea isn't it. Um – giving – giving people that kind of um – sense of self-esteem really – a sense of self.'*

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Professional	What is goal setting	What affects goal setting	Emerging theory
		Goals get lost in the notes: *'I guess if the person's got clearer goals, they're easier to pick out, but for a lot of patients it's – err – pause – what is written down is just what happens on a daily basis. So sometimes the goals get lost in that.'*	
Katie - WHAT SHE DOES	**Helps people to prepare for the future:** *Katie says "I think it's an opportunity to get things in writing and where you want things to go".* **Picks up on positive aspects of what patients are saying:** *Katie pauses before answering and then says "it sounds like*	**Acknowledges that illness gets in the way of goal achievement:** *Katie says "it sounds like you're frustrated" Eric replies "it's just the pain I'm in. I can't walk very far. If I could get the pain down, I would be able to do more things. The pain in my back's awful at times."*	**Acknowledges that patients are living with dying:** *Katie says that she has worked with people, making memory boxes. She adds "people think it's about saying goodbye. But it's about –'I loved you' and 'we had a good time'".*

Professional	What is goal setting	What affects goal setting	Emerging theory
	you're really on track.		
	Asks patients what they want to do.		
	She asks "so – the ultimate aim is what? *What do you want to do?"*		
	Suggests patient takes control: *Katie asks "is there stuff you'd like to be doing?" Eric replies: "I don't know. My head's – I sit here – on a right downer for a few minutes. It's like being on a roller coaster". Katie says "I think that's really normal. There's so much to think about". Eric tries to sound more up beat, saying "I'm going home tomorrow. I've a lot of things to do, to sort out".*		

Professional		What is goal setting	What affects goal setting	Emerging theory
		Shifts focus from pain to what patient wants to do: *Katie empathizes with Eric: "you're just trying to live with the unknown. – It's about what you want to do".*		
	Katie - WHAT SHE DOCUMENTS	**Writes about practical tasks done with patients:** *Case 9: 'MECS referral made'.* *Case 21: 'Met with wife to discuss process of moving to a nursing home.'*		
SAYS	Hazel - WHAT SHE	**Goals can be set with everyone:** *'I think it's really relevant. I mean it, it doesn't matter what stage their illness I think if you can set an achievable goal, that's good for them psychologically and physically as well.'*	**Disease progression:** *'we get concerned about sending them home because they have such chronic conditions – but we're finding goal setting with patients like that a bit more difficult because we're not familiar. Um – with*	**Goals give patients and families a sense of achievement:** *'But, when it did happen, she was quite high when she came back and she got over her concerns and I think she even said that she had done it once – that she*

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Professional	What is goal setting	What affects goal setting	Emerging theory
	Goals can be about achieving small things but should be achievable: *'trying to achieve something for um the patient or the families or even from the nurses side – for um – the patient or family that might be a very short term goal or a long term goal – but, really they have to be achievable.'* **Need to discover what patients _can_ do:** *'to achieve something that they didn't think they could achieve. Um maybe going to day care and finding a talent that they didn't know they had – so, with support from the staff here, they could – they could do that.'*	*their diseases'* **Patient and professional may have different points of view:** *'nearly every family that you're communicating with, you have to negotiate with – you know – sometimes – um – they're not realistic and you have to explain that. Um – with a lot of discussions, they might ask several members of staff – so you've got to work as a team'* **Documentation could be improved:** *'There's always room for improvement in documentation. Um – encouraging the multidisciplinary staff to be – to –write more*	*could do it again.'*

Professional	What is goal setting	What affects goal setting	Emerging theory
	The process is implicit: *'So you can do that tomorrow – and that probably is a goal. But we haven't said that to the patient.'* **Goal setting is about managing symptoms:** *'so – a goal for nausea might be um to try a certain medication. If that's effective, then maybe we'll get rid of the syringe pump – so our goal is to get onto oral medication so you can start enjoying your food. Um – another goal might be to alleviate pain – um – so if you ask for your analgesics before the pain gets too high then um – you'll achieve your pain free goal – so it could be on lots of*	*in the notes'* **Communication about goals between staff is not always consistent:** *'Yes. Um verbal handover is is good but you'll not always get the right information handed verbally'* **Patients don't always listen to advice:** *'and they just won't listen to professional advice – and they're sure that they can eat what they like – and we've had professional advisors that tell us – no, they need to have this sort of diet. Um – and we try to explain that to them'*	

Professional		What is goal setting	What affects goal setting	Emerging theory
DOES	Hazel - WHAT SHE	*different'*		
		Finds out patient's views: *Hazel starts the session by explaining that the purpose of their conversation is to find out* "*your thoughts about getting home*". **Makes suggestions:** *Hazel says* "*I know interior design was your speciality – we thought day care would be a good option*". **Focuses on patient's achievements:** *Hazel suggests that it was good for them to be somewhere else –* "*different than this room*".		

Professional		What is goal setting	What affects goal setting	Emerging theory
Hazel - WHAT SHE DOCUMENTS		**Documents interventions in relation to problems:** *Case 42: 'still feeling generally miserable due to loose stools. Has cancelled her visitors. Still aiming for home next week'.*	**Documents risks and patient safety issues:** *Case 65: 'Likes to use heat pad on back to ease pain. Sensitivity test done. No reaction no oedema. Patient informed to use for 10-15 minutes at a time. Night staff will be informed to monitor patient is adhering to 15 minutes.'*	
Iris - WHAT SHE SAYS		**Goal setting is important:** *'I think it's always important to have a, certain goals'* **You can always set goals with patients:** *'When people are at their last stages – but then your goal is to make them your goal is to make them comfortable – so there's still a goal'*	**Balancing risk:** *'so I was like – but how's he gonna manage – you know - There's too much to – you know, that he hadn't thought about. He just thought he'd be going home. That was it. Even though sometimes it does seem quite cruel, you have to – for their safety as well'*	**Goals change over time as people adapt.:** *'So he did get home, but not doing what he thought – you know, the thing is, if we were just to say yeah, that's fine, then he wouldn't have been able to – when at the time you feel a bit cruel because the man is like – you know you could see, but then afterwards it's like – well you're right, I'll take a commode – you*

Professional	What is goal setting	What affects goal setting	Emerging theory
	Goals should be achievable: *'if the patient comes in and the idea – they really want to go home – but you feel that's really a bit – too much – you just try and do something – do a goal that's achievable for them, as in as going out on pass – or – doing things that they'll be able to do and – trying to sort of facilitate it as much as you can'* **They can be about ordinary things:** *'there was not a long term goal – but short – you know, there was ways of facilitating short - You know, and he had friends coming in and watch the rugby and – you know. And it wasn't treated like – it was treated like - You*	**Patients and professionals may have different points of view:** *'so she says, at least I got, and I thought, well -you know, and that was kind of a lot of conflict there – and a lot of staff were like – he shouldn't be – that shouldn't happen – but that's what the man wants. – you know'* **Focusing on care rather than patient's preferences affects goal setting:** *'sometimes you'll get too caught up – not too caught up, but we do get caught up with the care, which is what we're there to do – but - you don't know their hobbies – you don't know. We had a lady I was looking – you know at her goals.*	*know, so he did think about it.'* **Goals give people hope:** *'I think so. I've noticed like – with patients – if they feel that their hope has gone – then – it's like – that's 'what's the point' whereas if there's always little things to – like a lot of people – if there's somebody's birthday – they're aiming for that day – they're you know – but once that day's gone, they just plummet.'*

Professional	What is goal setting	What affects goal setting	Emerging theory
	do what you need'	*She said, I painted that (points to the wall)'*	
	The process involves helping people to discover their limitations: *we had a gentleman not all that long ago and it was like – Ok so he was couldn't – he could – he was struggling with his breathing from chair to commode – and he's like –'so how far's your toilet?' He said – 'oh, just there' – I was like – so have you ever walked that distance before – 'no' – I said could you walk that distance? 'I'll be fine when I go home'. I says but if you can't walk it just now, how will you walk it when you go home – and he's like (pause) I says I'm not trying to put you off – I*	**Illness progression:** *'You know, we've got an incident the now in the ward where a lady's been promised that she'll stay here but she won't be* *SB: Right?* *I: So her goal was that she - in the kind of complete opposite way – that - to stay here – and now she may have to go to long term care –so'* **Documentation could be improved – it can be difficult to find goals in the notes:** *'there is sort of care planning but there's not an awful*	

Professional	What is goal setting	What affects goal setting	Emerging theory
	says it's just that – you won't miraculously be able to do these things. You know – and he's like - so he did get home, but he had to get a commode.	*lot on goal setting as you know – you know you're doing your daily care needs but other than that we're not really documenting.'*	
Iris – WHAT SHE DOES	**Focuses on practical tasks rather than goals:** *She looks a bit over whelmed by the amount of work she now has to do in order to get the discharge planned. She is not sure how realistic it is going to be if a care package needs to be organised for Sandra in time for Thursday.*	**Focuses on risk:** *Iris explains that the OT will be checking to see if Sandra needs any pieces of equipment at home, and to see what kind of things she will be able to do. Sandra picks up on this, saying "I don't want to go home and lie in my bed all day". Iris agrees, and adds that "we're focussing on how safe you are. We don't want you falling"*	

Professional	What is goal setting	What affects goal setting	Emerging theory
Iris – WHAT SHE DOCUMENTS	**Focuses on practical tasks:** *Case 22: 'patient complaining of not being able to pass water with previous catheter. Washout done. Catheter blocked so new one inserted.'* **And:** *Case 41: 'Had bath today. Hoisted with all transfers.'*		
Janet – WHAT SHE SAYS	**Goal setting is important:** *'I think it's just huge – just massive importance in our job. It is about individualised care'* **Patients understand and can relate to goals:** *'Patients just like it – I think almost – we call it a plan of attack some days. – like the plan*	**Patients and professionals may have different points of view:** *'There's conflict between family members, there's conflict between staff and em – but it's – it's about just really listening to them'* **Illness progression:** *'and that was maybe*	**Goals and hope are linked (having a goal and a plan gives patient's hope):** *'Ok, we're gonna get on top of your pain – that's the most important thing right now. Then, let's look at what we're gonna do after that – and I think they feel comforted by the fact that*

Professional	What is goal setting	What affects goal setting	Emerging theory
	is – Ok, we're gonna get on top of your pain – that's the most important thing right now. Then, let's look at what we're gonna do after that – and I think they feel comforted by the fact that we know what we're doing.' **Goals can be broken down into small steps:** *'maybe it's gonna be something less. Like – maybe just getting home for the spell and see how you do with that – rather than – I'm going to get home and I'm gonna look at this business stuff, when you know finally that they're gonna be knacked.'* **Goals give patients a focus:** *'It's choice*	*down to that diagnosing dying – you know – people's conditions change so quickly.'* **Documentation could be improved – it can be difficult to find goals in the notes:** *'I don't think it's well documented. Um – I maybe would write in the notes that he had – he had done that – and maybe – and but there's nowhere to say that that was his choice and that was his goal – so it's just like that's what he had and that's what he enjoyed but I don't think we document that well at all.'* **It can be difficult to tease out patients goals, particularly if they are unrealistic:** *'And it*	*we know what we're doing. By being able to set a plan – and we're consulting with them – whether they think it's achievable – but the fact that we – we think it is. That gives them so much – hope'* **Goals give patients a sense of achievement:** *'It was about a man saying everyday to us. 'I want to get home, I want to get home'. You know, he's noticing people dying all around him. He needed to get home. Even if it's for a day. It just. He needed to achieve it'*

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Professional	What is goal setting	What affects goal setting	Emerging theory
	again, you know – I think – I think goals – goal of the day is – where – you know, you're comfortable – your family are in. What is it – you're constantly asking – what is it you want to do today'	*was about her – she was going to die – and basically – hadn't been really aware herself. Had been denying any time you tried to have the conversation – it's coming quicker than it was – and she was actually dying in front of us.'*	
Janet – WHAT SHE DOES	**Negotiates short term action plans with patients:** *She talks about the steps towards achieving that, suggesting that Dave could try going along to the canteen, to see how he gets on. Dave asks if that would be "under your own steam?" He thinks this would be a good plan.*	**Focuses on risk:** *We don't want you to be too knacked." She also says that "safety's important".* **Acknowledges uncertainty and different points of view:** *Dave says that he will speak to the professor. Janet says "I'm not sure – I thought you didn't have an appointment with*	**Encourages adaptation and action planning:** *Janet summarises, saying that they will "work towards these goals – we may have to rein back and look at plan B, or set another one". She reminds Dave of the immediate plan: "this weekend. Sitting room". She reminds Dave that he should see how long he*

Professional	What is goal setting	What affects goal setting	Emerging theory
	Breaks goals into small steps: *Janet talks a bit more about the steps towards a visit home, saying that they will "need to show S how to transfer". She adds that Dave will need to "stay downstairs while you're at home".* **Discusses alternative ways of achieving goals:** *Janet suggests that "over the weekend – you can gauge how much time you're spending in the sitting room – it will help you decide how long you can go home for". She adds "it's about pacing yourself".*	*him. Thought he wasn't offering active treatment." She adds that they "can help with symptoms – not the cancer". Dave says "I've no idea"*	*can manage in the sitting room, and that will help him gauge how long he should go home for.*

Professional	What is goal setting	What affects goal setting	Emerging theory
	Explicitly asks patients about their goals: *"What's your goal there, with work?"*		
Janet – WHAT SHE DOCUMENTS	**Writes about what patients are managing in specific terms :** *Case 4: 'P feeling much stronger on feet – no dizziness/light-headedness. Mobilising independently around ward – managing full length of corridor'* **Reflects on how symptoms limit activities:** *Case 7: ''managing to mobilise with supervision to/from toilet. Is weak and admits same. Also sounds slightly dyspnoeic*	**Writes about balancing risk – patient's views versus professional advice:** *Case 21: 'Discussed we were keen to fulfil his wish to get home for a pass and would support him/family with same but that safety was ultimate priority.'*	**Writes about how patients feel after achieving goals:** *Case 12: 'Upper body strength very good and helping to wash and dress himself. Participated in active leg exercises in bed. Motivated ++ and pleased with his efforts today.'*

Professional	What is goal setting	What affects goal setting	Emerging theory
	also which ?limits activity. Wishing to get up and sit in recliner chair.' **Documents goals and makes notes about progress in relation to them:** *Case 44: 'patient keen to mobilise more frequently and maybe try a longer distance.'* **And later:** *'patient feels mobility much better since admission and pleased how well he has been doing'*		

In the next section I discuss the main themes which arose from the Framework analysis (*what goal setting is; challenges/what affects goal setting and emerging theory/conceptual underpinning*).

4.6.2 What goal setting is

i. Goal setting is important but implicit:

Many professionals agreed that goal setting is an important part of palliative care (Table 13: Alison, Becky, Debbie, Katie, Hazel, Iris and Janet). However, there was also a belief that the process of goal setting was implicit rather than explicit (Table 13: Alison, Becky, Charlotte, Debbie, Frances and Hazel). Some stated that they did not use the term 'goal' when working with patients and they emphasised an informal, low-key approach to goal setting, despite believing that it is important (Table 14).

Table 14 Goal setting is important but implicit

Goal setting is important	Goal setting is implicit
Alison (interview): *'Well I think in Palliative care it's very important to let patients goal set'*	**Alison** (interview) *'And for us that is the goal setting but we maybe don't use the word 'goals are'*
Becky (interview): *'I think it's hugely relevant.'*	**Becky** (interview) *'I don't think it's as formalised as that. I'm thinking at some of the MDT meetings, it's not a kind of a case of what does that individual want to do. It's probably, yeah, if it's a problem, maybe then that's probably when we do discuss it.'*
Frances (interview): *'For some people it is really important and I think that their main goals when they come in here tend to be like getting rid of the symptoms, getting their mobility back, getting back home.'*	**Frances** (interview): *'Because I think we do it automatically but don't necessarily think of it in terms of "we are goal setting".'*
Hazel (interview): *'I think there's always little goals you can, you know, even somebody that's bed bound, at the terminal stage .Your*	**Hazel** (interview): *'I think sometimes you say a goal today will be – but maybe we don't use that language – you know, you say maybe*

Goal setting is important	Goal setting is implicit
goal is to keep them pain free.'	*today it would be a good idea to have a rest in bed…….So you can do that tomorrow – and that probably is a goal. But we haven't said that to the patient.'*

The informal approach to goal setting which participants talked about appears to be at odds with their belief that goal setting is important. This was also reflected in practice as only two participants used the word 'goal' in their interactions with patients (Janet and Becky). Others alluded to goals by asking patients what they wanted to 'do' (Becky, Charlotte, Debbie, Frances and Katie – see Table 13). Although these participants indirectly asked about goals, only Becky and Debbie documented specific goals in the case notes.

One participant (Janet) appeared to have a different approach to goal setting compared to that of other participants. She openly talked about goals with patients and appeared to go through an explicit process to negotiate goals with them, as illustrated in the following example:

Janet talking to Eric (observation):

> *Janet comes back to talking about Eric's goals: "so while you're here, we're working towards the goal of decreasing your pain". She asks Eric if there is "anything you'd like to be doing" (while he is in the hospice).*

Janet also documented goals in the notes:

> *"Talked about M already having a list of things she would like to do and is already working through them. Has chosen hymns for her funeral and has had a discussion of what she'd like to give and to whom – to family. Suggested writing cards/letters or making memory boxes (if able)."*

In the following example, Janet was talking to Dave, a 55 year old man with metastatic melanoma with pulmonary metastases. He wanted to work towards the goal of going home:

> *'Dave says that he would like to "get to the house. Have a challenge, see what I can achieve." Janet agrees with this saying that they need "to think about your goal". She talks about the steps towards achieving that, suggesting that Dave could try going along to the canteen, to see how he gets on. Dave asks if that would be "under my own steam?" He thinks this would be a good plan.'*

In this example, Janet picked up on Dave's goal. She broke it down into small manageable steps which she negotiated with Dave, and together they agreed on an action plan. Later on in the interaction, Janet revisited the action plan:

> *'Janet suggests that "over the weekend – you can gauge how much time you're spending in the sitting room – it will help you decide how long you can go home for". She adds "it's about pacing yourself". Dave agrees with this, saying that talking tires him out.'*

As I have said, Janet's approach to goal setting was more explicit than that of other professionals. In the example above, she picked up on Dave's goal of going home. Although she was unsure about Dave's ability to achieve his goal (as she told me after the session), she used action planning as a way to break his goal down into something more manageable.

The only other occasion when the word 'goal' was used with a patient was when I observed Tony, a patient with metastatic prostate cancer who had just been transferred to the hospice from hospital. He talked to Becky about how he was adjusting to the hospice after his stay in hospital:

'Tony says "for me, my first goal would be to get walking – to get out of bed." He states that he would like to "find myself able to get out of bed for a fair amount of time every day by the end of the week. That would be a step in the right direction".

In this example, Tony articulated a specific goal, but the conversation which follows led Tony to agree on a much more general goal of 'going home'. Becky initially picked up on Tony's goal by asking him how he felt he managed when he tried to get up:

Becky asks "how do you feel you did?" (referring to Tony getting out of bed this morning). Tony replies: "I thought I did well. It was harder getting out of bed than I thought. My body felt about 24 stone".

With this type of question, Becky seemed to be trying to get Tony to reflect on his abilities, perhaps because she felt his goal was unrealistic. However, she did not pick up on the goal explicitly and this seemed to prompt Tony to talk more generally about *"getting up and about"* and *"getting things in place at home".* Becky seemed happier to pick up on this as a goal and finally summarised the conversation by saying *"so, we're aiming for home?"* Becky might have taken the opportunity to discuss an action plan with Tony, given that he initially articulated a specific, short term goal. However, she appeared to miss this opportunity, possibly because of the implicit nature of the goal setting process that she adopted. Equally, Becky may have had doubts about Tony's ability to achieve his goal of being able to walk, and this may have made her hesitate to pick up on his goal.

The implicit nature of the goal setting process is also reflected in the case note data. Examples of goals written by Becky and Janet (Table 15) show the contrast between implicit and explicit goals.

Table 15 Implicit and explicit goals from case note data

Becky (implicit goals)	Janet (explicit goals)
'Doesn't like large number of tablets' (Implied goal to reduce medication)	Mobility: *'keen to get as mobile as possible and see physio'.* Later: *'more steady and confident. Keen to increase distance'*
'Missing home ++' (Implied goal to go home)	*'Patient preferring to go through to canteen with wife and family for lunch.'*

Even though Janet appeared to be more explicit in her approach to goal setting with patients, she still wrote about goals informally and a degree of interpretation is needed to identify them as specific goals. This may be because there is not an explicit method of documenting goals in the case notes within the hospice.

In summary, although the majority of professionals agree that goal setting is important, there is evidence that professionals do not always pick up on patients' goals. This may be as a result of the predominant belief held by professionals: that the goal setting process should be an implicit one.

ii. Goal setting: discovering limitations or discovering possibilities?

During interviews, professionals talked about goal setting as a process of negotiation which involves coming and going between patients and professionals:

> *"- it's a too-ing and fro-ing – it might involve negotiation – or modifying what the goals are, depending on the situation"* (Becky, interview).

In practice, professionals genuinely asked patients for their opinions and gave patients multiple opportunities to raise issues. A phrase which was commonly used by all professionals was *"is there anything else?"* This was used as a method of checking that all relevant issues

had been covered and would often be used several times during a conversation with a patient.

Although interactions with patients often involved professionals in a process of checking patients' perspectives, these discussions tended to focus on symptoms and problems rather than what patients wanted to be able to 'do' *(goals)*. During interviews, professionals said that goal setting involves a process of problem identification and assessment. This was also seen during observations, as illustrated in Table 16.

Table 16 Goal setting involves problem identification and assessment

Problem identification	Assessment
Alison (interview): '*I ask them what they've been doing at home. What's been difficult for them.'*	**Alison (Interview):** '*To bring them along and do a small stair assessment and it lets them see either how impossible it is or how breathless that makes them feel.'*
Debbie (Observation 1): '*Debbie immediately starts the conversation saying she wants to "get a feeling for what's been most problematic".'*	**Debbie (Observation 3):** '*Hannah says that she just wants to "have a bit of normality back in our lives". Debbie says "let's get these assessments done and then we can be more realistic in terms of what is possible in terms of going home".'*
Frances (Observation 1): *Frances asks Eric if there is "anything else at home that is difficult?"*	**Frances (interview):** '*So they've got to see it for themselves by going into the home with me on an assessment and achieving that.'*

Assessment and problem identification are recognised components of the rehabilitation, medical and nursing processes (Davis 2006, Barnes, and Ward 2004). However, focusing on this did not necessarily lead participants to identify specific goals and action plans with patients. This was reflected in the data from case notes, which were characterised by a focus on symptom management and problem resolution. Examples are given below of summaries in the case notes of typical admission interviews:

> *"Weight loss and fatigue, nausea and vomiting, social (single mother with three children at home), bowels, psychological (not sure of intent/effectiveness of treatment or of what to expect)"* (Case note 14 – goals on admission)

> *"admitted (reluctantly) for symptom control. He is not clear of the main issues to be addressed, but problems include: Decreased oral intake; Low mood; Unsteady walking; Pain."* (Case note 11 – goals on admission)

When patient's goals were mentioned in the notes, these tended to be very general, for example:

> *"To give his wife a rest. To find out what's causing his pain."* (Case note 16 – goals on admission)

> *"get this pain better"* (Case note 17 – goals on admission)

Many participants believed that goal setting involved a process where patients discover their own limitations and that this is a way to help patients adjust their goals and develop alternative ways to achieve them. This is illustrated with examples from Alison's interview, observational and case note data (Table 17):

Table 17 Discovering limitations

Interviews	Observations	Case notes
Alison: '*It's easier sometimes to let them sit at the edge of the bed and let them see what that feels like. And they decide for themselves then that it's maybe not as realistic as they thought it might be'*	Alison working with Sarah: *Alison says that they will have to try some longer stairs and reminds Sarah that "it's been a long time" and that she needs to remember that "where you were before is very different to where you are now".*	Alison: *'Stair assessment. Managed well on 4 steps up and down. Aware to rest every 4th step when at home. Agrees it would help to have commode.*

Some professionals did try to focus on what patients wanted to do or achieve. In the example below I observed Katie, an AHP who was speaking to Eric, a 59 year old man with prostate cancer which had metastasised to his liver and spine. During the session, Eric talked about his pain and how much it was limiting him. Katie tried to shift the focus from Eric's pain to what he might like to do, saying:

> *"are there specific things you'd like to do?" Eric says that he has "a wee dog". He also says that he would like to do a few things around the house. Just sitting here. It's driving me mad. Watching TV all the time." He then adds "I'm going to talk to my wife – we're going to do things we never get done. Going out, seeing people, the pictures, a meal. We'll just do it. That'll make my life more meaningful. I don't know".*
>
> *Katie pauses and then says "They sound like important things".*

During this session Katie found out what Eric's goals were and he identified several concrete goals, which Katie acknowledged as being important. However, within the session, she did not offer any suggestions about how the multidisciplinary team might support Eric to achieve his goals. It appeared that Eric was left to take the issues forward himself. Perhaps the informal nature of the goal setting process in the hospice contributes to the fact that, even when professionals ask patients about their goals, there is no clear procedure or specific action planning process to guarantee that the team will work together to support patients to achieve their goals.

Although the majority of professionals focused on identifying problems with patients, two professionals (Hazel and Katie) felt that goal setting was about finding out what patients *could* do:

> **Hazel (interview):** *'a longer term goal for maybe somebody that's come in for respite um – would be to achieve something that they didn't think they could achieve. Um maybe going to day care and finding a talent that they didn't know they had.'*

> **Katie: (interview):** *'We focus on the 'I cans' so - this is the part of your life that you have power and control over. And that you can put your energy into.'*

In spite of talking about the importance of helping people find to possibilities rather than limitations, this did not appear to translate into practice for Hazel when I observed her. However, I did observe Katie picking up on activities that a patient could participate in and contribute to. An example is given in section 4.6.5 *(Adaptation).*

4.6.3 What affects goal setting

i. Deterioration

Staff felt that goal setting could sometimes be difficult because of patient's deteriorating and unpredictable health (Table 13, Alison, Charlotte, Debbie, Elaine, Katie, Hazel and Janet). This

was further complicated by the fact that some patients were perceived as unrealistic, which professionals found difficult to deal with (Table 18).

Table 18 Deterioration versus realism

Deterioration	Realism
Elaine (interview): '*If you've got time to do that. Sometimes you don't – because somebody's condition deteriorates unexpectedly – very quickly*'	Elaine (interview): '*goal setting when they're unrealistic about their condition. That em they think that – just for instance say oh, em - we know there's no further treatment or the treatment's palliative. Well, you know, that's fine, but I'm still gonna be here in 2 years time – so I'm gonna plan this big family holiday abroad. Next year.*'
Frances (interview): '*because you have plans with a patient to do certain things and you come in after a weekend and the patient has either died or they are on* [the Liverpool] *care pathway.*'	Frances (interview): '*Em it's just people who think that they are capable of a lot more than they are. You have patients who come in and they've got spinal cord compression and they are not able to weight bear. But they think that you are going to get them back on their feet and walking.*'

At times it was clear that illness and deterioration took priority over identifying goals with patients. During one of my observations, I saw the complexities of working in this setting:

I observed Elaine talking to Karen (a woman with breast cancer and brain metastases). Karen tells Elaine that she has a "funny feeling in my arm – like a tickly feeling". Elaine follows this up with a series of questions about the type of sensation, when it happens and if there are any other symptoms which go with it (such as facial weakness, dizziness etc.). During this dialogue, both patient and professional appear to be problem solving together, trying to work out a possible cause for the sensation. At the end of the conversation, Elaine offers Karen some advice:

'She double checks again that Karen gets her blood pressure checked and says that if

Karen's headaches get worse, or if she experiences any blurred vision or more severe

headaches, she should contact her GP. She says "don't ignore things". Elaine says that

she will speak to people at the hospice and then asks is there "anything else?"'

Elaine's goal as a professional appeared to be to get to the bottom of Karen's new symptom, which may suggest a change in her underlying condition. This example alludes to the fact that professionals and patients can be engaged in a complicated business of assessment, diagnosis, and planning within an unpredictable and limited time scale. Goal setting may not always be at the top of the agenda, particularly when someone's health is changing.

ii. Balancing risk

The context of the hospice meant that staff were working with people with a limited life span who were very ill. Unsurprisingly, this filtered into staff/patient interactions which sometimes came across as protective and risk averse. This was evident in interview and observational data, although not everybody who talked about this demonstrated it in practice. Others talked about risk but I did not observe them considering it in practice. There was also evidence of risk being considered in the case note data (Table 19).

Table 19 Balancing risk

Balancing risk (interview data)	Balancing risk (Observational data)	Balancing risk (case note data)
Alison: *'We have to do significant risk assessment looking at all things, and its only when, we are absolutely certain that it's just not a safe move, then we wouldn't do it.'*	**Alison:** *Alison replies saying: "I still think a full flight is too much just now." And "we don't want you to have a tumble". Alison suggests to Sarah that she can still get better on her feet, and Sarah agrees with this. Sarah then says that she has thought about walking to the 'red room' (Sarah has been setting herself little goals). Alison responds by saying it's a good idea but that it would be*	Alison: *'advised to keep stairs to a minimum – OT will advise on ?bed downstairs etc. After environmental visit'*

Balancing risk (interview data)	Balancing risk (Observational data)	Balancing risk (case note data)
	best if she tried this when her son is visiting, suggesting that he could walk with the wheelchair so that she can sit down if she gets tired. Once again, Alison says "we don't want you to have a tumble".	
Iris: *'and of course it had been said – he could go home on the Monday –so I was like – but how's he gonna manage – you know - There's too much to – you know, that he hadn't thought about. He just thought he'd be going home. That was it. Even though sometimes it does seem quite cruel, you have to – for their safety as well'*	**Iris:** *"we're focussing on how safe you are. We don't want you falling"*	**Iris:** *wrote notes which related to care she had given. She did not refer specifically to risk.*
Becky: *I think that at times – probably as health professionals we are, we tend to be – more cautious. I've certainly met people who are determined to get home – and it's worked despite reservations – and whether we are being – subconsciously just - yeah – almost - don't want to be seen as being negligent. That kind of medical legal – bit to it. I hope that wouldn't be the main reason for not doing something but it maybe – perhaps we are cautious.*	**Frances:** *John says that the arm chair was "not a problem – I've got ways of doing it". Frances asks "no pain?" John confirms "no pain". Frances asks "are you safe?" John replies "yes, I'm safe – I have people around".*	**Frances:** *'patient has his own method of using equipment and is not always safe.'*
Katie: *so, for example, with discharge planning – the main difference that comes up is that staff think that the patient is –at too much of a high risk to*	**Janet:** *"it depends on how you are, and what support you need." She adds "you've been doing really well. We don't want you to be too knacked."*	**Hazel:** *'Likes to use heat pad on back to ease pain. Sensitivity test done. No reaction no oedema. Patient informed to use*

Balancing risk (interview data)	Balancing risk (Observational data)	Balancing risk (case note data)
live at home.	*She also says that "safety's important".*	*for 10-15 minutes at a time. Night staff will be informed to monitor patient is adhering to 15 minutes.'*

The issue of risk was important, particularly for the AHP's involved in the study, who were often involved in ensuring that patients were safe enough to be discharged home. This led to some differences in opinion between professionals and patients, whose own problem solving ideas were sometimes disregarded. During one session, I observed one of the AHPs carrying out an assessment with Betty, a 65 year old woman with spinal cord compression. Alison wanted to find out if Betty could manage the stairs, in preparation for her discharge home:

> *Alison quickly follows up her question by saying that she will need to be able to 'do stairs' in order to get home. Betty states that she was managing quite well before she came in – she has a toilet downstairs and this seemed to be working OK for her. Alison does not explore this any further.*

During this session, Alison focused on her role in discharge planning rather than working in partnership with Betty to discuss the extent of the problem and if there are any ways around it. This perhaps reflects the pressure that professionals are under to ensure that they fulfil their requirements in relation to discharge planning and risk assessment.

iii. Focusing on significant goals

Whilst most professionals stated that goals could be about ordinary, everyday things such as sitting up in a chair or having a bath, when I asked them to tell me about a particular goal which they had helped a patient to achieve, they typically told me about bigger, more significant goals. For example, Alison told me about a lady who wanted to watch her grandson

perform in his Christmas nativity play. Janet told me how she and the team had helped organise a man's wedding just before he died. This focus on significant goals was also reflected in the case notes, where goals such as 'going home for Christmas' or 'sorting out adoption papers' were noted. Although participants told me that other, more ordinary goals were important, these did not tend to be documented in the case notes as specific, patient centred goals. They were documented in more general terms (for example *'improve pain, improve mobility'*). The general nature of written goals made it difficult to know whether or not they had been achieved during a patient's admission.

4.6.5 Emerging theory/Conceptual underpinning

In section 4.5 I showed that participant's ability to make a link between theory and practice varied. Some were able to articulate coherent beliefs about theories which might underpin goal setting, but there was little evidence that their practice was theory based. Others said very little about theory during interviews, and may not even have been aware of a theoretical basis for their practice (see Table 13). Rather than name and describe specific theories, staff talked about goal setting as a way of helping patients to adapt, giving them hope and a sense of achievement. These can be linked to theories of how people adapt to life threatening illness (Bye 1998), Hope Theory (Gum, Snyder 2002) and Goal Setting Theory (Locke, Latham 2002), which I discussed in chapter 3.3.3.

i. Adaptation

In Chapter 3.3.3 I highlighted that theories of adaptation to life threatening illness are identified in the literature (Jacques and Hasselkus 2004, Bye 1998). These propose that goal setting provides professionals with a tangible way to help patients connect with life rather than just focus on dying and illness. Interview and observational data suggest that professionals believe that patients have to adapt their goals (or at least pathways to achieve these goals) as illness progresses (Table 20).

Table 20 Adaptation to illness

Interviews	Observations
Alison: *'but overall if their goal was to get home, we're partially achieving some of that goal, but it may be that we have to change it, that we have to go downstairs with a bed.'*	**Charlotte:** *Paul talks about how his arm held him back from tying up the clematis as he could only move his arm "so far". Charlotte wonders if wearing the sling would help with this type of thing? Paul says that it "gives support but you cannae get the reach" and says that between he and Kate they managed to get the job done. Charlotte reinforces to Paul how well he is adapting.*
Debbie: '*They were both – you know, there were compromises made on everyone's part I think. She agreed to – come downstairs as she wasn't managing the stairs so that wasn't going to be an achievable goal if she got home.*	**Hazel:** *She says that she will be getting a "wee wet room". Hazel comments "that'd be good". Ruth agrees and says that it will be good for the future too, as she may need a wheel chair "later on".*
Iris: '*I says but if you can't walk it just now, how will you walk it when you go home – and he's like (pause) I says I'm not trying to put you off – I says it's just that – you won't miraculously be able to do these things. You know – and he's like - so he did get home, but he had to get a commode.'*	

In Table 20 we can see that professionals talked about adaptation in practical terms and linked it to ways that patients could make changes in their life style, for example, moving downstairs or using specific pieces of equipment. Professionals did not always make the link between how they might help patients adapt so that they could continue to participate in the activities they enjoyed.

There are two notable exceptions to this. I observed Charlotte talking to Paul who wanted to cut back his clematis but was having difficulty because of his immobile arm (see Table 20).

Although Charlotte did not provide a solution to Paul's problem, she provided encouragement and positive feedback to both Paul and his wife about how they were adapting.

In another example, Katie was talking to Sue (a 47 year old woman with advanced metastatic melanoma) about making up a memory box of photographs for her children:

> *Katie says that she has worked with people, making memory boxes. She adds "people think it's about saying goodbye. But it's about –'I loved you' and 'we had a good time'".* The way Katie explains this is so positive and seems to capture the living aspect of dying. *Sue thinks about the importance of the photos. She talks about the fact that her children will remember different things from different holidays that they have had in the caravan. Katie agrees saying "they'll have different memories from you". Sue adds "perceptions are different. It would be quite nice if they had my version of it too". She laughs as she says this.*

In this example Katie acknowledged that Sue was dying but encouraged her to engage with living by helping her to think about what she could leave behind for her children. Sue picked up on this and appeared to see it as a positive step which she could relate to and participate in.

Apart from Charlotte and Katie, participants predominantly focused on practical issues rather than specific 'engaging with life' goals. This is perhaps due to participants' tendency to engage in *solving problems*, rather than focusing on *goals,* which I gave examples of in Table 16.

ii. Hope and positive feedback

Professionals talked about the importance of hope and how setting goals helped patients to remain hopeful, sometimes in very difficult circumstances. Professionals felt that patients experienced positive feedback and a sense of achievement when their goals were achieved (Table 21).

Table 21 Positive feedback

Positive feedback
Becky (interview): *'The sense of achievement. – Was important – a sense that – still being in control, because I think initially the team's reaction was you know – it's not gonna work, it's not going to happen. – and I think that feeling of – yeah, I can and I've got a bit more autonomy back and I can make – I'm participating in – in decisions.   I think – the benefits for the patient, the patient's relative as well.'*
Katie (interview): *'setting goals that belong to the patient – that are theirs – that they want to get – want to do um – so that they – feel like they're achieving and that they feel good about themselves and they feel that they have some control over their lives – um – it's not being controlled by them – by their condition um – yeah, I think ….'*
Hazel (interview): *'I think it's really relevant. I mean – it – it doesn't matter what stage their illness I think if you can set an achievable goal, that's good for them psychologically and physically as well.'*
Iris (interview): *'I think it's feeling that you're not just lying stagnant – you know that there is – you know achievement – even just doing something simple.'*

Although participants talked about the importance of goal setting as part of giving patients a sense of hope and achievement, there were very few examples of this happening in practice. When participants had the opportunity to provide positive feedback on goal achievement, it was usually very general and tended to occur only when patients initiated discussions about things that they had managed, as this example shows (Elaine, a nurse, talking to Avril, a 64 year old woman with metastatic breast cancer):

> *Avril talks about the day hospice, and how much she enjoys it. She says "I did work I never thought I could do – cushion covers, a Christmas stocking, cards." She also says that she has made friends and can have relaxation sessions while she is there. Elaine talks about how isolated Avril had been before she started going to day care.*

One possible explanation for participants not providing specific feedback on goal achievement is because goals are not specifically identified. This makes it difficult to provide precise feedback or to track progress. This is particularly evident in the case note data where goals tend to be very general (Figure 17).

Figure 17 Examples of goals written in case notes

Patient 6: 'Hopes to improve vomiting'
Patient 7: 'to address pain, support self , husband and family, to revise will'
Patient 27: 'wishes to get home soon'
Patient 58: 'Wants to improve his mobility and jaw pain then get home.'

As part of the case note analysis, I checked the discharge letters to see if a connection could be made between goals on admission and what had been achieved on discharge. The discharge letters tended to focus on symptoms and problems, rather than specific goals, and it was not always clear what had been achieved in relation to the original goals (Table 22).

Table 22 Goals on admission compared to discharge letter

Patient code	Goals on admission	Discharge letter
6	Hopes to improve vomiting and mobility and get home with extra support	Discharge letter refers to improvements in terms of pain control and urinary incontinence.
7	To address pain, support self, husband and family, to revise will.	Letter states that patient's problems at time of admission included pain and emotional distress. Also mentions that she

Patient code	Goals on admission	Discharge letter
		needed to talk to her young daughter.
27	wishes to get home soon.	Patient was admitted for a week of respite. She discharged herself after two days.
58	Wants to improve his mobility and jaw pain then get home.	Letter outlines medication adjustments.

The lack of connection between goals on admission and what was achieved on discharge could suggest that patients do not receive feedback about how they are managing in relation to goal pursuit. This is an important part of Goal Setting Theory (Locke, Latham 2002) and Hope Theory (Gum and Snyder 2002) as it provides people with a sense of achievement if goals have been achieved. If goals are not achieved, patients and professionals can use this as information to help them think about their next steps and to adapt and change goals in response to this.

4.7 Summary

The aim of this phase of the research was to find out how goal setting is delivered in practice to patients and to find out multidisciplinary staff team members' experiences and perceptions of goal setting as an intervention. To my knowledge, this is the first study of its kind and the combination of interview, observational and case note data provides a detailed account of patient centred goal setting practice in this in-patient palliative care unit. Using Framework Analysis (Ritchie and Lewis 2003, Ritchie and Spencer 1994) I have been able to draw out themes from the data and make comparisons between and within cases. Goal setting is regarded as an important part of in-patient palliative care in this setting, but it appears to happen against a back drop of assessment, diagnosis and symptom management, within the

confines of organisational structures where issues such as patient safety and discharge planning need to be considered.

My analysis led me to focus on three main areas: *what goal setting is, what affects goal setting and emerging theory*. One of the striking features of the goal setting process in this hospice is that it is *implicit*. Whilst I observed some examples of explicit, formal goal setting, this was not routine practice, and participants tended to either focus on particularly significant goals or, more usually, on symptoms and problems. Clark (2002) has suggested that in recent years palliative care has become more medicalised, in spite of its early endeavours to focus on quality of life and dignity as part of the dying process. The data from this study confirms this and suggests that professionals tend to focus on problems and symptoms rather than patient-centred goals, in keeping with a more medical approach to care. I provide evidence that this problem based approach can lead to important goals being missed, which may in turn lead to missed opportunities for patients to take a more active role in managing their healthcare (Kasven-Gonzalez et al. 2010, Leung et al. 2009) and participating in life.

One participant in this study (Janet) stood out as someone who consistently tried to set goals with patients. This was shown during observations, interviews and in the case note data. The key feature of this Janet's work was that she negotiated action plans with patients which could be broken down into small steps which the patient could work on as an individual. These were then reviewed so that progress (or lack of progress) could be monitored and acted upon. Janet appeared to use some of the principles of Goal Setting Theory (setting specific, difficult goals and providing feedback on them, Locke and Latham 2002). She also appeared to have an understanding of the role of goals in relation to increasing self-efficacy and motivation (Bandura 1997). She discussed goals explicitly with patients as part of routine practice.

The link between theory and practice was an important aspect of the data and in section 4.6.5 I highlighted that participants did not consistently make a connection between the two. Many participants held the belief that goal setting had a role in helping people to maintain hope and a sense of achievement, but few were able to talk about specific components of theories such as Goal Setting Theory (Locke and Latham 2002) or Hope Theory (Gum and Snyder 2002) that might be used to do this. This, combined with a medical approach to care resulted in a tendency for goals to be general in nature and typically associated with problems and symptoms (such as 'improve nausea, improve mobility'). Palliative care aims to support people to live actively until death (WHO 2007) and rehabilitation and goal setting have been identified as ways to help people do this (NCPC 2006, National Institute for Clinical Excellence 2004, NCPC 2000). Within this hospice, professionals tend to focus on goals based around illness rather than what patients want to be able to 'do' or achieve. As a result, professionals do not appear to consistently support people to live actively by engaging them in setting goals.

During this phase of the study I have investigated current goal setting practice in one hospice and have begun to identify areas which could be developed in order to ensure that goal setting is delivered more consistently. The implicit approach to goal setting adopted by most professionals in this study meant that staff sometimes missed opportunities to support patients to work towards and achieve goals. A more formalised approach which structures how professionals approach goal setting with patients may help improve this situation. This should be underpinned with theory in order to give professionals a framework from which to work. Some of the professionals in the study talked about theories which they felt were relevant to goal setting in palliative care. These, alongside theories already identified in chapters two and three provide a good starting point to begin to devise a formalised, theory based intervention.

This phase of the research suggests that, from the perspective of the professional, goal setting is an important and relevant component of palliative care. In order to provide a more complete picture of goal setting, I also conducted a series of interviews with patients, to find out their perceptions of goal setting. In the next chapter I report on findings from these interviews.

Chapter 5: Goal setting in a single hospice setting: the patients' perspective

5.1 Introduction:

In preceding chapters I highlighted that goal setting is an important part of contemporary palliative care. This has been emphasised in both policy and the literature on goal setting in palliative care. In Chapter four I reported on findings from 10 case studies of professionals working in an in-patient palliative care unit. The use of case study design allowed me to look at goal setting from different perspectives and make comparisons between what people do, what they say and what they write about. However, this did not give me an insight into what patients think and feel about goal setting. In order to do this, I conducted a series of semi structured interviews with patients.

In this chapter I focus on the methods used, analysis and results of the interviews with patients. I have described the setting where this research took place in Chapter 4, section 4.2, and this remains the same throughout the project. The patient interviews were conducted whilst I carried out the case studies with professionals, although in order to ensure that links could not be made between patient's comments and the professionals I observed, the sample of patients interviewed were separate from those who were observed. I present the findings from the interviews and discuss them in relation to the case studies and the literature review.

5.2 Study aims and research question

The aim of this phase of the research was to gain an insight into the process of goal setting in a single hospice setting, from the patient's perspective.

The specific research question was:

What are the expectations, experience and perceptions of patients who are admitted to the hospice for symptom control, maximising potential or therapeutic assessment with regard to goal setting?

5.3 Research Design

Semi structured interviews were used to investigate the experience and perceptions of a sample of patients admitted to the hospice for symptom control, therapeutic assessment or maximising potential with regard to goal setting. I focused on this group of patients because, as I have already said in Chapter 4 (section 4.2) I hypothesised that explicit goal setting was most likely to occur with patients who were receiving some form of rehabilitation during their in-patient stay. They were also most likely to be well enough to participate in interviews.

Interviews are commonly used as a method of finding out about phenomena from the perspective of the participant (Tod 2006) and the use of interviews as a method of data collection has been endorsed as an appropriate method to find out about complex situations about which little is known (Kumar 2005). I chose to conduct semi-structured interviews rather than standardised interviews, focus groups or questionnaires because I felt that it would be unlikely that patients would have considered the concept of goal setting before. I wanted to find out about the experiences of *individual* patients rather than those of a *group*. The use of semi structured face to face interviews allowed me to clarify questions, be flexible in relation to patient's experiences and to collect in-depth information by asking follow up or probing questions (Mason 2002). This allowed me to find out what each patient thought and felt about goal setting whilst allowing me to clarify any questions if they were unfamiliar with the concept of goal setting.

There are significant differences between clinical and research interviews, and many of the qualitative research text books highlight the need for clinicians to adapt their style and interview methods if they are to become good research interviewers (Tod 2006, Patton 2002).

As a clinician, I found the patient interviews particularly challenging as I had a tendency to want to take on the role of 'therapist' rather than research interviewer. As a result, my early interviews consisted of more closed questions than later interviews, along with comments which tried to focus the discussion, rather than leaving it open. I was also very aware that many of the patients I interviewed were very ill and at times I felt that I was limited as to how far I could probe and ask follow up questions. I trained myself to allow people enough time to collect their thoughts and answer my questions and I was constantly aware of the types of questions I asked and the manner in which I asked them. For the duration of the research I was given feedback during supervision so that the quality of the interviews could be monitored and improved.

5.3.1 Strengths and limitations of using semi-structured interviews with patients

I used semi-structured interviews as opposed to informal conversational interviews or more formal standardised interviews because I wanted to be able to make comparisons between data collected from different interviews, whilst having some flexibility over the questions. I used an interview topic guide (Appendix 9) so that I could ask each patient the same broad questions, eliciting thoughts and perspectives which could be compared at a later date. This type of interview also gave me some flexibility so that I could rephrase my questions if necessary and follow up and probe if I wished to explore anything in greater detail (Mason 2002).

Because patients were receiving input from the hospice when the interviews were being conducted, there was a possibility that they would be reluctant to say anything negative about it or the services they were receiving. In an attempt to address this, I made it clear at the beginning of each interview that all comments would be treated confidentially and that patients were free to tell me about positive and negative experiences. In practice, patients did

come across as being very positive about their experience, but they also articulated some negative thoughts about their involvement in the goal setting process.

5.3.2 Sample for patient interviews

Initially I set out to interview a sample of ten patients on two occasions: once at the beginning of their admission and again just prior to or shortly after they had been discharged, as I wanted to make comparisons between patient's expectations and what actually happened in relation to goal setting. In practice, it was very difficult to carry out the second interview with patients as the health of many of them deteriorated and they were no longer able to take part. It also proved very difficult to interview patients at the beginning of their admission as many were too ill to be approached when they first arrived. I had anticipated this as a potential problem when designing the study and a contingency measure was written into the original proposal, that if people were unable to participate in second interviews, I would interview a larger number of patients on just one occasion. This was approved by the University of Stirling and NHS ethics committees. As I had some difficulties early on in managing to carry out second interviews, I discussed this with my supervisors and we agreed that I should interview fifteen patients on just one occasion. The interview topic guide was modified in order to take this into account (Appendix 10).

Patients were identified by staff at the hospice. They were approached and asked if they would consider participating in the research if they met the following criteria:

- Adult patients (16 and over) with cancer or chronic life-limiting disease who were admitted to the ward for symptom control, maximising potential and/or therapeutic assessment;

- Patients who were able to give informed consent;

- Patients who were medically well enough to participate in interviews.

Patients were given an information sheet (Appendix 11) by the member of staff which they were asked to read and discuss with others before deciding whether or not to take part. They were given at least 24 hours to make up their minds about participating, and it was made clear to them that it was their choice to take part. Before interviews were carried out, I met with potential participants to answer any questions and to check that they understood what the interview process would entail. The group of patients who were invited to take part in the study were separate from those who were observed as part of the case study design. This was to reduce the likelihood of individuals (both staff and patients) being identifiable.

Patients who were approached by staff as possible participants were keen to find out more about what was involved. Some patients were concerned that they or their families could be identifiable in the final report, and discussed this with me and other members of staff. They were reassured that all data would be anonymised, and were then happy to take part. A total of 19 patients were initially approached and asked if they would like to participate in interviews. Of these, 15 actually took part, as four people decided not to after they had been provided with more information about the study.

Interviews were carried out in various places, dependant on choices made by the patients and their ability to mobilise. Some were carried out in a private sitting room away from the main ward, others were conducted on the ward with the curtains closed around the patient's bed, and others were carried out in the patient's own home, once they had been discharged. I made a note of where each interview took place so that this could be taken into account during analysis, as I was aware that the location of the interview may have affected what people were prepared to talk about. In practice, people did not seem to be aware of their surroundings once the interview was underway, and patients told me about both positive and negative experiences, regardless of where the interview took place.

Each interview was digitally recorded and I transcribed each verbatim to allow me to become very familiar with the data. Following each interview, I wrote up field notes which included information about the environment as well as a descriptive summary of each patient. As stated in section 5.3, I discussed the interviews with my supervisors and spent time reflecting on my own performance as an interviewer in order to continually improve my research interviewing techniques.

5.3.3 Ethical considerations

The protocol for this study was scrutinised and approved by the University of Stirling School of Nursing, Midwifery and Health and NHS research and ethics committees (REC Reference number: 08/S0501/98, see Appendices 6 and 7). All recording and field notes were anonymised through the use of codes and all names were changed to pseudonyms from the outset. Patients were assured that they and their families would not be identifiable in the final report and they all had the chance to ask questions about the research, including the types of questions that would be covered, prior to agreeing to take part.

Patients involved in this study were receiving input relating to end of life issues. As a result, sensitive issues were sometimes raised during the interviews, and occasionally, patients became upset. I made sure that patients were aware that they could stop being interviewed at any time and that they could decline further participation. Although patients did, understandably, become upset, at times, informal feedback from patients and professionals suggested that patients welcomed the opportunity to discuss their experiences. This is in keeping with published guidance on involving patients in palliative and end of life services which states that:

"many people are very keen to 'give something back', leave a legacy for others or have some control at a time when they may feel powerless." (National Council for Palliative Care / NHS Centre for Involvement 2010:12)

On the occasions when patients became upset, I offered to stop the interviews, but all patients wished to continue. At the end of each interview, I made sure that nursing or medical staff knew that the patient had been upset so that they could provide appropriate support if required.

5.4 Analytical approach

I used Framework Analysis (Lacey and Luff 2001), to analyse the patient interview transcripts. The stages of Framework have been outlined in Chapters 3 (section .2.4) and 4 (section 4.5). I read through each transcript in order to become familiar with the data and then identified an initial thematic framework which is shown in Figure 18:

Figure 18 Initial themes
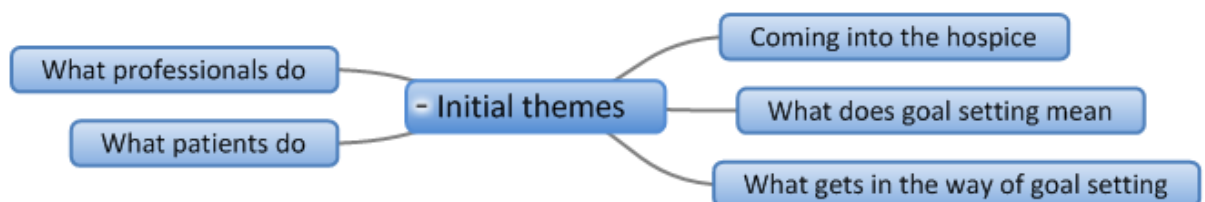
I initially coded all the data using the themes in Figure 18. One of my supervisors read the coded data, to ensure there was agreement on my initial coding. He also read a sample of original interviews to make sure I had coded all the relevant data. We then discussed the initial themes in relation to the original aims and research questions. I had set out to find out about the *expectations, experience and perceptions* of patients admitted to the hospice. We felt that the initial themes could be aligned with the original questions, in the following way:

Table 23 Themes mapped to research question

Coming into the hospice = *Expectations*
What professionals do, what patients do and what gets in the way = *Experience*
What does goal setting mean = *Perceptions*

Following initial discussions and agreement that the themes could be mapped as above, I began to index the data. During this process, sub-themes developed so that final charts looked like this:

Table 24 Expectations

Expectations	
1a. Purpose of admission/goals of admission	**1b. Involvement in decision to come into hospice**

Table 25 Experiences

Experiences	
2a. Organisational	**2b.Personal**
(**Balancing risk, Missed opportunities**)	(**Adjustment/adaptation, Making plans, What happens in practice**)

Table 26 Perceptions

Perceptions	
3a. How goals are viewed/what they are	**3b. Beliefs about goal setting**

Although we agreed on the above themes, which were based on the research questions, I was also open to unexpected themes. I checked the original transcripts to make sure that all of the relevant data had been coded and that I had not missed out any themes which did not 'fit'

with my framework. During the analysis process I was very aware that qualitative data analysis is subjective, so I regularly checked the original data to ensure that quotes were not taken out of context or over interpreted. I abstracted direct quotes from each interview under individual themes and summarised them onto data charts. Having the data displayed on charts really helped me to be confident that I was giving an honest account of the data and I also discussed this issue with my supervisors. An example of a data chart is provided in Table27.

Table 27 Example data chart

Participant	Organisational			Personal	
	Balancing risk	*Missed opportunities*	*Adjustment/adaptation*	*Making plans*	*What happens in practice*
2. Ruth, a 61 year old woman. She was admitted to the hospice a few weeks ago for symptom control and therapeutic assessment. She has breast cancer, and was transferred to the hospice from hospital where she had been undergoing treatment. She had had an adverse reaction to chemo therapy and is now having difficulties mobilising.	R: I suppose they make their decisions - sometimes I think they make bad decisions, other times they're SB: Right? R: Like I wasn't to sit on the edge of the bed cause they keep the sides up at night in case I fall over or out SB: Right, and do you think you would fall out?	R: I don't know, I'd like to do more for myself SB: Right? Can you give me an example? R: I'd like to wash myself, which I can do in the bed but they insist that they'll wash me. R: Well I have that it's just like, they can bring me a basin and I can wash my face and my hands	R: Well, I thought I would just come in here for a week or two, I'd be up on my feet walking SB: Right? R: But it just does nae work like that. Take everyday as it comes. A wee bit at a time like two or three minutes every day doing exercises R: Well, it's a slow progress when	R: If I get on my feet and start walking that's a different kettle of fish. SB: Right R: I'll be able to go to the toilet myself which I can't do now. SB: Ok R: That's very embarrassing isn't it? SB: Yeah R: Then I'll be able to go and have my shower and things	R: Well I do my exercises in the morning if I wake up early and then J'll come, stand me up, um she's coming this afternoon. This morning I was a bit upset so she said she'd come back That's their instructions isn't it. Their rules. So I've got to abide by them I suppose eh?, Until I get on my feet

Participant	Organisational		Personal		
	R: Probably! cause I'm a restless sleeper R: Well, like, I want to help myself. If I can't do it myself, who's going to do it when I go home? So I've got to learn to do things myself. That's the point I was trying to get over to them, but they said 'no'. SB: Right R: You just sit there, we will wash you in here you know what I mean?	SB: uh huh R: I can get down to wash my legs and my bottom and things like that and I can dry myself off SB: Uh huh R: But they will persist - you feel you're treated like a bambino sometimes you know SB: OK Em and - did you have –were you clear about the goals you were working towards? R : Yeah SB: And did they ever	you're getting back on your feet again. It just takes time. And I'm still no there yet, you know? But I'll get there eventually. Cos it takes time to get back on your feet again R: But err – I'm still getting there. It's gonna take time before I'm back walking normally but - I'm getting there R: I'm beginning to do a wee bit for myself but I've just got to be very careful – cos I get tired –	like that SB: Right R: I'm waiting - From next week I think I should be on the move – hopefully SB: Do you think they'll be steps towards you getting home – like a visit home? R: Well I don't know eer I've got two friends there, so we'll see what the weather's like this weekend. They might take me away an hour in the car out for coffee	R: But that was four weeks that I was in for. – before I got home SB: Right and how did you feel about that? R: Well it was a long time. I thought maybe three weeks would have been ample you know, but no, I had to wait four weeks before they let me home. SB: Did you feel it would have been – you could have got home sooner?

Participant	Organisational		Personal	
	talk to you about those in the hospice? R: No – er no not really no SB: So how did you know –what… R: Well I had to get myself – if I didn't help myself nobody else was going to help me so I had to do it myself	yes, just wee bit. So apart form that I'm getting there fine	somewhere else SB: Oh that sounds good. R: They came last week. And we went along to the cafeteria R: Well I would do a wee bit extra and things like that. I was able to wash myself and dress myself and get myself moving again. SB: Ok – You felt that it came from you? R: It all came from me. Yes, well the nurses were fantastic right enough they were really good –	R: Yeah, probably - Probably – after three weeks I would've got home – but they kept me in an extra week for some reason – I don't know R: Well there were doctors there in everyday – come to visit you every day so that was quite good and they- (Pause) SB: What kinds of things did they tell you? R: Well they told me when they thought I'd be getting home and that. Em but one

Participant	Organisational	Personal	
		but - I didn't want to lie in bed all day you know. You've got to push your self at some time – to get yourself up and push yourself on. There's nobody else there to do it – you see it's up to yourself	said one thing and another said another.

Once I had transferred all the data onto charts, I was able to look at it as a whole and make comparisons between participants and themes. In the next section I report on findings from my analysis.

5.5 Findings

Fifteen patients took part in interviews. Demographic details of participants are provided in Table 28.

Table 28 Demographic information about interview participants

Name	Age	Diagnosis	Reason for admission (from the case notes)
Kay	Under 65	Neurological	Respite
Ruth	Under 65	Cancer	Symptom control and rehabilitation to help with mobility
Susan	Over 65	Neurological	Symptom control (severe pain and poor mobility)
Anne	Under 65	Cancer	Symptom control (pain)
Jane	Over 65	Cancer	Symptom control (pain and poor mobility)
Liz	Under 65	Cancer	Symptom control (pain and continence issues)
Jenny	Under 65	Cancer	Symptom control
Dan	Under 65	Respiratory	Symptom control (breathing)
Gemma	Under 65	Respiratory	Symptom control (breathing)
Amy	Over 65	Cancer	Symptom control

Name	Age	Diagnosis	Reason for admission (from the case notes)
			(mobility)
Frank	Under 65	Cancer	Symptom control (mobility and review of medication)
Peter	Over 65	Cancer	Symptom control (Reduce vomiting)
Diana	Over 65	Cancer	Symptom control (breathlessness and mobility)
Ron	Over 65	Cancer	Symptom control (mobility)
Gwen	Under 65	Neurological	Respite and assessment

The patients who took part in interviews are representative of the typical range of patients who are admitted to the ward for symptom control, although in this case more women than men agreed to participate.

In the next section I report on findings under the three main themes: patient's expectations, experiences and perceptions of goal setting.

5.5.1 Patient's expectations

During interviews I asked patients why they had been admitted to the hospice. I also asked for information about the circumstances which led to their admission and how involved they had been in making the decision to come into the hospice. All patients were clear about why they had been admitted to the hospice. The majority of people told me that they had been admitted so that particular symptoms could be sorted out, and pain was typically the

symptom that patients talked about. Anne explained to me how she needed to be monitored by medical staff over a consistent time period so that staff could control her pain:

> *"well I was at home. I had taken ill and I was at home, and the Macmillan nurses were coming in err once – twice a week some weeks and it was just actually err try and get a balance with the pain. I was having terrible pain and it was getting worse. Even with the Macmillan nurses coming in and what she decided (Sandra was my nurse) and what Sandra decided was that I would actually be better in here where they could monitor me 24 hours a day"* **(Anne)**

Three patients told me that they had come into the hospice in order to have a rest and also to give their partners a rest. Dan had been in the hospice for respite before and appeared familiar with the idea that he could come into the hospice for this:

> *"so I - needed a break, and my wife needed a break. So, I mean I come in here to have – absolute rest."* **(Dan)**

Only three patients told me that they were in the hospice for help to become independent. Gemma, for example said:

> *"Obviously the aim is to go out as well as possible and doing as much as possible. That's obviously the first aim – and that's what you're aiming for."* **(Gemma)**

Most people's goals for admission were very general in nature and focused on symptom management rather than goals based on participating in specific activities. One patient, Ruth did have a specific goal in mind which she wanted to work on:

> *"Well, I thought I would just come in here for a week or two, I'd be up on my feet walking"* **(Ruth)**

However, she appeared to be frustrated by the length of time it took for her to achieve her goal of walking and during our interview she told me that she felt staff had missed opportunities to help her work towards her goal (see section .5.2).

Anne, Jenny, Liz and Diana talked about their initial feelings about coming into the hospice. They regarded the hospice as a place where people come to die, and it seemed that they had needed some convincing before they were admitted. Liz told me that having a specific reason for admission had helped her to make the decision to come in:

> "*Joan* [Homecare nurse] *said you know, explained about coming in here and of course I just said "hospice?", you know but – I got a bit nervous about it – but she explained to me why– and everything and the reason I was going in was for pain control and that they would start at the beginning and try and find a tablet that would work – so – um - her object was to get me in here to do this and that's why I'm here basically. And it's working."* **(Liz)**

The extent to which patients were involved in the decision to come into the hospice varied according to how unwell they were prior to admission. Some patients felt that they had been too ill to contribute to discussions about admission:

> **Ruth:** *'Well I was very ill at the time'*

> **Sally:** *'Right?'*

> **Ruth:** *'So I couldna make a straight decision actually to tell you the truth'*

Others felt that they were fully involved in the decision, for example Kay, who was admitted for a period of respite:

> **Sally:** *'who would you say was the person who made the decision about coming in here?'*

> **Kay:** *It was between Peter and I. He said that this would be a good time for him. As long as it was a good time for me.'*

In summary, patients were able to tell me why they had been admitted to the hospice and, if they had been well enough, felt that they had been fully involved in the decision to come in. The reasons for admission predominantly focused on symptom management and problem resolution and there was little evidence that patients were aware of or working towards specific goals based around activity when they were admitted.

5.5.2 Patient's experiences of goal setting

Patients talked about two types of experiences in relation to goal setting in the hospice. These can be categorised as organisational and personal. Three patients talked about some of the restrictions that they felt the hospice placed on them in relation to achieving goals. These related to how professionals balanced risk and also how opportunities for helping them work towards their goals were sometimes missed. All patients talked about their experiences on a personal level, which included how they experienced the hospice routines, made plans and adjusted to deteriorating health.

i.   Organisational experiences

One patient in particular (Ruth) voiced frustration about what she perceived as overly protective attitudes of staff which she found restrictive:

> *'Like I wasn't to sit on the edge of the bed cause they keep the sides up at night in case I fall over or out'* **(Ruth)**

When asked whether or not she thought she would have actually fallen out of bed, Ruth had to admit that she might have done:

> *'Probably! cause I'm a restless sleeper'* **(Ruth)**

Jane also believed that staff were safety conscious and felt she needed to make sure staff knew where she was going if she wanted to go to the toilet on her own:

> *'they'll say if you want to go to the toilet, just buzz and someone will come with you which I don't require any more – I can go myself now. It's quite a short distance – but I always say to any of the staff that are about – particularly the ones who are at the station – you know, I'll just say I'm going to the toilet so they don't come and say 'where did Jane go!'* **(Jane)**

Ruth, Jane and Liz all talked about the caring attitude of hospice staff and felt that at times this stopped them from being able to do things for themselves, which they believed might restrict their independence in the future:

> *'They constantly want to wash my back for me and I'm – no - I'm capable – I can do that myself, no that's – you know – you – I need to do this myself – I need to keep going with these things as long as possible.'* **(Liz)**

> *'one of the nursing staff will say – 'do you want to get into your pyjamas now' – and I'll say right OK then, I'll get into my pyjamas now – 'Right I'll be with you' and I say no it's OK I can do that myself because I don't want to be completely – dependent on someone else – I want to do what I can.'* **(Jane)**

Other comments about goal setting in the hospice related to more personal experiences.

ii.   *Personal experiences*

Patients told me about what happened in practice in the hospice and related this to their goals, which were often about controlling symptoms. I was able to get a sense of the hospice routine and tasks that were regularly carried out from what patients said about their experiences:

'Well, you get up, get washed, and ready. You know, these kind of things – obviously.'

(Gemma)

Some patients felt that they could not always achieve their goals (particularly those relating to pain management) because they did not want to over-burden staff by pressing the buzzer too often, in spite of having been told that asking for breakthrough pain relief was an important way of controlling pain:

'Because that's when you should get your drugs you know. But it wasn't always – you weren't always able to do that because the nurses had other more important things to do you know.' **(Susan)**

I asked patients if staff had asked them what their goals were during their stay at the hospice. Only one patient (Susan) could remember being specifically asked about goals:

'she said [the doctor]*– "do you have any goals in mind – when you get out of hospital?" I says yeah, well, the first thing I want to do – I want to go down to see my sister who I hadn't seen because her husband's so ill.'* **(Susan)**

In the example above, the question that the staff member asked Susan in relation to goal setting appeared to be about what she wanted to achieve when she got home rather than what she wanted to do while she was in the hospice. Another patient (Gemma) remembered being asked about goals, but this appeared to be in relation to advance care planning:

'they asked me – when I first came in, they asked me a barrage of questions – about how I felt about certain things – If this happened, what did I want to do. If that happened, what did I want to happen. Who did I want contacted and things like that.'

(Gemma)

Even though patients did not appear to be explicitly asked about goals whilst in the hospice, there was evidence that patients were supported to work towards specific goals. Liz told me how staff supported her to go home 'on pass' so she could attend her husband's birthday celebrations:

> *'But my husband's celebrations – and we've got meals booked and everything. But the girls have - what they're doing is – the bed is being held'* **(Liz)**

She also told me how the physiotherapist had helped her to do some knitting:

> *'the physio's been wonderful – you know – she – because I wanted to do some knitting and things – Oh Right, we'll find the chair – low enough arms. Poor girls were pushing chairs! – but she got me organised and everything.'* **(Liz)**

Liz did not feel that professionals had asked her about specific activity based goals on admission, but it was clear that the goals of knitting and attending her husband's birthday celebrations had been identified. Perhaps they came out of the informal conversations that professionals talked about during their interviews (see Chapter 4 section 6.2). Liz was not able to tell me exactly how they had been identified, but did feel that the whole team had taken time to listen to her and that they had communicated with each other effectively:

> *'But they do pass on information well and are always aware of my situation – what's happening to me and where I am and you know, what my needs are – so that's good'* **(Liz)**

Other patients had more general goals, for example, Peter who told me that the physiotherapist was helping him to achieve his goal of improving his mobility:

'I've become more – dependent on my bed – err – cause I've just lost all the strength in my legs. But in saying that, the physiotherapist's trying to keep me – got me up and running – and aye, we're getting there.' **(Peter)**

Patients did not always appear to tell professionals about their specific goals, but there was evidence that they made their own plans and set themselves personal goals which they wanted to achieve (Table29).

Table 29 Patients made plans and set goals for themselves

Patients made plans and set goals for themselves	
Patient	Example
Jane	*'I've seen me work with young Emily* [AHP student] *there, and I'll say right, I'll walk to that corner and Emily will say "right, turn round if you want – if you want" and I'll say well, can I try the next corner – 'if you feel up to It and I do that, and that is my goal – is to do that wee bit more everyday.'*
Dan	*'Well, I tend to have a shower every morning – and I manage that myself – err It takes me round about 45 minutes cause I'll go along – and I'll have a shower – then I'll sit for a little while till I get my breath back. I take this all with me (points to oxygen cylinder) – then I'll start to dry myself, then I'll have another breather – so by the time I do that, have a shave, get dressed and come back along – it can take about 45 minutes.'*
Peter	*'Well, we were sitting last night – or the other night and – my brother's in Melbourne with his family in Australia - and we thought that we could maybe Skype – so we brought the computer in to see how successful it might turn out to be. I cannae say it's a success yet cause we have nae got there – but err, we're certainly trying hard'*
Ron	*'I spoke to somebody about getting one with the wheels on it. They're going to check up on that –see if they can get one delivered to the house. I use the zimmer in the house – for moving about. But, if it's a good day – well – I like a wee smoke of a wee cigar. If it's a good day, I go out – the zimmer's not much good – but the one with the wheels – would be ideal. I've got arm crutches, but I've not had them on for a wee while yet – but err. One of them would be an awful lot easier for moving about the back garden and that'*

In the examples above, patients appeared to set their own small goals in order to push themselves and maintain their independence (Jane and Dan). Peter and Ron seemed to be thinking about particular problems and working out ways to overcome them. These specific examples were goals based around activity and participation, rather than goals about controlling symptoms (impairment based). Patients themselves seemed to take on the responsibility of sorting out these goals and did not necessarily regard professionals as part of the solution. When I asked Peter who had come up with the idea to arrange a Skype call with his brother in Australia, he told me that he and his wife had thought of it, and that they had worked on sorting it out together, independent of hospice staff.

An exception to this pattern was Amy who told me how one of the Allied Health Professionals (AHPs) had helped her to have a visit home (this lady had severe aphasia so the dialogue is broken up with lots of hesitation. This is indicated in the text with the use of hyphens):

> *'My goals – I speak about goals – I since my husband died, I have not been able to go home. And in my heart I wanted to be in my own house – not to stay because I knew I couldn't manage – but I wanted to be there – so that I could be – feel close to him – and the wonderful Frances [AHP]– she get it all. She get it all sorted …….. And I have listened to my music and I have lie on my bed and feel close to my husband.'* **(Amy)**

In the example above, Amy told me about a very important, personal goal which she had been able to achieve, with the help of staff. In Chapter 4 (section 6.4) I mentioned that staff appeared to be most likely to pick up on what they regarded as 'significant goals', rather than ordinary, everyday goals (such as showering independently or using a computer). This is perhaps why Amy was supported to work towards and achieve this very specific and significant goal.

Patients talked about how they had to adjust to their illness and scale their plans and goals back accordingly. Liz told me that she had recently discovered a new lump in one of her breasts. This had shattered one of her goals, which had been to go abroad with her husband:

'But this is all up in – as I say, I don't see that coming now at all um – The - you know the consultant oncologist told me about 6 months ago that I had 2 or 3 years left um of which, even I knew I might get about 18 months out of that of em – good you know maybe quite a good life you know, with not too much medical or nursing interference – you know what I mean. That's what I'd sort of, set myself as – then – but now that's – until we know what this lump is - and if it's a breast lump –There's, I mean there's no way I'm going through treatment – operations or anything – so everything is completely and utterly up in the air' **(Liz)**

Liz appeared to cope with this new, life threatening uncertainty by becoming even more determined to maintain her own independence around day to day activities. She told me that nurses had suggested that she try a catheter to help with some of her urinary symptoms:

'Oh yes, there's no way I'm giving up any of my independence. If I can – because I'm having a lot of urinary problems and em water works is just going to pot. Um And one of the nurses had mentioned catheter and of course, I nearly had a loopy.' **(Liz)**

Liz felt that having a catheter would be like 'giving in' and resolved to maintain her independence by managing her urinary symptoms in a different way. Whilst she had a different opinion to nursing and medical staff about a solution to her problem, she told me that her opinion had been listened to and that staff had been happy to support her with this decision, at least for the time being.

Other patients appeared to make more gradual adjustments as their conditions worsened (Table 30).

Table 30 Examples of patients adapting to deteriorating health conditions

Adaptation to deteriorating health

Patient	Example
Gwen	**Gwen:** *this is such a debilitating disease – you actually – you maybe don't know that something's no functioning till you go to – to do it – and use it – and you discover it's got weaker or it's – no functioning and that knocks the head on maybe whatever you were thinking you could manage.* **Sally**: *Right – so then what?* **Gwen:** *Oh well, I just have to give in gracefully. But – not very gracefully – but (laughs)*
Ron	*So at home I sleep on a recliner. – because the toilet's downstairs. And – I'm a lot easier sleeping in that and getting out of that – but I've got hand rails on the stair – we put in for a – see if we can get a chair lift put in –but I'm maybe better without a chair lift.*
Dan	*To be honest, it's just with having this kind of illness, you've really got to – re-think your outlook – because as I said I thought it* [a mobility scooter] *was going to take away independence. It's given me more – so, I mean, the likes of MECS (Mobile Emergency Care Service) etc. is doing away with my independence but – it won't – you know, it's just getting your head round these things.*

In the examples in Table 30, patients used their experiences of the limitations that illness placed on them as information and then adjusted and changed their plans accordingly. Peter summed up the importance of goal setting as a way for him to get feedback on progress:

> *'if you don't set goals, you don't set yourself targets, err – how are you going to know you're progressing.'* **(Peter)**

None of the patients I interviewed seemed to be unrealistic about what they could or could not manage at that point in time. This is in contrast to what professionals believed. They told me in interviews (see Chapter 4 section 6.3) that patients could often be unrealistic and that this could make goal setting difficult. I also highlighted in Chapter 4 (section 6.5) that professionals did not always explicitly support patients to adapt to their changing situation.

The patients that I interviewed did not particularly believe that professionals had a role in sorting out practical problems for them, and tended to regard their role as one primarily concerned with medical and symptom management.

5.5.3 Patient's perceptions about goal setting

Patients were asked what goal setting meant to them, and this provided an insight into their beliefs about and understanding of goals. For four patients there seemed to be a contradiction between their initial response to the question '*Does the term 'goal setting' mean anything to you?*' and later responses, once they had had time to reflect on the concept of goal setting (Table 31).

Table 31 Initial thoughts about goal setting compared with later reflections

Patient	Initial thoughts	Later reflections
Ruth	'*Setting goals? Well I'm no really a goal person. I take every day as it comes*'	'*I've got one – goal, next year, my youngest son's getting married so I'm, that's my goal to go to his wedding so - hopefully – are you listening up there?* [looks up] *I want to go to his wedding so we'll wait and see what happens. It's a goal.*'
Ron	**Sally:** *does the term goal setting mean anything to you?* **Ron:** *I've never heard of it – no.* **Sally:** *No?* **Ron**: *I don't know what that is.*	'*I want to try and get moving.* [Pause]. *Cause I've just been sitting in a chair.*'
Gwen	**Sally:** *does the term goal setting mean anything to you?* **Gwen:** *Not really. No.*	'*Well, the feeding's the main one – really – I would say. And I still manage to – sort of fill in the crossword, you know. I do crosswords. Easy ones, I may say – but, em, I still manage, but sometimes I have to stop because my finger gets too – err – s – not sore because I'm no bothered with pain. It*'

Patient	Initial thoughts	Later reflections
		just, I run out of steam.'
Liz	**Sally:** *Do you set yourself little goals – you know – for each day? Or parts of the day?* **Liz:** *Um Not particularly.*	*'I knew I was going to get up and wash my hair today em things like that – and I want to get on with this knitting –cause – I think number two daughter might have a family quite quickly um – and I don't have the strength for – you know, knitting as I used to do – so I want to get on with that – you know – that sort of thing. So I suppose, yes I am setting myself some goals, yes.'*

Other patients like Anne felt that setting goals was very important. She told me how her goals had helped to keep her going:

> *'Yeah, it means a lot to me. Because when I when I was told I had cancer, you know and then I was told it was really serious, you know – after the chemo and everything, I did set goals for myself. I've got three grandkids and my oldest one was making his first Holy Communion. And I said, right. I'm gonna be there. I'm gonna be well for that. And I was – I was well for that. I was in a wheelchair. But I was well. And then I thought – my grandson – he was in a football team and there was a tournament day – a tournament day – and I thought Right I says, I'm gonna be there for that. So I was there for that.'* **(Anne)**

Although Anne felt that setting goals was important, when I asked her if hospice staff should set goals with her, she did not feel that this would be very helpful:

> *'I would say no because if they did set goals in here, and didn't meet them or achieve them, I think it would be worse.'* **(Anne)**

In fact, Anne kept her goals completely separated from her life in the hospice

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Sally: And what about – do you set yourself little goals in here, while you're here?

Anne: No

Sally: Right – why do you think that is?

Anne: Well it [pause] I don't know [pause] it's just [pause] haven't even thought about it since I was in. I haven't even thought about it. You know. You see, I'm just in here, and at the back of my mind I'm not in here to die.

Although a keen goal setter in her home life, Anne did not appear to feel that goal setting was relevant in the hospice. This could be partly be attributed to the fact that, as Anne said, she did not want to work towards goals that might not ultimately be achievable, but it could also be because goals are rarely mentioned explicitly by hospice staff (see chapter 4 section 6).

Other patients also seemed to regard their goals as being separate from what was happening in the hospice, but many of them were able to give me examples of a range of short, medium and long-term goals (See Table 32).

Table 32 Examples of goals

Patient	Goals
Susan	**Susan:** *my greatest goal is to go up to C* [holiday destination] *next year for a week's holiday* **Sally:** *Right* **Susan:** *We've been before and it's a wonderful place for disabled people*
	Sally: *What about little goals on a day-to-day basis?* **Susan:** *Little goals – um – I want to sit up longer* **Sally:** *Right* **Susan:** *At my computer.*

Patient	Goals
	Sally: *Uh huh? You use the computer?* **Susan:** *Yeah, I try my best – I write books.*
Jenny	**Jenny:** *Well to me when I come here my goal is to get better.* **Sally:** *Right* **Jenny:** *And to get hame to my weans and the doctors and nurses kinda help you achieve that by just coming in and doing wee bits wi you everyday day and eh... Aye, so my goal setting is to come here, get on my feet and go hame to my weans.*
	'Before I went back into hospital I was wanting to get my theory test and that done and get my driving lessons for going back to work and that. So that still, as it stands the noo that's - cos wi everything happened so fast and that, I never got very far. So that's my next step, hame and get my lessons and that done afore I go back to work.'
	'So I'd like to get hame and get things back to normal and take a wee bit of control back.'
Gemma	*'Go out with my friends. Well M – she's got her hen night, so I've got that. My younger sisters getting married as well – so I've got that – and my youngest sister's just had a wee baby. I'll see her. Seemingly my sisters getting engaged. That was all weeks ago. See the baby.'*
Frank	*Yes, goal setting means that I want to try and get past the date I've been – they've just gave me a date. It's not an exact date. So, I'm gonna try and go as far as I possibly can – until I can't move any more. That's my goal.*
	Move about as much as I can – and err be determined – make sure I don't lie in bed feeling sorry for myself.
Diana	*'I've made a will and done things that we just – try and get things – you know – because you're sort of – you. I know my husband's there – but it's me that's did everything.'*

In the examples above, goals seemed to have different significance for individual patients. Frank talked about goals in relation to his survival. He had a broad goal to live for longer than professionals had predicted. Diana's goals were about planning for a future after she had died. Jenny talked about getting on with life once she got home. This included very ordinary things such as booking a driving test and being able to look after her children. Susan talked about long term goals such as going on holiday, but also told me how she wanted to be able to sit up for longer so she could use her computer. During her interview, Susan told me that she was in the hospice for pain management. This seemed to be the main focus for staff, and she had not told them about things that she might want to do if her pain was better managed.

Although some patients initially felt that goal setting was of little relevance to them, everyone ultimately told me about goals that were important to them. There were a range of goals, and these appeared to concur with theoretical underpinnings discussed in Chapter 3 (Section 3.3). Some goals were about maintaining hope (for example, Frank, who wanted to live past a particular date; Anne who set a series of targets to keep herself going). Other goals were about preparing for death whilst affirming life (for example, Diana who talked about writing her will and sorting out her affairs; Amy who wanted to go home for one last time to feel close to her husband). The majority of goals were about doing simple, everyday things such as washing, showering and dressing independently. Patients did not appear to believe that these 'ordinary' goals were relevant to what was happening to them during their hospice admission and did not tend to tell staff about them. Goals did however seem to be relevant and important to the majority of patients.

5.6 Limitations

I have been able to gain an insight into the patients' experience of goal setting in the hospice through the use of semi-structured interviews. There are several limitations which need to be considered. Firstly, I depended on hospice staff to initially approach patients to ask them if

they would like to be interviewed. This method of recruitment has obvious disadvantages, as staff may have selected patients who they thought were particularly positive about their experiences. In addition to this, I interviewed patients within the context of the hospice, which may have altered what they said about their experiences. In practice, the patients I interviewed told me about both negative and positive experiences in relation to goal setting. Many of the patients I interviewed were very ill. This limited my ability to probe and ask follow up questions, and I was very aware of this at times during the interviews. This may well have affected the quality of data, and I may have obtained a wider range of views if I had carried out more interviews. However, within the timescales of this project, I was unable to interview any more patients. The 15 patients I interviewed told me about their thoughts about goal setting during their hospice admission. This has provided another perspective which adds to information gained from the case studies.

5.7 Discussion

Patients who took part in this study were all able to tell me why they had been admitted to the hospice, and these corresponded with reasons for admission written in the case notes. Clear aims for admission appeared to make coming into the hospice more acceptable to them. However, goals of admission were predominantly symptom or problem focused. Two patients told me about specific, activity based goals which they had discussed with staff, but the majority of patients worked towards their goals independently of professionals. A more explicit discussion about activity based goals prior to coming into the hospice might make admission to the hospice more acceptable for some patients. Patients felt that, at times, opportunities for maximising their independence were overlooked. This appeared to be because of the caring attitude of staff who often wanted to do things *for* patients rather than let them do things for themselves and also because staff did not want patients to take unnecessary risks. The implicit nature of the goal setting process in the hospice (see Chapter

4.7) may have contributed to the fact that patients rarely articulated their personal goals to staff. As a result, professional goals (which were most likely to be problem and symptom focused) and patient goals (which tended to be activity based) tended to run in parallel with each other, and opportunities for staff to support patients in achieving their goals were missed.

Patients for the most part understood and valued goal setting and were able to give examples of goals that were important to them. In contrast to professional's beliefs that patients were often unrealistic (see Chapter 4.6.3), the patients in this study often set themselves small goals (which appeared to be realistic) and used information gained from their experiences of trying to achieve goals to inform what they did next. They were able to scale back their goals as they adapted to the limitations that progressive illness placed on them, but wanted to hold on to maintaining independence around everyday tasks for as long as possible. They valued being able to achieve even small, everyday goals. Whilst patients believed that goal setting was important and relevant, they did not routinely discuss goals with staff and, in keeping with findings from the case studies (see Chapter 4.7), the implicit nature of goal setting in the hospice meant that goals were not always identified in partnership.

There are similarities between the issues which have arisen from the patient interviews, the case studies and the literature review: goal setting is important but the process is an implicit one; opportunities for setting goals can be missed; patients derive hope from setting, working towards and achieving goals; and patients adapt and scale back their goals as illness progresses.

Goal setting is established as an important part of palliative care which is recognised in policy, the literature and in practice (see Chapter 3.4.1 and Chapter 4.6.2). Few structured approaches to goal setting currently exist, but there is an appetite for developing theory based, explicit approaches. Findings from the patient interviews show that patients also value

goal setting, even if they do not call it that. From the case studies we found that goal setting in this hospice is both informal and implicit. The patient interviews support this finding. Given that in both the case studies and patient interviews, there was evidence that patient centred goals were missed, a more explicit, structured approach to goal setting may help improve the consistency and reach of goal setting in this hospice.

In the literature review, I identified key theories, which might underpin a structured approach to goal setting in palliative care: Hope Theory (Gum and Snyder 2002, Snyder 2002,) and Affirming life: Preparing for death (Bye 1998). Professionals in the case studies talked about the value of goal setting as a method of engendering hope in patients, and in the interviews, patients appeared to find setting and working towards goals a useful, tangible way of maintaining hope. Hope Theory (Snyder 2002) provides an explanation of how people's goals adapt as illness progresses. He suggests that patients can use feedback on their own goal performance as information and then adapt their goals by either developing alternative pathways to achieve goals or deciding to work towards new goals. Patients I interviewed did this and contrary to what professionals believed, were able to identify apparently realistic goals or scale back their goals if necessary. Based on findings from the case studies and patient interviews, Hope Theory merits further exploration as a theory to underpin a more structure approach to goal setting in palliative care.

Interview data also resonates with theories of how people adapt to life threatening illness, such as Bye's conceptual framework ('*Affirming life: Preparing for death'*, Bye 1998:8). Patients were able to work towards several goals at the same time, which could range from goals associated with everyday things (such as putting on pyjamas or walking to the toilet) to goals about the future (such as writing wills and discussing funeral arrangements). Exploration of a framework that enables people to reflect on living whilst dying simultaneously may be of

help to professionals working in palliative care and should be considered during the development of a theory based goal setting approach.

The patient interviews have confirmed that goal setting is an important part of palliative care but that it can be difficult to do. Currently there appears to be a mismatch between the goals that patients identify and work towards compared with those that professionals focus on. In practice, professionals focus on symptoms and problems rather than goals based around activity. Lack of an explicit method of goal setting leads to important goals being missed. It results in professionals and patients focusing primarily on illness rather than on what they can do to make life more meaningful. Developing a theory based, structured approach to goal setting may help palliative care professionals change their focus and help them work with patients to help them to live actively until they die.

STAGE 3: DEVELOPMENT AND EVALUATION OF A RESEARCHED-BASED GOAL SETTING AND ACTION PLANNING FRAMEWORK FOR USE IN PALLIATIVE CARE

Chapter 6: Development of a research based goal setting intervention for use in an in-patient hospice

6.1 Introduction

In previous chapters I examined the evidence base for rehabilitation and goal setting in palliative care within the literature and current clinical practice, and identified relevant theories to underpin the goal setting process (development phase, MRC framework, Craig et al. 2008). I showed that rehabilitation is seen as an essential element of palliative care which has an important role in helping people live whilst dying. Goal setting is a key component of the rehabilitation process, and several authors agree that it lacks theoretical development (Rosewilliam et al. 2011, Wade 2009, Wade 2005, Siegert and Taylor 2004). Encouraging progress has been made to address this, particularly within the field of stroke rehabilitation. Scobbie et al's theoretically informed goal setting framework for use in stroke rehabilitation (Scobbie et al. 2011, Scobbie et al. 2009) provides a starting point from which to develop structured approaches to goal setting in other settings such as palliative care.

Although goal setting is identified in both policy and research as an important part of palliative care, in this context it is poorly understood and defined. In the review presented in chapter 3 I identified Hope Theory (Leung et al. 2009, Gum and Snyder 2002) and Bye's framework for Affirming life: Preparing for death (Bye 1998) as having the potential to inform a new approach to goal setting in palliative care. In practice (chapters 4 and 5), my research has shown that professionals and patients regard goal setting as important but there is a lack

of consistency as to how it is delivered, and opportunities are missed to support patients to identify and work towards their goals. This is due, in part, to lack of an explicit approach to goal setting and also because of the challenges of working with patients who are deteriorating.

Having identified the evidence base and potential underlying theories to underpin a goal setting intervention for use in palliative care, the next step, according to the MRC framework (Craig et al. 2008), is to model process and outcomes. This involves taking time to find out how the developed intervention might work in practice and considering how its effectiveness might be measured. In this chapter I describe how I worked with a group of palliative care professionals to refine and develop a goal setting intervention for use in palliative care settings. Firstly I arranged meetings with the larger staff group at the hospice to discuss Scobbie et al's original G-AP framework (Section 6.3.1). I later convened and met with a small task group of professionals on several occasions in order to further develop the goal setting intervention and discuss the practicalities of implementation prior to testing it in one hospice setting (Chapter 7). I used a theoretical framework (Normalization Process Theory, NPT, May 2010) to structure discussions and analysis (Section 6.3.2).

6.2 Study aims and objectives

The aim of this phase of the study was to develop a research based intervention to enable staff and patients to effectively engage and participate in patient centred goal setting in an in-patient palliative care setting.

The objectives of the study were to find out:

1. Which theories underpinning an existing goal setting framework for use in stroke rehabilitation (G-AP) 'made sense' to professionals working in palliative care;

2. Whether Hope Theory (Snyder 2002) or Bye's framework for Affirming life: Preparing for death (Bye 1998) could be used to adapt the existing G-AP framework so that it is applicable and useful in palliative care;

3. How the developed goal setting framework could best be implemented in an in-patient palliative setting.

6.3 Methods

This phase of the research focuses on how patient centred goal setting practice might be improved in an in-patient palliative care setting. I approached this as a 'real world researcher' (Robson 2011). Real world research has been described as an approach which:

"focuses on problems and issues of direct relevance to people's lives, to help find ways of dealing with the problem or of better understanding the issue". (Robson 2011:4)

It is a pragmatic approach to research which allows a variety of methods to be used, depending on the research questions and focuses on problems within the context that they happen. As a practicing clinician, I was keen to develop an intervention which would be of direct benefit to patients and professionals and would be taken up and used in practice. I was also aware that those currently working in palliative care would have a valuable contribution to make in developing an intervention and that a new approach would be more likely to be relevant and useable if it was developed with those who work in the settings for which it is intended. I chose to include participatory and action elements into the design of this phase of the study. These originate from action research (Froggatt and Hockley 2011), which aims to implement change and improve practice (McNiff and Whitehead 2011). It has been used extensively in healthcare settings where change is often difficult to implement, particularly if it is imposed on practitioners by researchers and policy makers without consultation (May 2006, Meyer 2006). The participatory aspect of action research *"bridges the theory/practice gap"* (Froggatt and Hockley 2011:783) and has been identified as a suitable research method

in situations where the researcher wishes to develop or test an intervention in partnership with health care workers. It has been used successfully in palliative care settings to do this (Blackford 2012, Hockley 2006). Action research involves a cycle of action and reflection which can be repeated several times (Reason and Bradbury 2001). I firstly consulted with the overall staff group at the hospice and then recruited a small task group (or 'inquiry group') of staff who worked with me to discuss, try out and revise the proposed goal setting intervention (see section 6.5.1, Figure 22). During this process we not only refined the intervention, but also began to plan how it might be tested in practice.

Action research has been criticised as being unscientific, difficult to evaluate and limited to specific contexts so that there may be little scope for change being generalised into different settings (Patton 2002). At times, I did find discussions with the task group difficult to manage and the 'reflection- action' cycle was not always clear cut, but the insights gained from task group members were very valuable in shaping how use of the goal setting intervention might work in practice. Because I aimed to develop the goal setting intervention for use in the hospice where this research was taking place, I was aware my findings might not be generalizable into other settings. However, I based the framework not only on opinions and ideas of staff at the hospice, but also on theories which were applicable to palliative care patients, regardless of context (Gum and Snyder 2002, Bye 1998). I felt that this combination of practical, clinical experience matched with theory would increase generalizability of the developed framework into other palliative care settings. This could be explored in a future study.

6.4 Initial development of the goal setting intervention

My starting point was Scobbie et al's Goal setting and Action Planning framework (G-AP), which was developed for use in stroke rehabilitation (Scobbie et al. 2011, Scobbie et al. 2009). I used this framework because, from the literature on rehabilitation and goal setting, G-AP

appeared to be the most robust, theoretically informed goal setting intervention available. I had also used it in clinical practice and from these experiences I knew that it was useful and workable from a practical point of view. First, I examined the theories included in the framework. Table 33 shows which theories, key constructs and active ingredients underpin G-AP (based on Scobbie et al. 2011:470, which I discussed in chapter 2.4.4).

Table 33 Theories, constructs and active ingredients of G-AP

Theories	Key constructs	Active ingredients
Social CognitiveTheory: Self Efficacy **(Bandura 1997)**	• Efficacy beliefs • Outcome Expectancies	↑ motivation
Goal Setting Theory **(Locke and Latham 2002)**	• Goal specificity • Goal difficulty • Feedback	↑ persistence + effort ↑ goal related performance
Health Action Process Approach **(Schwarzer 1992)**	• Action Planning • Coping Planning • Feedback	Bridge the gap between intention and behaviour Activate & maintain goal directed behaviour

To find out whether or not the G-AP Framework made sense to palliative care professionals, I set up a series of feedback sessions for all qualified staff at the hospice (ward and homecare staff). I chose qualified staff because they would be the ones involved in delivering a new approach to goal setting. They had also been the focus of the study to date. The purpose of each workshop was to:

1. Provide staff with feedback on the research study;

2. Provide staff with the opportunity to make comments on and discuss the findings;

3. Provide staff with the opportunity to learn about G-AP and discuss whether or not it was relevant and applicable for use in palliative care;

4. Begin to engage the whole staff group in the research process.

These initial workshops provided an important foundation for the next steps in the research process and were well supported by senior management, who invited and encouraged all staff to attend. A total of 26 staff members attended the first workshop and 29 the second, representing 95% of qualified staff who could have attended. The format for each workshop was the same. Initially, I presented the findings from the project (data from the literature review, the case studies and patient interviews). I then presented G-AP (Figure 19), giving detail about the theories underpinning it and how it works in practice.

Figure 19 G-AP Framework
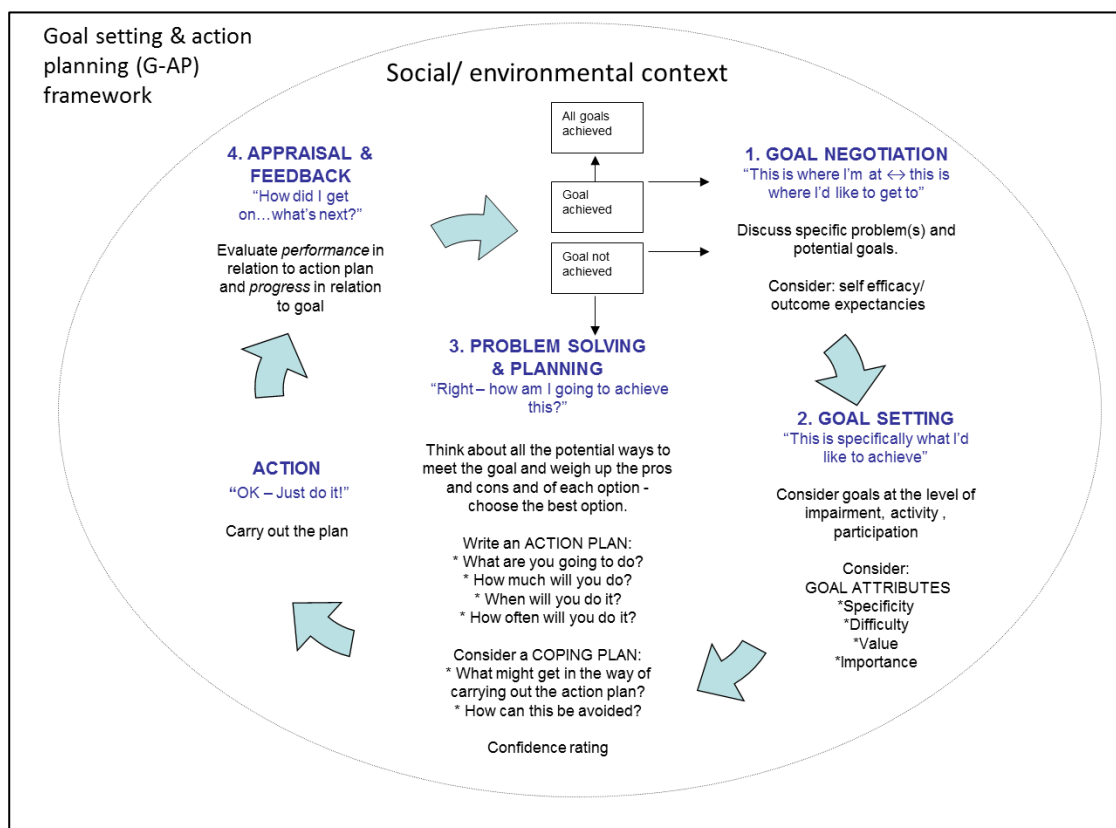
Following the presentation, staff were split into five groups and asked to discuss each stage of G-AP using the following questions to frame their discussions (Figure 20).

Figure 20 Questions used to discuss each stage of G-AP

1. How and where does this stage already happen? Are we missing any opportunities?
2. Is this stage directly transferrable to palliative care? If yes, how can we make it happen more consistently? If no, how does it need to be adapted?
3. Are there any tools that you already use that help you do this? (e.g. questions on admission documents, specific assessments and checklists).
4. Where should we record this phase and who should record it?
5. Anything else?

Each group was asked to provide feedback to the wider group following their discussions. I took field notes during each session and summarised the answers which each group presented on a flip chart (Tables 34– 38). The issues which came up at each workshop were broadly similar.

Table 34 Goal negotiation (this is where I'm at - this is where I'd like to get to)

Question	Summary of discussion
How and where does this stage already happen? Are we missing any opportunities?	Groups felt that this stage happens during the initial assessment, but that goals might be led and identified by health professionals rather than patients at this stage. Staff felt there was potential for goals to be missed and that it would be useful to have a goal setting tool for the whole team to use.
Is this stage directly transferrable to palliative care? If yes, how can we make it happen more consistently? If no, how does it need to be adapted?	Yes – staff felt that this stage was very important and goals may need to be renegotiated due to changes in a patient's condition. There was agreement that more explicit methods of recording goals in patient's notes would help to improve the consistency of the process.
Are there any tools that you already use that help you do this? (e.g. questions on admission	The initial assessment proforma has a space

Question	Summary of discussion
documents, specific assessments and checklists).	for writing down patient's goals.
Where should we record this phase and who should record it?	Some staff felt that the Advanced Care planning document might be a potential place to record goal negotiation discussions. However, there was no agreement about this. Some felt that there should be a separate sheet for recording goals (for example, a specific sheet in the multidisciplinary notes).
Anything else?	All staff agreed that goal negotiation should involve the whole team and that it was part of a process which might need to be revisited several times by different members of staff. Staff were also cautious about raising expectations and managing patients who had unrealistic goals.

Table 35 Goal setting (this is specifically what I'd like to achieve)

Question	Summary of discussion
How and where does this stage already happen? Are we missing any opportunities?	Staff felt that this was an informal process and that patient's goals emerge over time through conversation. They acknowledged that this informal approach might lead to goals being missed. They felt that because there is no specific goal setting documentation, there is a lack of continuity and it can be difficult for other staff to pick up on goals set by other.
Is this stage directly transferrable to palliative care? If yes, how can we make it happen more consistently? If no, how does it need to be adapted?	Yes – Staff felt that this stage was transferable to palliative care. They liked the fact that 'big goals' could be acknowledged but that the main focus would be on something more specific and perhaps manageable. Staff felt that things might change quite quickly for patients, so they would have to be aware of that and respond

Question	Summary of discussion
	appropriately.
Are there any tools that you already use that help you do this? (e.g. questions on admission documents, specific assessments and checklists).	The group felt that the admission document touched on goal setting but most goal setting is done informally.
Where should we record this phase and who should record it?	There was lots of discussion about where goals should be documented. Some staff felt they should be recorded in the multidisciplinary medical notes, and others in the psychosocial notes. There was agreement that all staff should document goals.
Anything else?	There was agreement that a more explicit method of eliciting and recording goals was needed.

Table 36 Problem solving and planning (this is how I'm going to get there)

Question	Summary of discussion
How and where does this stage already happen? Are we missing any opportunities?	Staff felt that this stage happens when the patient is ready, but acknowledged that this may not always happen, particularly if the professional is unwilling to take risks or has not acknowledged a patient's goal.
Is this stage directly transferrable to palliative care? If yes, how can we make it happen more consistently? If no, how does it need to be adapted?	Yes – but the process may be impeded by the patient's changing condition.
Are there any tools that you already use that help you do this? (e.g. questions on admission documents, specific assessments and checklists).	Staff felt that current documentation focuses on problems rather than goals and that this hinders the goal setting process. There is currently no documentation to support action and coping planning
Where should we record this phase and who should record it?	Staff agreed that a separate, concise tool was needed to support this phase of the goal setting process and that all staff should

Question	Summary of discussion
	contribute to this.
Anything else?	Staff felt that taking time to problem solve and make action and coping plans with patients would help them to avoid a 'we will fix it' approach.

Table 37 Action (OK, just do it)

Question	Summary of discussion
How and where does this stage already happen? Are we missing any opportunities?	Staff felt that they did try to address patient's goals as a multidisciplinary team but that the lack of a structured, explicit approach led to missed opportunities. Patients did not always get the opportunity to work on and achieve their goals, sometimes because staff were too busy on the ward to focus on goals and sometimes due to deterioration. Staff felt that there needed to be a mechanism for reviewing goals.
Is this stage directly transferrable to palliative care? If yes, how can we make it happen more consistently? If no, how does it need to be adapted?	Yes – Staff agreed that the action and coping planning stages were very important in this context but that there needed to be goal focused documentation to support the process.
Are there any barriers/facilitators for helping goals to be worked on and achieved in practice?	Barriers: fluctuating patient condition; staffing; relative/patient anxiety.

Facilitators: Patient and staff motivation; Practical resources; Holistic ethos |
| *Where should we record this phase and who should record it?* | There was agreement that there should be separate, goal focused documentation and that goals should be discussed explicitly at multidisciplinary team meetings. |
| *Anything else?* | Staff felt that 'rehabilitation' was not the right word to use in palliative care as this might raise patients expectations too much. |

Table 38 Appraisal and feedback (how did I get on....what's next?)

Question	Summary of discussion
How and where does this stage already happen? Are we missing any opportunities?	Staff felt that this stage happens informally at handovers but that this is poorly documented. It was agreed that goal achievement is rarely celebrated.
Is this stage directly transferrable to palliative care? If yes, how can we make it happen more consistently? If no, how does it need to be adapted?	Staff felt that this was an important stage of the goal setting process and that more formalised ways were needed to help patients reflect on their achievements/set new goals.
Are there any tools that you already use that help you do this? (e.g. questions on admission documents, specific assessments and checklists).	Staff felt that goals identified on the admission document could be reviewed on discharge.
Where should we record this phase and who should record it?	Staff felt that goals should be reviewed on a daily basis and that this should be documented in the multidisciplinary notes by all staff.
Anything else?	Goals could be referred to in the discharge letters which go out to community services.

The discussions which took place at each workshop suggested that there was a strong appetite for developing a more explicit method of goal setting within the hospice. Staff acknowledged that opportunities for identifying and supporting patients to work towards goals were sometimes missed. They all felt that the G-AP framework could be used within a palliative care setting, although there were some concerns about how goal setting would work with patients who were thought to be 'unrealistic' (for example, patients who were planning a holiday for next year but were predicted to live for only a few more weeks) or for those who were rapidly deteriorating. It was clear at this stage that there might be some practical challenges to implementing a new goal setting framework, particularly in relation to agreeing on supporting documentation, and where this should be kept.

6.5 Formation of the task group

During the workshops I had established that staff recognised the need for an explicit, consistent approach to goal setting within the hospice and that G-AP provided a coherent starting point. I wanted to explore some of the issues which had arisen in the workshops in more detail (particularly around implementation). In order to do this, I recruited a multidisciplinary group of staff to participate in a task group. My rationale for forming a task group was that I was keen for my research to be relevant and usable in a clinical setting. I wanted to give key stake holders a voice so they could shape the research. By doing this I hypothesised that they would be more likely to implement the changes that developed from it (Meyer 2006, Kumar 2005). In this context, the key stake holders were the professionals who worked at the hospice and patients receiving input from the hospice. I set up the staff task group to meet on a monthly basis over a six month period. The aim was that the task group would:

a) shape the goal setting intervention;

b) try it out in practice and

c) re-shape it, based on their experiences.

Members of the task group were able to actively collaborate in the refinement of the intervention and voice their opinions about the next steps in this research study (Patton 2002).

I was keen to involve patients from the hospice in the development of the intervention, and I sought advice about this from my advisory group at the hospice. They felt that genuinely involving current in-patients at the hospice in developing the intervention would be challenging, due to their health, and that this would be more feasible during the piloting phase when I would have the opportunity to interview a sample of patients. They suggested that I contact the local palliative care Patient and Public Involvement (PPI) group in Forth

Valley. I approached this group (which is made up of palliative care patients, families and professionals) and was invited to one of their meetings. I presented the results of the literature review, the case studies and patient interviews and asked those present to comment on the proposed goal setting intervention. The group felt that the theories underpinning the intervention made sense to them, and that the appraisal and feedback component would be particularly important for patients and families to let them chart progress (or lack of it) in relation to their goals. The group felt that during the pilot phase of the research, all patients should be given the opportunity to have goals set with them. I took these suggestions into consideration when designing the pilot study (see Chapter 7.3).

The task group was made up of a representative range of senior staff from the multidisciplinary team at the hospice (Table 39). All of the staff (apart from the senior manager and one member of the education department who could help think through training implementation issues) had active responsibility for clinical work on the ward and were likely to be involved in goal setting as part of their job. Members of the task group were identified by my advisory group. They suggested people who they thought would be likely to be 'champions' of the framework (Campbell et al. 2006) and who would be able to lead the implementation of change. I approached individuals, gave them information about the project and asked them if they would like to become involved. All staff I approached agreed to participate, although in practice, not all were keen to try out the framework in the early stages. Reasons for this are discussed under 'cognitive participation' in this section.

Table 39 Members of the task group

Consultant	Chaplain	Social worker	Nurse	Senior manager	Education staff	AHP
1	1	1	2	1	1	1

Members of the group worked together to discuss whether the goal setting framework 'made sense' and also identified possible barriers and facilitators to using it in practice. The process of having discussions in a group meant participants could talk about their attitudes and develop new meanings and thoughts about goal setting. I could also identify extreme views (Green 2005, Patton 2002) which would be useful in preparation for the implementation stage of the project.

Research aimed at understanding and assessing how complex interventions and new innovations become 'normalized' into everyday practice (May 2006) has resulted in the development of a theory which can be used by healthcare researchers (May 2010). Normalization Process Theory (NPT, May 2010), provides a model for assessing how change or innovation is embedded into everyday practice, in terms of both *implementation* and *integration*. A toolkit, based on NPT has been developed which can be used to ask questions around four key constructs:

- **Coherence** (does the intervention make sense, can it be distinguished from current practice and do participants see it as worthwhile?);

- **Cognitive participation** (how will key players work together to introduce, use and sustain use of the intervention, and will it make a valuable contribution to working practices?);

- **Collective action** (how or if the key players would be able to make the intervention work at an operational level – what skills would people need to develop, how would it work in practical terms);

- **Reflexive monitoring** (How will we know if the intervention is effective, who will it benefit, what outcome measures could we use, and would it be feasible to use these?).

I used NPT as a framework to structure task group sessions and to guide analysis of group discussions. I found it a useful theoretically based conceptual map for guiding discussions and my understanding of the implementation of this complex intervention. The purpose of the first task group meetings with professionals were to find out:

- Participant's initial thoughts about the developed intervention **(coherence)**;

- If participants felt that there should be any changes made to the intervention and to identify what these were **(coherence)**;

- If participants felt that using the tool would be worthwhile and workable within their work setting **(cognitive participation)**.

Subsequent meetings focused on practical implementation issues **(cognitive participation and collective action)** and design of the pilot study **(reflexive monitoring).**

6.5.1 Task group meetings

Five task group meetings took place between September 2011 and March 2012. Each meeting lasted up to two hours and was digitally recorded. After each meeting, I wrote up detailed field notes and later made notes from the digital recordings. I transcribed any particularly relevant discussions verbatim. After each meeting, I sent a summary of the issues discussed to each participant so that they could review and verify them, thus reducing misinterpretation on my part (Mays and Pope 2000). The topics discussed at each meeting are summarised in Table 40.

Table 40 Topics discussed at task group meetings

Meeting date	Main topics discussed	Who was present
16.09.2011	Discussion of G-AP. To what extent did the theories 'make sense' in palliative care? What needed to be changed?	Consultant, Chaplain, AHP Education

Meeting date	Main topics discussed	Who was present
		staff, Senior Manager, Social worker, and one Nurse
07.11.2011	Presentation of modified G-AP (now called 'G-AP PC'). Discussion about whether it 'made sense' and discussion about implementation. Beginning to look at specific questions for professionals to ask patients as a way of guiding the process, as well as documentation to support the process.	Consultant, Chaplain, AHP Education staff, Senior Manager, Social worker, and two Nurses
12.12.2011	Presentation of prompt card and documentation to guide the G-AP PC process. Task group members asked to start trying out the process with patients.	Consultant, Chaplain, Education staff, Senior Manager, Social worker, and one Nurse
27.01.2012	Discussion about group member's experiences of using G-AP PC in practice in relation to acceptability of use and any changes that needed to be made for it to be used more routinely.	Consultant, Chaplain, AHP, Senior Manager, Social worker, and two Nurses
05.03.2012	Feedback on task group members' use of G-AP PC. Use of role play to facilitate practice in using G-AP PC. Discussion of training needs within the hospice – and what this should include. Discussion about design of the pilot study.	Consultant, Chaplain, AHP, Senior Manager, and two Nurses

The task group meetings evolved over the six month period and during this time the original G-AP Framework was adapted, and became Goal setting and Action Planning for Palliative Care (G-AP PC). I now describe the main issues that arose from task group discussions, analysed under the NPT headings and describe how G-AP was developed, following initial discussions, into the first iteration of G-AP PC.

i. Coherence (first and second task group meetings)

(does the intervention make sense, can it be distinguished from current practice and do participants see it as worthwhile?)

The feedback sessions with the whole staff group suggested that G-AP as an intervention had a high level of coherence for the majority of staff, although many felt that the different stages of G-AP were already happening informally. During the task group sessions, members of the group discussed whether or not G-AP 'made sense'. The theories underpinning G-AP were discussed and there was agreement that all the constructs were relevant to goal setting in palliative care. One task group member felt that setting goals and working towards them could help patients see what was and what was not achievable:

> *"And that could be either done mentally through communication or through a trial – well, can we try that – a test, so then the patient comes to their own insight. – and hopefully can move on from there in the future."* (Participant 1, first task group meeting)

Another participant felt that using a more explicit method of goal setting such as G-AP would help them to pick up on goals more consistently:

> *"If we became more goal focused then we wouldn't miss goals"* (Participant 2, first task group meeting)

Participants recognised that use of G-AP would help them to work in a different, more positive way:

> "Perhaps another way of looking at it is to – it's a positive, goal setting. With symptom control it's actually negative – I want to get rid of something. My physical problem – then the goal would be something positive" (Participant 1, first task group meeting)

It was also regarded as a worthwhile addition to current working practices:

> "I think it really does. It makes explicit what is currently implicit." (Participant 3, second task group meeting)

It was acknowledged that some changes would need to be made to G-AP in order to make it workable and useful in palliative care. The main issue was that participants felt that patients needed an opportunity to reflect on goals that were not achieved and that patients might need to be encouraged to develop alternative goals or different pathways to achieve them. There was agreement that including Hope Theory (Gum and Snyder 2002) in the framework would help with this:

> "It was interesting – I had the advantage to read this Synder article about hope – he himself stresses the importance of mourning when goals are not achieved – and it was really interesting for me on Tuesday to hear people say on the other hand, when goals are not achieved – so I think here's a great opportunity to bring emotions in – um – and I think that also could be a step towards 'being' - because the emotions are closer to the 'being'. I wonder if this [Hope theory] could be very explicitly in the wheel – because it's a real chance to - to mourn - to realise this is not possible." (Participant 1, second task group meeting)

Participants also talked about specific challenges of working with people who are dying:

> *"But the challenge is - people are dying – at the end of the day they are ill"*
>
> (Participant 4, first task group meeting)

And acknowledged that at times patients are thinking about goals or hopes which are beyond their control and which may happen after they have died:

> *"But for me there's a distinction between hopes and goals. I hope that my grandchildren have a really good life or something because of the heritage – that's nothing to do with any of my goals – so there is again – hope and goals is quite different in some ways"* (Participant 1, first task group meeting)

This links closely with Bye's framework of Affirming life: preparing for death (Bye 1998) which proposes that people may want to work simultaneously on achieving goals which are associated with living as well as goals which are about life going on after they have died.

The first task group meeting informed changes that needed to be made to G-AP in order to make it relevant and workable *(coherent)* in palliative care. Task group participants felt that Hope Theory (Gum and Snyder 2002) and Bye's framework of Affirming life: preparing for death (Bye 1998) were relevant to goal setting in palliative care and agreed that they should be included as theoretical underpinnings of an adapted G-AP framework. There was some concern that formalising goal setting might take away from the conversational style of current practice. Participants agreed that there needed to be a mechanism for maintaining structure and ensuring consistency, whilst allowing people to preserve their low-key, informal approach to goal setting. The group came up with specific questions which could be used to guide practice, and which were underpinned by theory. I discussed these with my supervisors and we agreed that a prompt card could be used to help professionals consistently ask the identified questions (Figure 21).

Figure 21 Prompt card

1. What's important to you right now?
2. What do you want to do in the next wee while?
3. Action and coping plan:
   (how confident do you feel about it?)
   - 'What if' plan
   - Who does what plan
4. Carrying out the plan - provide support, as agreed
5. Appraisal and feedback:
   - How did you get on?   What went well?
     What didn't go so well?
   - How do you feel?
   - Is it still important to you?
   - What next?

Participants also suggested that on admission to the hospice, many patients have immediate problems that need to be sorted out:

"we need a pre-phase of goal negotiation, as when people come into the hospice, they are often very unwell, frightened and need to have their problems sorted out – probably not ready to think about goals at this point" (Participant 1, task group meeting 1)

They proposed that an additional stage should be added to G-AP PC (pre-goal setting phase) which would allow professionals to sort out immediate problems on admission and enable patients to adjust to being in the hospice before setting goals.

Working from comments from the task groups, I refined Scobbie et al's G-AP framework (Scobbie et al. 2011) by incorporating Hope Theory (Gum and Snyder 2002) and Bye's framework of Affirming life: preparing for death (Bye 1998). I presented the refined framework (now called 'Goal setting and Action Planning for Palliative Care' or 'G-AP PC') at the second task group meeting (Figure 22).

Figure 22 G-AP PC

(how will key players work together to introduce, use and sustain use of the intervention, and

will it make a valuable contribution to working practices?)

The modified G-AP PC and supporting documentation was presented to the task group who were asked to try it out with at least one patient before we met again. I designed three versions of the documentation (see Appendix 12 for an example) and asked task group members to use them and comment on them. I also asked them to complete a reflection sheet following their experiences of trying out G-AP PC (Appendix 13).

When task group members came back to discuss their experiences of using G-AP PC, only two people out of a possible six had tried using it in practice. Given that group members had been enthusiastic about trying it, I was surprised by the lack of uptake and discussed this with the group. Reasons for not using G-AP PC were:

- People felt that they needed to choose the 'right person' to use G-AP PC with, but as a result they had avoided using it. They reflected on this and felt that for a pilot study, staff should be asked to try it with *every* patient and if not, reasons for this should be recorded.

- AHP, social work and chaplaincy staff felt that they would become involved in the action and coping planning rather than the goal negotiation and goal setting phases of the framework and for this reason had not been able to initiate goal setting with patients. The group felt that using the framework as individuals was a false way of trying it, and that if it was to be evaluated properly, it should be implemented by a whole team, rather than a few individuals.

In spite of low initial use of G-AP PC by the task group members, subsequent discussions provided vital information about how it might be introduced into routine practice within the

hospice. It became clear that task group members felt that the framework should be implemented by a whole team rather than a group of individuals, as different team members might take the lead at different stages of the process:

> *The issue seems to be that different people slot in at different times, and what we have done so far hasn't really given us an idea of how G-AP PC might help with the goal setting process - we really need to use it, altogether, with one person (from beginning to end, with everyone contributing to it).* (Summary of discussions from fourth task group meeting)

The documentation of G-AP PC and where it should be kept was discussed at length at each task group meeting:

> *"And I think that's where people have said that's where the documentation's a problem - I never look at the nursing notes – I would only ever look at the medical notes – and I would record information in medical notes, but in pink* [psychosocial notes] *instead of yellow – generally. Depending what the issue is."* (Participant 5, First task group meeting)

Task group members felt that it was important for patients to have the option to keep their own paperwork and contribute to it if they wished. One task group member who had tried using G-AP PC had given the paperwork to the patient to work through:

> *"I took the paper work to her and we went through all the things and I said - what do you think, and although she took it away, and she felt it was like homework. She actually got quite a buzz out of it. It was something she could do physically - but I never got it back in or anything like that - but sitting down doing it with her was good. So I think it was really important and even to pick out those bits and feel -for me it's*

definitely not been a wasted venture at all because it's good to ask the questions as

they are." (Participant 2, fourth task group meeting)

However, everyone agreed that not all patients would engage with or wish to use the paperwork themselves:

"but – some just don't want it, and sometimes you just solidify things too much –

sometimes it can be graceful just to drop a goal without much fuss about it – so – but

for some it would be really helpful –so you have to use your own personal judgement –

and that comes out of the relationship with the patient – what the individual needs."

(Participant 1, First task group meeting)

This led to further discussion about how goals should be documented. After some debate, it was agreed that the documentation should be kept in a place where all staff and the patient could access it. In practice, this meant a separate goal setting folder which could be kept beside the patient's bedside. Task group members opted for a version of the goal setting documentation which addressed the patient in the first person (Appendix 12).

Because use of G-AP PC was envisaged as an approach to be used by the whole team, task group members felt it would be important to have a mechanism to signal whether or not goal setting had been commenced with an individual patient:

"there is no way of knowing that the process has been started with someone – so we

need to agree that we're using it and all contribute to the process together"

(Participant 6, fourth task group meeting)

It was agreed that a prompt would help with this:

"there could be a prompt to say – has goal setting documentation been given? You

could tick the box and sign and date when it's been given – but if you look through,

and it's not there, you can actively look for the documentation and/or follow up on it."

(Participant 2, fourth task group meeting)

This was an important part of the implementation of G-AP PC, and the mechanism which was finally agreed on was discussed at length by the implementation group (see Chapter 7.6.2). This aspect of the intervention was an important local alteration which influenced the success or otherwise of the implementation. The importance of adapting complex interventions to suit local situations has been discussed by Hawe et al. (2009) who state that:

"the way an intervention is delivered does not have to be the same in every site"(p96)

In other words, the 'form' that an intervention takes can be adapted to suit local circumstances, but the 'function' and 'process' should remain the same and be recognisable across different contexts (Hawe et al. 2004). In the case of G-AP PC, the 'form' is the supporting documentation, the prompt card and organisational mechanisms which were put in place. The 'function' is the G-AP PC framework itself and the theories that underpin it.

iii. Collective action

(how or if the key players would be able to make the intervention work at an operational level – what skills would people need to develop, how would it work in practical terms)

As members of the task group used G-AP PC (either with patients or during role play at task group meetings), they began to see that, in order for it to be used consistently across all disciplines, people would require training. The following topics were identified as important components of a training programme before G-AP PC could be implemented:

- Information providing background to the study and the importance of goal setting in palliative care;

- Information about the results of the study to date – why we need an explicit, theory based goal setting framework;

- Overview of the theories which underpin G-AP PC;

- Information about the documentation and discussion about where the goals will be documented and by whom;

- Information about the research process for all staff.

During the final task group meeting, participants were asked to take part in a role play where they used G-AP PC with a 'patient' (taken from data from the first phase of the research project). During this exercise, participants reflected that use of G-AP PC was different to their normal practice and that in fact they would need to significantly adjust their behaviour in order to deliver the intervention consistently:

> *One AHP reflected that she felt she had led the patient and hadn't let her see how she was going to achieve the goals for herself.*

Following the role play, task group members felt that training would need to include role play and provide opportunities for staff to practice completing the paperwork. They also felt that successful implementation of G-AP PC would involve a whole team approach, and it was agreed that non-qualified staff (such as auxiliary nurses) should be included in the training.

iv. Reflexive monitoring

(How will we know if the intervention is effective, who will it benefit, what outcome measures could we use, and would it be feasible to use these?)

During task group discussions, participants became aware of the complexities of evaluating the use of G-AP PC in the hospice. This led to discussion about the design of the implementation and evaluation of G-AP PC. Task group members felt that G-AP PC should be used by all professionals in one of the in-patient teams at the hospice rather than by a few individuals working independently, and suggested that it should be implemented with one specific team in the hospice over a three month period. The hospice ward is divided into three

teams, and the task group felt it would relatively be easy to select one team and provide training for core staff, as well as those who work across teams (such as AHPs, complementary therapists etc.). The task group felt that it was important to find out who G-AP PC could and could not be used with and suggested that during the implementation, attempts should be made to use it with all consecutive patients admitted to the team over the implementation period. They suggested that I design a form for completion if G-AP PC was not used with a patient.

Discussions with the task group helped to shape my thinking about the design of the implementation of G-AP PC, especially in relation to practical issues such as where the documentation should be kept and who should complete it. Because I had already completed stages one and two one of the research and had carried out a combination of interviews, observations and case note analysis, I knew that it would be feasible and acceptable to use at least some of these methods to evaluate the implementation of G-AP PC.

6.6 Methodology critique

During this stage of the project I aimed to develop a research based intervention to enable staff and patients to effectively engage and participate in patient centred goal setting in an in-patient palliative care setting. I used a participatory element, taken from action research (Meyer 2006) so that I could work closely with staff to find out about issues that were relevant to them. I felt that if I developed a goal setting framework based only on the literature review and my research to date, it would be very unlikely that staff within the hospice would change their practice by implementing it and also that it would be unlikely to be relevant to everyday practice in a hospice setting – for that practical experience is essential.

My intention in working with a task group was that staff members would actively collaborate on the development of the intervention, using their clinical expertise and experience to shape

it and to comment on its theoretical underpinnings. In practice, the group made no changes to the first iteration of G-AP PC, being happy for it to be piloted and evaluated as I presented it at the third task group meeting (Figure 22). I had expected the group to give me suggestions about changes that needed to be made to G-AP PC once they had tried it. They seemed to be reluctant to make comments about the theoretical underpinnings of G-AP PC, preferring to concern themselves with potential implementation issues. My original intention had been to take a mutually collaborative approach, but in practice I was seen as the 'expert', particularly regarding the theoretical underpinnings of G-AP PC, and so as far as theory was concerned, there was very little collaboration between me and the task group. In contrast, the group were very helpful in designing the pilot study and making suggestions about implementation of the framework. In this respect, using a participatory action research approach during this phase of the project proved to be very valuable.

I used NPT to structure discussions and analysis of the task group meetings because it provided me with a conceptual map for understanding how G-AP PC might be implemented in the hospice. At times I found it difficult to distinguish between the NPT constructs. For example, to begin with I found it difficult to differentiate between 'cognitive participation' and 'collective action'. I found the on-line resources very useful (May 2010), and referred to them frequently during analysis of task group discussions. When looking at the resources, I realised that others also found it difficult to understand and distinguish between some of the constructs, as this quotation, taken from the website in response to a question about how NPT impacted on a researcher's coding suggests:

> *"It was tough because we were not confident that we understood the intended meaning of the models constructs."* (May 2010)

During analysis, I discussed my coding with my supervisors and other colleagues. This helped to ensure that I understood each construct and that my coding was consistent.

Other frameworks exist which could have enabled me to structure my analysis in a similar way. For example the RE-AIM framework (Glasgow et al. 2001) provides a structure for evaluating the sustainability of interventions using five evaluation dimensions: Reach, Efficacy, Adoption, Implementation and Maintenance. This framework is perhaps more suitable for the evaluation of well-established interventions, rather than during the development and early implementation phases of complex intervention development. Use of NPT at this stage meant that I could check whether or not the intervention 'made sense' to professionals and it provided a structure to begin to think about how it might be implemented in practice. RE-AIM would not have allowed me to focus as much on issues of coherence, which were very important during the early stages of developing the intervention.

6.6 Summary

Over the six month period, I worked with a task group of professionals in the hospice to refine and develop a goal setting and action planning framework for use in palliative care (G-AP PC). I used NPT to guide the structure and analysis of task group meetings, which I summarise below.

i. Coherence

During meetings with the task group, there was agreement that G-AP PC 'made sense' and that it could be distinguished from current practice. However, when I asked task group members to use it with patients, only two out of a possible six tried it in practice. Subsequent discussions with the task group provided important information about how the framework might be introduced, piloted and evaluated:

a. Task group members felt that G-AP PC should be piloted across a whole team so that each staff member could contribute to the process at different stages, depending on their role (for example, medical and nursing staff might be most involved at the goal

negotiation and goal setting stages, whilst auxiliary and AHPs might be more involved during the action and coping planning stages).

b. Use of a prompt card would help to retain the conversational nature of goal setting, whilst supporting a more structured approach.

These are examples of how the task group influenced the design of the pilot study.

ii. Cognitive participation

Task group members discussed how the multidisciplinary team would work together to use G-AP PC. The documentation was a central focus to these discussions, and the task group commented on different versions of the paperwork and agreed where it should be kept to ensure that it would be accessible to the whole team. These discussions were very important in shaping the design of the pilot study. This 'insider knowledge' of how the team worked together in practice, particularly in relation to how staff would access notes, helped to maximise the chances of G-AP PC being used during the pilot study.

iii. Collective action

The task group drew on their clinical experiences and use of G-AP PC in practice and role play to agree on what should be included in training prior to starting the pilot. All agreed that it was important to train staff in the use of G-AP PC and this should include information about goal setting in general, why this study is important (based on findings from the first phase of the project) and theories which underpin G-AP PC. They also suggested that training should be practical, incorporating role play and opportunities to practice use of G-AP PC and also ensure it was relevant to this setting.

iv. Reflexive monitoring

The task group agreed that use of G-AP PC needed to be evaluated. Throughout our discussions, the task group advised me how it might be used in practice. They became aware

that in order for G-AP PC to be evaluated properly, it would need to be used by a whole team rather than just a few individuals. They were also aware that information would need to be collected about who G-AP PC could and could not be used with. I used information from the task group discussions, and took advice from my supervisors in designing the pilot study.

Conclusions

The objectives of this phase of the study were to investigate whether or not theories underpinning an existing goal setting framework for use in stroke rehabilitation (G-AP) 'made sense' to palliative care professionals and if Hope Theory (Gum and Snyder 2002) and Affirming life: Preparing for death (Bye 1998) could be used to adapt G-AP to make it more applicable and useful in palliative care. I worked with a task group of professionals at the hospice who agreed that G-AP could in principle be used with patients in this setting and that the additional theories would enhance its usefulness and applicability for patients who were deteriorating. From this, the first iteration of G-AP PC was developed. The task group provided advice about the implementation and evaluation of G-AP PC. At the end of this process, members of the task group and the wider hospice management team agreed that G-AP PC should be piloted in the hospice in order to find out whether it was feasible and acceptable to use as part of routine clinical practice. In the next chapter, I describe the pilot study, which was carried out between September and December 2012.

Chapter 7 Implementation and preliminary evaluation of G-AP PC

7.1 Introduction

In chapter six I described how I worked with a task group of professionals to refine G-AP PC and to begin to think about how it might be implemented and evaluated in an in-patient palliative care setting. The partnership with a multidisciplinary group of staff at the hospice provided insights about possible challenges which I might face in trying to introduce a new way of working into practice, and use of NPT provided a structure for thinking about potential barriers and facilitators to implementation. This was important groundwork in the development of this complex intervention. The next step was to try using the developed intervention in the 'real world' (Robson 2011), to find out whether or not it was acceptable and feasible to use in this setting. This will provide insights about the intervention itself (for example, what works and what does not work in practice) and about how future studies should be designed so that G-AP PC can be evaluated in other settings.

7.2 Study aims and research questions

The aim of this phase of the study was to implement and evaluate G-AP PC in one hospice setting.

Specific research questions were:

1. How feasible is it to use G-AP PC as part of routine care in a single hospice setting?

    a. Which patients can G-AP PC be used with?

    b. How is G-AP PC documented in practice?

2. How acceptable is G-AP PC as a method of eliciting patient's goals, from the professional's perspective?

3. How acceptable is G-AP PC as a method of eliciting goals, from the patient's perspective?

7.3 Study design

In this phase of the study, I continued to use a 'real world' research approach (see Chapter 6.6.3, Robson 2011). I worked with a group of staff to implement and evaluate the use of G-AP PC and used a variety of data collection methods to ensure that it could be appraised from different perspectives. Staff from one team in the hospice underwent training in the use G-AP PC (section 7.6.1) and then used it with all consecutive patients admitted to the ward over a three month period. Previously, I had collected data about how individuals set goals with patients in the hospice through observation, interviews and case note analysis (Chapters 4 and 5). This, alongside the literature review (Chapter 3), had informed the development of G-AP PC. I did not incorporate direct observation into the design of this part of the study because, during my work with the task group, there was agreement that use of G-AP PC should involve a whole team approach to goal setting and therefore it was not appropriate to focus on individual working practices during the pilot. A combination of semi-structured interviews with patients and professionals, case note analysis and questionnaires were used to collect data. I also collected data about patients who G-AP PC had not been used with over the three month implementation period (Figure 23).

Figure 23 Data collection methods used for pilot study
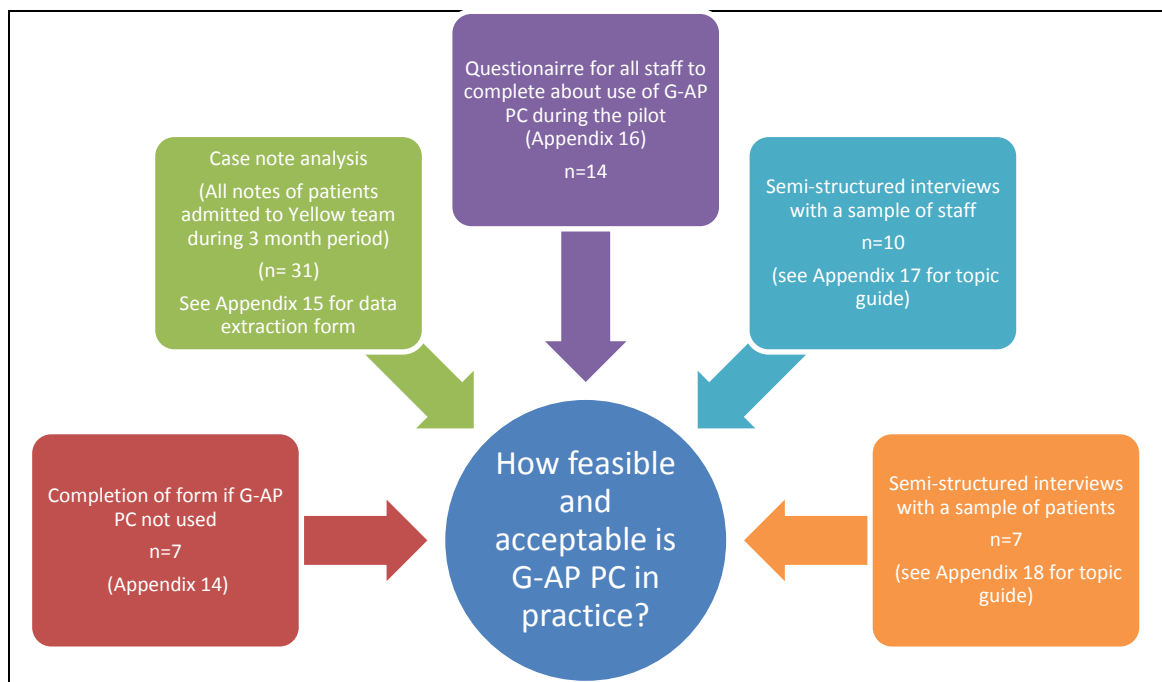
I now discuss each data collection method used during the implementation period.

7.3.1 Completion of form if G-AP PC not used

If staff were unable to use G-AP PC with a patient (for example, if they were too ill on admission, or had severe communication or cognitive problems), they were asked to complete a form giving reasons why they had not been able to use it (Appendix 14). This allowed me to find out which patients G-AP PC could and could not be used with.

7.3.2 Case note analysis

I extracted data from completed goal folders written by professionals during the three month implementation period. This gave me an insight into how professionals documented and understood each stage of G-AP PC, and essentially provided a *"behind-the scenes look"* (Patton 2002) at use of G-AP PC in practice. I designed a data extraction form which corresponded to the goal folder, based on each stage of G-AP PC (Appendix 15). In contrast to the case note analysis which I carried out before (Chapter 4, section 4.5), this time it was easy

to find documented goals. The structure of the G-AP PC folder meant that I could extract data verbatim from the goal folders and map it onto the data extraction form without any dubiety.

7.3.3 Staff questionnaires

At the end of the implementation period, all staff were asked to complete a questionnaire (Appendix 16). The purpose of this was to give staff who had used G-AP PC the opportunity to tell me about their experiences of using it through the free text comments and to provide general information about how useful (or not) each element of the process had been. The questions asked were based on each stage of G-AP PC. I asked staff to tell me how often or if they had used each stage, and how useful it had been and to comment on each stage using a free text box. In designing the questionnaire, I referred to the literature on questionnaire design (Murphy-Black 2006, Oppenheim 1992) and sought advice from a colleague with experience in this area, particularly in relation to the wording of the rating scale. My supervisors also checked and commented on it before the final version was agreed.

7.3.4 Staff interviews

Towards the end of the implementation period, a purposive sample of staff were invited to take part in individual interviews to find out their views about using G-AP PC. Use of an interview topic guide (Appendix 17) allowed me to ask each professional the same broad questions, eliciting data which could be compared at a later date. Because I interviewed a range of different professionals, I needed some degree of flexibility so that I could rephrase my questions if necessary and follow up and probe if I wished to explore anything in greater detail (Mason 2002). The use of very structured interviews would have limited my scope for this level of flexibility. During interviews, I asked staff to tell me about their experiences of using G-AP PC by giving me examples of when it had worked well and not so well. I asked them if they felt there were any differences between using G-AP PC and usual practice and if

there were any advantages or disadvantages to using it. Each interview was digitally recorded and transcribed verbatim. I also kept detailed field notes throughout the study.

7.3.4 Patient interviews

During the implementation period, patients were invited to take part in interviews. I used semi-structured interviews as opposed to informal conversational interviews or more formal standardised interviews because again, I wanted to make comparisons between data collected from different interviews, whilst having some flexibility over the questions. Using this type of interview meant that I could rephrase my questions if necessary and follow up and probe if I wished to explore anything in greater detail (Mason 2002). I asked patients to tell me about a goal that they had been working towards during their hospice admission. I asked about specific stages of G-AP PC in relation to the goal that they spoke about, in order to find out if they were aware of or had experienced the different components of G-AP PC (Appendix 18). Each interview was digitally recorded and transcribed verbatim. I also kept detailed field notes throughout the study.

7.4 Study environment

The implementation of G-AP PC took place in the hospice, previously described in chapter 4.2. During task group discussions (Chapter 6.3.3), we had agreed that G-AP PC should be implemented by a whole team rather than individuals working in isolation. Within the in-patient unit at the hospice, there are three teams (Yellow, Red and Purple). Each team is made up of a core group of staff (doctors, nurses and auxiliaries). Other staff (AHPs, social workers and chaplains), work across all three teams. On admission to the hospice, patients are assigned to one of three teams. I sought advice about which team to choose to implement G-AP PC from my advisory group. They felt that the Yellow team would be best placed to take part because:

a. One of the consultants from the Yellow team had been in the task group and was keen to implement G-AP PC within the team;

b. The Yellow team were not currently implementing any other new projects and had stable staffing, so in principle would be able to take on this project (one of the other teams was involved in a hand hygiene project and the team leader of the other team was on maternity leave);

c. The Yellow team leader was particularly keen on patient centred care, and it was felt that she would be a good 'champion' for implementing this change in practice. Champions are internal to organisations (Thompson 2006) and can be key to implementing change in practice and bring *"leadership and vision to the group and ensures that rigorous evidence is sought and followed on the journey"* (Campbell et al. 2006:513).

In practice, the Yellow team were very keen to take part in this project. Although the team leader (Anne) had not been involved in the task group, it quickly became apparent that she would have a positive impact on the implementation of G-AP PC. She was well respected amongst Yellow team staff and was a keen advocate of patient centred goal setting. She readily took on board the role of championing the use of G-AP PC and was able to monitor its use throughout the pilot phase. I use Anne's real name (with permission) when referring to her in her role as champion in this chapter in order to give her credit for her contribution, but have used a pseudonym when referring to any of Anne's comments from the interview which she took part in.

The consultant who worked with the Yellow team became involved in another project, and was therefore not able to take on as much responsibility as anticipated, so Anne's role as the champion became even more important (Campbell et al. 2006). One factor which I had not anticipated in choosing the Yellow team was that they oversee a five

bedded room for male patients. As a result, there were a large number of male patients included in the study.

7.5. Ethical approval

The project proposal was submitted to the University of Stirling's School of Nursing, Midwifery and Health's Research Ethics Committee and the NHS East of Scotland Research Ethics committee and was granted ethical approval in June 2012 (12/ES0044, Appendices 19 and 20). Once this had been granted, I organised training sessions for all Yellow team staff prior to the pilot study commencing at the beginning of August 2012.

Goal setting is part of routine care at the hospice, and all patients should be asked about their goals during admission, if they are well enough. For this reason, all patients who were admitted to the Yellow team during the pilot period were automatically included in the study. I conducted an analysis of the G-AP PC folders documented by professionals during the pilot, but did not gain consent from patients to do this. This was discussed during the ethical approval process, and the NHS research ethics committee asked me to clarify why I was not going to ask patients for their consent to analyse their notes. My justification for doing this was:

1. I hypothesised that many of the patients admitted to the Yellow Team at the hospice would be unwell and that some would have very limited life expectancy: approaching patients and families on admission may have produced unnecessary distress and delay.

2. The hospice patient information leaflet, given to all patients on admission states that: *"We may use some of this information for other reasons – for example audit, quality control and planning the service for the future. Whenever we can we will remove details that identify you. Everyone working for us has a duty of confidentiality."* As an

employee of the hospice, and the chief investigator of this study, I worked within those guidelines.

On this basis, the NHS research ethics committee gave me permission to go ahead without gaining consent from patients prior to conducting case note analysis.

7.6 G-AP PC Intervention

Yellow team staff were asked to use the G-AP PC framework outlined in chapter 6 (section 3.3, Figure 22) with all patients who were admitted to their team over a three month period from 1st August – 31st October 2012. If staff were unable to use G-AP PC with a patient, they were asked to complete a form giving reasons why they had not been able to use it (Appendix 14). Prior to implementing G-AP PC, all Yellow team staff underwent training in use of the framework.

7.6.1 Training for staff

Once they had been recruited (section 7.7.1), Yellow team staff were invited to attend a half day workshop which covered the topics identified during the task group meetings. I started each session by presenting the results of my research to date. This included the literature review (Chapter 3) and the study of goal setting practice which I had carried out in the hospice (Chapters 4 and 5). I highlighted problems which had been identified in current practice and discussed how a more structured, systematic, theory based approach might improve goal setting practice within the hospice. I then presented G-AP PC, and went through the theories which underpin it. I asked staff to reflect on the differences between using G-AP PC and current goal setting practice. During each session, staff were given scenarios to role play so that they had the chance to try using G-AP PC for themselves. The task group had felt that staff would benefit from doing role play during the training in order to get a feel for how G-AP PC might work in practice. Role play is also recognised as an essential component of communication skills training in palliative care (Wee and Hughes 2007). Once staff had had a

chance to try using G-AP PC, we discussed the practicalities of the implementation project, how the documentation would work in practice and what was expected of each member of staff (Figure 24, section 7.6.2).

7.6.2 Procedure for using G-AP PC

Each member of staff was given a prompt card (see Chapter 6, Figure 31). We discussed the practicalities of using G-AP PC with patents during the three month implementation period and went over the procedure which staff were asked to follow for all patients admitted to the team from 1st August – 31st October 2012 (Figure 24).

Figure 24 G-AP PC procedure for staff to follow during pilot

1. Patient admitted to Yellow team. Aim to start the goal setting process within first few days of admission.

If using G-AP PC

If not using G-AP PC

2a. Start using G-AP PC with patient. Write 'G-P' on white board in duty room

Folder to be kept at end of bed and referred to when working with patient

2b. Complete 'non-use of G-AP PC' form

3. Use G-AP PC with patient throughout their admission. Refer to it during handover and ward rounds as well as during patient care. The folder should be filed with the main notes at the end of the admission

After the training sessions, a folder with worked examples of the documentation was put into the duty room for staff to refer to. A prompt card was also stuck to the ward notes trolley to remind to staff to use it (Figure 25).

Figure 25 Photograph of prompt card on notes trolley

7.7 Recruitment and participants

7.7.1 Staff involved in implementing G-AP PC

All staff who worked in the Yellow Team (as well as those who worked across it) were eligible

to participate in the study (Table 41).

Table 41 Yellow team staff

Core Yellow Team staff	Staff who work across all teams
3 doctors	AHPs (1 occupational therapist, 1 physiotherapist, 2 complementary therapists)
9 qualified nurses	2 social workers
5 Auxiliary nurses	2 chaplains

I provided staff with information about the study and what it would entail (G-AP PC Staff

information sheet – Appendix 21). At this stage they were invited to take part in the study,

although it was made clear that participation was voluntary. In practice, all 25 staff who I

approached agreed to participate and completed the G-AP PC staff consent form (Appendix

22). All staff and patients were given pseudonyms at the beginning of the study, which I use when reporting results. Throughout this chapter I have grouped AHPs, complementary therapists, chaplains and social workers as 'AHP/Other' to help maintain anonymity.

7.7.2 Staff interviews

At the end of the three month period, a purposive sample of staff from the Yellow team were invited to take part in individual semi-structured interviews. The purpose of the interviews was to find out staff member's views about the feasibility and acceptability of using G-AP PC in this setting. I aimed to interview at least one person from each staff group, and selected names from each group out of a hat. Staff were given information about the interviews (Staff interview information sheet – Appendix 23) and were asked to complete a consent form (Staff consent form Appendix 24) prior to being interviewed. Ten members of staff were initially approached and of these, one declined. I then selected another staff member, who agreed to take part (Table 42).

Table 42 Sample of staff interviewed

Professional group	Numbers interviewed
Nurses (n=9)	3
Auxiliaries (n=5)	1
AHP/other (n=8)	4
Doctors (n=3)	2

Staff member's level of palliative care experience varied (Table43).

Table 43 Staff who took part in interviews

Name	Profession and length of time working in palliative care
1. Julie	**AHP/other** (over 20 years)
2. Sarah	**AHP/other** (over 20 years)
3. Mandy	**AHP/other** (between 10 and 20 years)
4. Wendy	**Qualified nurse** (between 10 and 20 years)
5. Lisa	**Qualified nurse** (less than 5 years)
6. Mary	**Qualified nurse** (between 10 and 20 years)
7. Jane	**Doctor** (between 5 and 10 years)
8. Sue	**Nursing auxiliary** (between 10 and 20 years)
9. Fred	**AHP/other** (less than 5 years)
10. Evie	**Doctor** (less than 5 years)

7.7.3 Staff questionnaires

All Yellow team staff were also asked to complete a questionnaire. These were completed and returned by 14 out of 25 members of staff (Table 44). In spite of sending out reminders to staff, asking them to complete the questionnaire (Robson 2011, Murphy-Black 2006), the response rate of 56% was disappointing. However, it did provide an insight into participants' views on the feasibility and acceptability of using G-AP PC in practice.

Table 44 Staff who completed questionnaires (n = 14)

Consultant/Doctor	Qualified Nurse	Nursing Auxiliary	AHP/other
1	5	2	6

7.7.4 Patient interviews

During the implementation period, 42 patients were admitted to the Yellow team. Goals were set using G-AP PC during this time with 31 patients. A sample of 10 of these patients were invited to participate in semi-structured interviews. The purpose of the patient interviews was to find out how acceptable use of G-AP PC was in this setting, from the patient's perspective.

Patients were invited to participate if they were:

- 16 and over with cancer or chronic life-limiting disease living in the catchment area of the hospice;

- Medically well enough to participate (decided by medical staff at the hospice);

- Able to give informed consent (all patients were assessed regarding their capacity to give consent by medical staff on admission to the hospice).

Yellow team staff identified patients who met the inclusion criteria to participate in semi-structured interviews. These patients were given more detailed information about the study (patient interview information sheet, Appendix 25) and were asked to tell the member of staff if they were interested in taking part. Prior to being interviewed, I spoke to patients and went over the information sheet and answered any questions that they had. They were given a consent form to complete (patient interview consent form, Appendix 26) and a suitable time and location for the interview was arranged. I am aware that relying on staff to identify patients for interviews may have meant that they selected patients who were particularly motivated or positive about the goal setting process, and this is a limitation of this part of the study. Recruitment for patient interviews was difficult because many of the patients deteriorated rapidly over a short time. Because I was only at the hospice on a part time basis, I sometimes missed opportunities to discuss the interviews and gain consent from patients. Ten patients were invited to take part and all initially agreed. However, one patient became too ill and was unable to participate. Two other patients changed their minds and decided not

to be interviewed. Interviews were carried out with seven patients. Six were men with a cancer related illness, and one had a neurological condition (Table 45).

Table 45 Patients who took part in interviews

Name	Age and type of illness
1. Sam	80 years old. Cancer related illness
2. Henry	67 years old. Cancer related illness
3. Pete	63 years old. Cancer related illness
4. Alan	81 years old. Cancer related illness
5. Bob	67 years old. Cancer related illness
6. Jack	67 years old. Cancer related illness
7. Norman	64 years old. Progressive neurological condition

7.7.5 Case note analysis

Goal setting is part of routine care at the hospice, and all patients should be asked about their goals during admission, if they are well enough. For this reason, all patients who were admitted to the Yellow team during the pilot period were automatically included in the study. Over the three month pilot period, a total of 42 patients were admitted as in-patients to the Yellow team (Table 46).

Table 46 Patients admitted to the Yellow team

	Male (n = 34) (age range 42 -86)	Female (n = 8) (age range 48 -79)
Malignant disease	32	5
Non malignant	2	3
Discharged home	16	3
Discharged to another care facility	1	0
Patient died	16	4
Patient still in hospice at end of pilot	1	1

As I have already said, a high proportion of male patients were included in the study because the Yellow team oversee a five bedded room for male patients as well as three side rooms which are usually reserved for people who are very ill. Men are usually are transferred from the main room to a side room if their condition deteriorates. The small number of women who were admitted during the pilot were accommodated in the side rooms.

Goals were set using G-AP PC with a total of 31 patients. The number of goals set with each patient varied. Some had just one goal set with them, others had between one and six goals. Eleven patents did not have any goals set with them. Reasons for non-use of G-AP PC are summarised in Table 47.

Table 47 Reasons for not using G-AP PC

Reasons for not having goals (n = 11)	Male	Female
Patient on Liverpool Care Pathway (LCP)	2	2
Patient had cognitive/communication impairment	3	0
Goal folder unaccounted for	3	0
Patient transferred from another team	1	0

Three patients appeared to have had goals set (according to staff), but I was unable to find the paperwork. This was a problem raised by several members of staff during interviews (see section 7.9.1) and was also something I made a note of in my field notes. The separate goal folders seemed to make it difficult for staff to keep track of the files, which was a barrier to ensuring they were completed. I extracted data from 31 sets of notes.

7.8 Data analysis

Each data set (questionnaire, interviews and case note analysis) has been analysed separately.

7.8.1 Analysis of staff interviews

I used Framework analysis (Lacey and Luff 2001) to structure analysis of the staff interviews, but this time I coded it in two ways. Initially, I read all the interview transcripts several times and made a note of any themes which arose. At this point I kept an open mind to any themes which were relevant to the research questions. I then used a priori themes based on NPT (see Chapter 6.5) and coded the transcripts using the NPT constructs (Coherence, Collective action, Cognitive participation and Reflexive monitoring, May 2010). The interviews provided me with detail about how G-AP PC had been implemented in practice and whether or not it was acceptable and feasible to use, from the perspective of staff. I needed to be able to break each NPT construct down into more detail for analysis of the interviews. In NPT, each

construct is made up of four components. I used these to code interview data as they provided me with a way to 'fine tune' my data (Table 48). At times I found it difficult to distinguish between some of the components of each NPT construct and initially spent a lot of time referring back to the NPT web resources (May 2010) to check what each construct and component meant. My supervisors also checked my coding and another colleague looked at and commented on the coded data. This process was important as it provided a forum to discuss the components of each NPT construct and helped clarify what each one meant.

Table 48 Example of data analysis using NPT (coherence)

Staff member	Differentiation (what is different about G-AP PC cf. usual practice)	Communal specification (How do team players work together to develop a shared understanding of the aims of G-AP PC?)	Individual specification (What does the individual have to do to help them understand specific tasks and responsibilities to make G-AP PC work in practice)	Internalization (Understanding the value, benefits and importance of G-AP PC)
Lisa (RGN)	I thought - well I mean, it's something we do anyway. Em - so it was quite a good way of documenting it I think - em - It was really nice to actually have those discussions - and I know we do in a roundabout sort of way but actually to sit down and have specific discussions about goals was quite nice. Um and I found that sometimes we actually had goals that maybe wouldn't	I think some people put more effort in than others but um - I think everybody was aware and everybody worked towards the goals - so yeah, I do.	I think most of the -most of the goals were um achievable and - I think the paperwork kind of led you to think of 'what ifs' - so even if the initial goal wasn't achievable em - you could achieve some of it or could work towards it

A lot - some of them required quite a bit of planning and organisation and to | I remember one guy wanted to go in a bath and have his whisky and things. Em and that wouldn't have necessarily been identified as a goal before -so - He did want to go in a bath but em - I don't think we would have quite discovered how much he wanted to go in a bath em - and I think that then became a real goal for us as well as him - so - things like that wouldn't |

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Staff member	Differentiation *(what is different about G-AP PC cf. usual practice)*	Communal specification *(How do team players work together to develop a shared understanding of the aims of G-AP PC?)*	Individual specification *(What does the individual have to do to help them understand specific tasks and responsibilities to make G-AP PC work in practice)*	Internalization *(Understanding the value, benefits and importance of G-AP PC)*
	have actually been discussed beforehand - so, it *was* good. Um I felt that some of the paperwork was a bit repetitive - um - but um – yeah, overall I thought that it was OK. I did feel that you uncovered things that maybe wouldn't have been prompted before – without the questions.		know that you've - you've pulled it off. Because a lot of it wouldn't necessarily have happened - it's quite nice.	have necessarily come about. Yeah I think - I think it's really appropriate here, and I think it definitely prompts us to go that little bit further. I think. And really follow up on things. Um you know and - I did find that some people would say – 'Oh yeah I want to do this', and actually it wasn't important to them, and they were probably saying it to - you know, but for most people - you know, these

Staff member	Differentiation *(what is different about G-AP PC cf. usual practice)*	Communal specification *(How do team players work together to develop a shared understanding of the aims of G-AP PC?)*	Individual specification *(What does the individual have to do to help them understand specific tasks and responsibilities to make G-AP PC work in practice)*	Internalization *(Understanding the value, benefits and importance of G-AP PC)*
				things were really important. Um - and it did - it did mean we were prompting and going back. And getting that feedback - which was nice - it makes you feel that you're doing a good job as well.

Although NPT provided a structure for analysing the staff interviews, not all the data fitted with the constructs. I identified additional themes and made an additional data chart so that these could be included (Table 49).

Table 49 Themes arising from staff interviews

Staff	Patient's understanding of goal setting and options available	Deterioration	Organisational barriers	Confidence rating
Sarah	Yes, if it's a specific goal that the person has wanted help with say - relaxation or say helping them sleep or to feel better. You know, those specific goals really. It's also probably highlighted as well for us - how many people often don't know about our service [complementary therapies]. There have been several people who haven't known about our service. And that's maybe because we haven't had a chance to get to them. You know, to give them a leaflet or they've not been told about it	but I suppose that's what didn't go so well really. I think -well, I know a few times people just shrugged their shoulders really. Because - I think the other thing is – if people then move on - certain people move on to - you know, they become iller. Their goals are changing because of their illness. You know, the deterioration and so it's something that's not clear cut really - so it's difficult to answer that question - because things have changed. Yeah, because they're - you know, to go back to *them* and say - I know you	One of the patients – and that was really because any time I went to see her – she had relatives or her grandson there or next time I went a bunch of friends who used to work with her – it was – it just happened that I – and then she went home – so that You know – It had been initially when I'd seen her – she'd been seen here in day care – and that is always a bit tricky because they knew of us in day care and they would be expecting that same thing – but she – she hadn't had any goals set at that point – and I said to the nurses – oh you really know her – could you do – could	

Staff	Patient's understanding of goal setting and options available	Deterioration	Organisational barriers	Confidence rating
		wanted -to - I can think of somebody in particular um that your muscles - you wanted your muscles to be um - more flexible. But the person had really got - not so well. So to go back and say - oh well, we haven't achieved that because - it's difficult because you're getting iller! So it's err - I found that a wee bit - how do I? yeah. I think if it's a static thing then that's OK – or if people are getting better, but if people are declining -it's difficult to review because the review is that they're declining and they you can't, well it depends on the person's goal	you set a goal? You start the goals off – and then when I went back – the relatives were in. I don't know whether – I would presume she's get some goals or whether the nurse –I said to the nurse I've been twice and I haven't seen her.	

Staff	Patient's understanding of goal setting and options available	Deterioration	Organisational barriers	Confidence rating
		really, but you can't -review it - or do you think you maybe need to review it earlier. Maybe that's the thing. Maybe we weren't reviewing enough.		

7.8.2 Analysis of the staff questionnaire

I collated responses from the questionnaire and categorised free text under the NPT constructs, for example: the comment below was coded under 'coherence':

"I found the section on what to do in the next wee while a bit more of the same as page 3. I found page 3 very good. All in all it really makes us think about goal setting. Keeps us focused on each goal we may be involved in so that we do not 'lose the plot'." (AHP/other)

Coding free text in this way enabled me to organise the data so I could compare comments from the questionnaires with comments from the interviews.

7.8.3 Case note analysis

I extracted data from 31 G-AP PC folders over the three month study period using the data extraction form (Appendix 15). I collated data relating to each stage of G-AP PC and put it onto a spread sheet so that I could see how many goals had been set with each patient and whether or not they had been achieved. I then coded data according to each theory which underpins G-AP PC. This allowed me to see if each stage of G-AP PC was being used in practice.

7.8.4 Analysis of patient interviews

I used framework analysis to analyse patient interviews (Lacey and Luff 2001). Initially, transcripts were read through several times. I identified themes and categorised them under three headings: *patient's goals*; *patient's experiences of goal setting in the hospice* and *evidence of the G-AP PC constructs* (Tables 50, 51 and 52). I carried out initial coding and these were checked by and discussed with my supervisors.

Table 50 Patient's goals

Patient	Goals	Goal achievement
Pete	To get back to – the goals- when I came in was – I was immobile when I came in…. Sally: Right – OK… Pete: and then they got me – sorted out. Pain free - and then we started to set goals after that – which was to try and get me back - to a little bit – knowing fine I'll never get back to – complete normality – which has been, actually, successful. But I'm looking for support for my good lady. For after, after being married 39 year – I've still got to, to look after her – when I'm not here. Cause she's looked after me all that time.	Well I expected to be in a lot longer – but, it seems to be – whatever they're doing, whatever they've set their - theirselves to achieve, whether they've achieved it earlier – than probably even they expected. Cause even they're saying they're quite amazed – to take such a short time to get back where I was. From what I was when I first came in. Cause I was bad when I first came in. I had no mobility whatsoever. Well just now, I can walk right round my bed, right up to here and sit down. I can err – change – I've got stomas. I've got two stomas. I can change them myself – back to change them myself now. Get back to - err renewing them – when they require renewed and now I can wash my own hands and face, and things like that. I'm not saying I'm completely – back but – I'm a hundred percent better than I was when I first came in. your mobility a wee bit. I've even, I've even surpassed my own thoughts of what I was going to be - thanks to them. Cause it's thanks to them –It's mainly because of them, it's thanks to their care. And the goals that they've thought up and agreed with us.

Table 51 Themes relating to patient's experiences

Patient	Patient focused	Attitude to goals	Knowledge about goal setting	Paper work	Communication
Sam	It was very much patient focussed rather than – what would you say, organisational focused They do appear to have a very fair interest in what the patient's done who the patient is, you know, so that they know a fair amount before they start explaining the treatment	And almost taken from the starting point, in life, both M and I – and myself and M, before we were married and everything. Have always been goal setters. I knew what I wanted to do when I left school. And I worked towards that – and even, throughout the illness, we've worked towards various things		I'm aware, and that's because I've had a professional background. I do notice the workers bringing care plans up to date. Err – I know what they're doing actually when they're doing it. Cause that's the expectation I had of workers and I had err – I ran – and it's absolutely essential in medical or social work case work. To have	Then if you watch in this room - They've got to interact with each other. So that resources are spread evenly and goals are met – folk arrive in hospital and at times they're going for scans and things. So they do communicate well, and they do seem to get on well with each other.

Patient	Patient focused	Attitude to goals	Knowledge about goal setting	Paper work	Communication
	as I said at the beginning, it's based on patient care and patient's needs. You know – they have targeted themselves properly. They're actually zapping the real problems.	So, you know, goal setting – I think it's essential in life for God's sake, you know. Um. It's something we've always done.		effective records. Without records, how the hell do you manage if you don't. You've got to go back to evaluate etc. So I've been every aware of the good lady sitting in the corner, - err , you know, filling in the paper work	

Table 52 Evidence of G-AP PC stages

Patient	Self-efficacy	Action plan	Adaptation	Confidence	Review
Henry		Sally: And what about the steps towards achieving the goals? Did you come up with a plan? Henry: I've no plan. Sally: No? Henry: No. I'm not the planning type.	I know I won't be walking like I used to…but I'll still be able to take them out into the field behind us – which is great –I'll be able to sit and let them run –um – and just get back, amongst the family.	Sally: and did anyone ever ask you how confident you felt about being able to achieve those goals? Henry: Not really. Sally: Do you think that would have been important? Henry: No.	Sally: Do people come and check how things are going? Henry: Well – people do actually, you know, but not always in a direct way. Quite often, you could have a conversation with one of the staff and all of a sudden you realise that it wasn't a chance conversation. It had been a detailed way of questioning. But most of the time the girls will just say – how are you? You know.
		basically um – the way I look at it is – do what you're told…..um try and…If they tell you the best way to do something – is this way. Try and do it. And –I've got the silly sticks and things – and I	a bit more detail, yeah. Before all I was really interested in was getting rid of the pain. This pain – you know, I couldn't function properly. Now we're getting on top of the pain. So it now		

Patient	Self-efficacy	Action plan	Adaptation	Confidence	Review
		use them – funnily enough they've been a bit useful (sounds surprised). They're not life saving as such, but they do – they do help.	means that I can now start thinking about. Right ok – we've had a bit of luck here and there. We can convert…		
		They've got a plan. They've got a plan! Oh aye, they've got a plan to get me out of here.	Basically, basically. I was in here to get the pain sorted. Now that the pain is getting sorted, it's not completely sorted out, otherwise I'd be home. But - the other		
		they have a plan and err and whatever their plan is, is fine with me……	aspects of it. I will not be able to walk, up the stairs, as I used to – which means that – I might have to sleep downstairs. So it's these		
		That planning is slowly now beginning to take effect–	things are now becoming		

Patient	Self-efficacy	Action plan	Adaptation	Confidence	Review
		because I'm beginning to get to the stage where I could leave. You know? Was chatting about the house in general and she was saying you know….two rooms downstairs and I said yes, and before I knew it, she'd more or less told me what we'd have to do. I don't mean it in a nasty way. But she – she was very - subtle about it - is that the word, subtle? (laughs) Um – so yeah, but you know, it's that sort of little	really important.		

Patient	Self-efficacy	Action plan	Adaptation	Confidence	Review
		conversations. Those things…			

In the next section, I report on the findings from each data set.

7.9 Findings

7.9.1 Staff interviews

I firstly present the findings in relation to the NPT constructs and components and then present the additional themes which arose from the data.

i. Coherence

(did the intervention make sense, could it be distinguished from current practice and did participants see it as worthwhile?)

Differentiation *(what is different about G-AP PC cf. usual practice)*

The majority of participants felt that using G-AP PC was distinct from current or 'usual' practice. For example, the structured, explicit approach meant that individual staff members were more aware and focused on patient's goals:

> *"But because we've set a goal that states the fact, that that's what they want to do – officially, - it's almost like – I'm – I think I'm more focused on it. But I don't know if my practice is different – but mentally, I'm much more focused on it. And em –I do think that – I think maybe we work harder to achieve it. I don't know but – I would like to think that I've always done these things, but really, when I look back, I think I'm much more mentally aware – and focused on trying to achieve that with the patient - because they've particularly said – this is what I want to do"* (Julie, AHP/other).

Others felt that using G-AP PC helped the whole team to work together and sometimes meant that they went further to help people achieve or work towards their goals. One patient wanted to be able to walk his dogs in the field behind his house when he got home. Wendy

(one of the nurses) told me how the whole team had helped him practice walking outside on uneven ground, in preparation for achieving his goal:

"So I don't think we would have went that far. We would have helped him with his mobility, but maybe not went out into the fresh air – and that actually gave him a wee buzz when he was out in the fresh air – getting out of the hospice environment, just getting outside really meant a lot to him." (Wendy, Qualified Nurse)

One of the doctors told me that using G-AP PC had helped her to change how she thought about and treated symptoms and problems:

"And it just kind of changed how you think about pain as well – so instead of saying – well, tell me about your pain, you'd say – well, what's your pain stopping you from doing at the moment, and then that would become the focus of setting a goal." (Jane, Doctor)

Although the majority of participants felt that G-AP PC made a difference to how the team identified and worked towards goals with patients, three participants were less convinced. One felt that she already asked the questions included in G-AP PC as part of her routine practice:

"Well, that's difficult to say because, it's something that we've always done - as [AHPs]. These kinds of questions would be in our assessment of a patient and their family anyway. Um – so, consciously thinking about using it - isn't something that I've done, to be honest. Um – because as I say, we would be asking them all these things and making sure that – you know, anything that was a big thing for them – was being addressed." (Mandy, AHP/other)

However, she did feel that use of G-AP PC had been helpful for other members of the team as part of raising their awareness about goal setting and helping them to pick up on ordinary goals more consistently:

> *"No, I think that's good. I mean, it was like not only, just the big things like [patient's name], it was little things that would have got missed before. You know, other patients – I can't remember names and things but – um – the goal might just be that they wanted to get up and sit in a chair. Or just to try and stand or something – or wear their teeth that day. You know, and I thought – that would never have been picked up before. I don't think it would – not – not consistently."* (Mandy, AHP)

Other members of staff who were less convinced that G-AP PC was different to 'usual' practice' felt that a more structured approach to goal setting helped to ensure that goals were set with patients more consistently:

> *"I think we always did kind of do it – you know, in a – not so much a structured way, if you know what I mean. But it was – I suppose you probably missed some people that didn't get asked, you know."* (Sue, Nursing Auxiliary)

> *"I thought - well I mean, it's something we do anyway. Em - so it was quite a good way of documenting it I think - em - It was really nice to actually have those discussions - and I know we do in a roundabout sort of way but actually to sit down and have specific discussions about goals was quite nice. Um and I found that sometimes we actually had goals that maybe wouldn't have actually been discussed beforehand - so, it was good."* (Lisa, Qualified Nurse)

Interview data suggests that most staff agreed that using G-AP PC was distinct from 'usual' practice and resulted in a more consistent approach to patient centred goal setting.

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<u>Communal specification</u> *(How do team players work together to develop a shared understanding of the aims of G-AP PC?)*

Participants agreed that, if G-AP PC was to be used successfully, all members of the team needed to work together to use it and contribute to the documentation. One participant talked about a patient who wanted to be able to sit up in a chair. She described how, using the action and coping plan, team members had worked together to control his pain and seize the moment so that he could work towards and achieve his goal:

> *"In actual fact, in his first week here, we stood him up and we transferred him into an arm chair. And he managed. And he sat up for about fifteen minutes – cause he had some pain issues. But he was really pleased with that – and then we popped him back to bed. The second time he got up, we had somebody ready to take him out – so we didn't miss the chance – and it was a nice day, and we got him into a wheelchair. And he managed to go out for half an hour. And straight back to bed when he came in. He got pain control first, and it worked beautifully for him. So he achieved a goal really quickly."* (Julie, AHP/other)

Participants acknowledged that there were some practical barriers to ensuring that the whole team contributed to the G-AP PC process. One of these was paperwork. Participants were aware that this had not always been completed and there was a sense of frustration about where the paperwork should be kept and who should write in it:

> *"I mean, there's nothing worse than trying to find something that you want to fill in and you can't find where it is."* (Jane, Doctor)

One participant told me how different professionals might be more involved at different stages of G-AP PC, and reiterated the importance of working as a team:

"I would be formulating the plan - you know, how do we do it, who does what, we would definitely talk about. Um - you know, what do we need to make this achievable. What could go wrong. We would do all of that – is there anything you're worried about – you know, that might make it not happen. That kind of thing we would do. But that's probably as far as I took it – um – because this bit here [carrying out the plan] *would then get taken on by the nursing staff – and they would go back so – actually, they were really important being involved in this first bit, because if they'd not been involved in this first bit, I think this bit would get forgotten about. So you'd set the goals but maybe not actually assess if you're achieving them. So, I mean, it would be interesting to see what the nursing staff perspective on that was – if that works. But I think it has to be a team approach in that sense."* (Jane, Doctor)

Others stressed that it was important for everyone to be aware of a patient's goals and that all members of the team should be prepared to discuss them with patients:

"I think everybody who would have contact with a patient should be aware of – you know – things that maybe a patient feels they want to do or pick up on." (Fred, AHP/other)

"And that's why it's good if everybody can do it – because people will talk more casually with some people than others. Don't they – they have more of a rapport with you or the auxiliary or nurse than they might with the doctor." (Sarah, AHP/other)

Participants agreed that G-AP PC needed to be used by each member of the multidisciplinary team and that mechanisms such as paper work and prompts to promote discussion at ward rounds and handovers should be in place to ensure that patient's goals were discussed. It was acknowledged that, during the pilot study, not all team members had used it consistently.

<u>Individual specification</u> *(What does the individual have to do to help them understand specific tasks and responsibilities to make G-AP PC work in practice)*

Participants talked about what they needed to know and do as individuals in order to use G-AP PC effectively. This included being aware of the need to talk to patients about action and coping plans and helping them to put these into action:

> *"A lot - some of them* [action plans] *required quite a bit of planning and organisation and to know that you've - you've pulled it off. Because a lot of it wouldn't necessarily have happened - it's quite nice."* (Lisa Qualified Nurse)

Lisa felt that the action and coping plan stages of G-AP PC helped her to break goals into small steps and that this made them more manageable for patients to achieve:

> *"I think most of the -most of the goals were um achievable and - I think the paperwork kind of led you to think of 'what ifs' - so even if the initial goal wasn't achievable em - you could achieve some of it or could work towards it."* (Lisa, Qualified Nurse)

Some participants discussed the documentation of goals, and some people felt that they needed to make a concerted effort to write goals and action plans. At times this seemed burdensome:

> *"So in one way it was great to have the extra paperwork and in another way we have so much paper work, that like anything – you think 'oh, I have this thing to do' and more paper work and it nearly put you off doing it."* (Mary, Qualified Nurse)

Within the hospice, some members of staff use electronic notes and they were reluctant to duplicate what they had written by writing in both the G-AP PC documentation and their electronic notes. They were also concerned about confidentiality:

"Well at the moment, anything that we put on is only accessible by our team. Because of confidentiality aspects." (Mandy, AHP/other)

Currently, the hospice is developing electronic notes for the whole team, so this may address the problem of duplication. This would mean that notes would not be accessible to patients, which may be problematic, although in practice, patients did not feel that it was important to have access to the notes themselves (see section 7.9.4).

Another participant recognised the importance of the appraisal and feedback stage of G-AP PC. Although this is an important stage, the case note analysis (see section 7.9.3) showed that this part of the paperwork was not always completed during the pilot study.

"I think the appraisal and feedback part – how did you get on. That's really important. It lets them talk about how it made them feel. And what went well for them. What went well – and what didn't go so well." (Julie, AHP/other)

Participants were aware that in order for G-AP PC to be implemented and used successfully, they had an individual responsibility to complete the paperwork as well as ensuring that each stage was completed.

Internalization *(Understanding the value, benefits and importance of G-AP PC)*

Participants clearly valued G-AP PC and found some of the questions used to guide the process particularly helpful. One participant felt that use of G-AP PC had really changed her practice:

"I found the opening question really helpful. 'What's important to you right now?' And that would just open it up. I've started using that question just day to day – so much more since this project started. I've just found it really helpful. It just opens up so many

avenues. Actually –so it's really changed my practice actually in that sense." (Jane, Doctor)

Another participant felt that the questions were particularly relevant within a palliative care context because they made patients feel valued and worthwhile:

"But even having the discussion with these patients who deteriorated maybe before fulfilling their goals, you saw um – just the look on their faces that you were asking them what was important to them, and it was nice that you were asking – although they were recognising that they had a terminal disease, and they didn't have long. They still had worth and you could say – well, what's important to you, and we can help you try achieve what's important to you in the next wee while. And I think these words were really good – in the next wee while, because it didn't say days, weeks, months, it's just in the next wee while – what is important to you – and I think they were great words to use." (Wendy, Qualified Nurse)

Participants found that using G-AP PC had a number of benefits, which relate to 'internalization' (u*nderstanding the value, benefits and importance of G-AP PC)* within NPT (Table 53).

Table 53 Perceived benefits of using G-AP PC

Provides a focus for the whole team	Changes focus from symptoms and problems to goals	Provides evidence of people working towards and achieving goals
"I think the good thing about it is it probably focuses the mind of the professional in terms of the things that are ultimately important to –	*"I think sometimes you get caught up with symptoms – and because he was sore, and sore when he got up – that could have been our goal – to*	*"I think it really provides the documentation of what we're actually doing on a day to day basis. Some of these things we might be*

Provides a focus for the whole team	Changes focus from symptoms and problems to goals	Provides evidence of people working towards and achieving goals
to the patient." (Fred, AHP/other)	get that better. And we might have missed what actually – he wanted to do. And yeah, I'm sure he wanted to have no pain, but that in his mind, it wasn't what he said – He wanted to go out in the wheelchair – outside with his grandchildren." (Julie, AHP/other)	doing anyway – but actually having it down on paper and providing the evidence for what we're doing and how it impacts upon the patient experience – it's a really good thing for clinical governance as well. Um – you know – when we're trying to show to healthcare commissions and all the rest of it – the impact of what we do – then I think it's a really useful tool for that." (Jane, Doctor)
"I liked the fact that it was raising awareness in everybody. Because what bothers me, is if there's only one or two people who ever think to ask folk what they want to achieve, then if you're too busy and never see that patient, it'll never happen – so it's great to feel that the awareness is raised in everyone." (Mandy, AHP/other)	"we tend to be a bit more task oriented – if you've got a pain we'll fix it, if you're nauseated we'll fix it. Not sitting down and talking to somebody about how they're feeling emotionally, psychologically. You can't do two or three minutes. You have to sit there. Cause you need to get the confidence of the person to get them to open up. And I think when you do that – and we've been doing that through this, you do get to see other sides of people which is really nice." (Wendy, Qualified Nurse)	"And I think it's a really good opportunity to do that and to not miss that evidence based practice. I think – I think we're always goal setting, but I think we've not always been as good at writing it down." (Julie, AHP/other)

The majority of participants believed that G-AP PC was valuable as a way of helping them to adopt a goal-based rather than a symptom/problem-based approach and also helped the whole team to work together to help patients achieve their goals.

ii. Cognitive participation

(how did key players work together to introduce, use and sustain use of the intervention, and did it make a valuable contribution to working practices?)

Initiation (*how did key players work to drive forward use of G-AP PC)*

Participants believed that, in order to use G-AP PC effectively, all team members needed to be aware of it and that this should be sustained over time. Julie felt that this was particularly important:

> *"so I think it's like anything new – raising the awareness, but it needs to stay raised"*
>
> (Julie, AHP/other)

And that it was everybody's responsibility to sustain it:

> *"I think it's not up to any one person individually. I think err, everybody should be driving that. And I think if it's left to one person, what do you do when she's off for a fortnight's holiday – so we stop goal setting – so no, everybody needs to stay completely focused"* (Julie, AHP/other)

One participant pointed out that one of the reasons why G-AP PC had been used effectively by the majority of staff during the pilot period was because of the team leader (Anne, who became the goal setting 'champion' during the implementation period):

> *"I think you're lucky. You've got the team leader who is completely sold on it. Absolutely. I mean, my impression is a hundred percent – thinks it's a good idea. And*

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she has influenced her team I think – I mean, I don't know whether there would have been any resistance or not. But I think because she's been so positive about it, they've been, or all appear to be positive about it." (Mandy, AHP/other)

I wrote about the team leader (Anne) in my field notes, and she did appear to be instrumental in providing day to day support and encouragement to staff in order to help them sustain their use of G-AP PC:

On the whole, with lots of encouragement from Anne, people are beginning to use G-AP PC more routinely. (field notes, 13.08.2012)

In spite of Anne's efforts to ensure that everybody was aware of and used G-AP PC, people felt that it tended to be used predominantly by a core group of staff:

"So it was a shame – it was either the nurses, or the doctors occasionally the physio or the complementary therapist. The social work department, the chaplaincy – they didn't seem to" (Wendy, Qualified Nurse)

Participants agreed that if G-AP PC was to be used successfully over time, it would need to be given a high profile and that this could be sustained by key people who could champion and encourage its' use.

Enrolment *(how did people re-organise themselves in order to use G-AP PC)*

During the pilot study, participants were asked to write patient's goals in the G-AP PC folder, which had been adapted and agreed by the task group. This meant that participants had to consciously remember to write in an additional piece of paperwork, and this was sometimes challenging for people:

"Unfortunately. I think it needs hammering in. As far as - sorry, as far as the paperwork went, for me I think it's possibly a lack of - ooh should I – and whether that is just a familiarity thing of - cause obviously it's another thing that you've got to sort of get used to doing really." (Sarah, AHP/other)

Participants described how they worked together in order help patients achieve their goals. This appeared to involve a change in how they worked together. One of the doctors described how they changed their routine during ward rounds to accommodate use of G-AP PC:

"routinely there would be – a consultant, myself, em from the medical side of things and a member of nursing staff – the consultant would be leading the consultation and asking the questions. I would be documenting in the usual notes and the – by trial and error we got the nurses to do the other bit of documentation – so we were all doing a separate job on the ward round." (Evie, Doctor)

Evie found this change to how the ward round was organised helped to ensure that goals were documented and that nursing staff were aware of patients' goals, which meant that they could be followed up at a later stage.

Sarah talked about how using G-AP PC led to more opportunities to work jointly with other members of the multidisciplinary team:

"I saw J and I said you know, this is what this guy would like to achieve so – what - will we write down here together? We worked on that together – so that's how that worked." (Sarah, AHP/other)

In order for G-AP PC to be successfully implemented, professionals had to make a concerted effort to remember to complete the paperwork. They found this difficult to do at times. They

also re-organised themselves to work together in different ways in order to enhance communication about goals and to ensure that documentation was completed.

Legitimation (*To what extent did people believe it was right for them to be involved and that they could make a valuable contribution*)

Most people believed that they should be involved in helping patients to identify and achieve goals through use of G-AP PC. Wendy described a patient whose goal had been sit up in a chair and hear his friend play the bagpipes. He had achieved this, and later on, staff had organised to have some bagpipe music put on an MP3 player so that he could listen to it in his room. Wendy told me that achieving this goal had been beneficial, not only to the patient, but also to his family:

> *"And he just, they felt the staff pushed themselves that wee bit to try and get him up to the chair that day, to get out for a wee bit fresh air and then for his friend to come in and play the bagpipes, and then when he wasn't there, having his music on in the background, and they really appreciated the staff taking the time because it was important to him – it was a huge big part of his life and it would have made- when they came in – and his music was on in the background – so it was good."* (Wendy, Qualified Nurse)

Through this example, Wendy indicated that she was convinced that she had a role to play in using G-AP PC. Jane told me that using G-AP PC had benefits for the whole team, and again appeared to be convinced that she should be involved in this process:

> *"We formulated a plan to try and get him transferred into a wheelchair and go outside – and I think he achieved that. I think he got out um –albeit briefly – out of his room, in another part of the hospice and spent some time with them. Um so – and it gives you*

a real sense of achievement. If it happens. Because even if it is a little thing, you know

how important it is to them and that gives you a real sense of fulfilment and reward

for the team looking after the person – that you can see something working." (Jane,

Doctor)

Other people were not convinced that they had a contribution to make to the process. Mandy

felt that, although she did set goals with patients, it was not up to her to document them:

"What I do know is that anything that we did, in terms of a patient's goal setting, the

nurses tended to write it in. If we'd done something. It wasn't us that actually wrote it,

it was them." (Wendy, AHP/other)

Sue, an auxiliary nurse, felt that, although patients might talk to her about their goals, it was

her responsibility to pass this onto nursing staff rather than follow anything up herself:

"we wouldn't do anything personally you know with the notes or anything – we would

just go and say to the staff nurse –would you have a wee chat. With such and such –

because he wants to do this – or you know, something that he fancies doing." (Sue,

Nursing Auxiliary)

However, other participants felt that the whole multidisciplinary team should be involved,

including auxiliary staff:

"I mean, kind of, going back to the man who wanted a bath - well, that would

generally be – the, the auxiliaries as well as the nurses, and it may well be just the

auxiliaries. Who'd be doing that - so I think it would be important for them to be

involved." (Lisa, Qualified Nurse)

Most people believed that it was right for them to be involved in using G-AP PC and that there

were benefits for patients, their families as well as members of the team. However, there

were exceptions to this, and those who did not believe that they had a role to play did not appear to engage in the process during the implementation of G-AP PC.

<u>Activation</u> *(How did people work together to sustain use of G-AP PC)*

Professionals talked about changes which could be put in place to help sustain and encourage use of G-AP PC. Most of these were organisational changes which had the purpose of triggering discussions about goals. It was felt that, if goals were discussed between team members, then this would increase the likelihood of each stage of G-AP PC being carried out. One of these was a change on the agenda of the weekly Multi-Disciplinary Team meeting (MDT). At the MDT, each patient is discussed individually. Firstly, the doctors check that statutory forms such as *'Do Not Resuscitate'* and *'Adults With Incapacity (AWI)'* forms have been completed. The focus is then on each patient's symptoms and problems. Potential discharge dates and plans (if appropriate) are also discussed. Participants felt that it would be beneficial to add 'patient's goals' as an item on the agenda:

> *"I think it should be one of the things documented in MDT. I think that should be a routine thing. What goals have the patient's achieved – it's like – do they have AWI. It wouldn't be at that point in the report, but I think it's part of – it should be – was there any goals achieved this week that the patient wanted to do. And that should be a formality."* (Julie, AHP/other)

Another suggestion, which was implemented during the pilot study, was to encourage discussion about goals during the nurse's handover meetings:

> *"It might be worth even in each team having an auxiliary and a staff nurse for instance. Just to keep an eye on goals and every shift just having a wee look to see*

how the patient's – and to have a wee chat to staff about it. Cause I think that's

something we just have to keep on top of." (Wendy, Qualified Nurse)

During the pilot study, I sat in on several handover meetings and once 'goal setting' was introduced as an item on the handover agenda, this did appear to increase the likelihood of nurses discussing patient's goals at the meetings. However, this was reliant on the individuals who were present at meetings and depended on was happening on the ward, as alluded to in my field notes (Figure 26).

Figure 26 Excerpt from field notes

Today at the handover, there is a feeling of exhaustion from everybody and someone jokingly says that there will be 'no goal setting' because they have been too busy.

One of the patients (the man with dementia) is discussed at length. Because he is at risk of falls, he has a special alarm so any movement can be detected, and staff can monitor him. Unfortunately, the alarm is too sensitive and keeps going off. This is causing staff ++ stress and there is a lot of discussion about the appropriateness of this alarm system.

A lady is discussed. She is on the LCP, and did have a goal of getting out and about.

The next gentleman who is discussed is due to be discharged on Tuesday or Thursday. The focus of discussion is on managing symptoms and problems. There is also discussion about his discharge plan, which leads onto discussion about discharge planning. The nurses seem very stressed about how much they have to do. Someone suggests that there should be one person responsible for discharge planning as it always takes up a lot of time.

Another man is discussed – this is a man who I have interviewed, who has ++ oedema in his legs and wants to increase his weight and improve his sleeping. The nurses seem exasperated

> *by him as he keeps going out for a smoke, and won't put his feet up for any length of time. I wonder if they have sat down and made a plan with this man.*
>
> *At the end of this handover I feel quite disheartened. It seems that, when the nurses are busy, patient centred goal setting goes by the wayside.* (Field notes: 29.10.2012)

During the implementation period, participants felt that there was room for improvement in the consistency of their use of G-AP PC. They recognised that organisational triggers such as having goal setting on the agenda of the MDT and handover meetings might be useful mechanisms for this.

iii. Collective action

(how or if key players made the intervention work at an operational level – what skills did people need to develop, how did it work in practical terms)

Interactional workability *(How did people work together and what mechanisms supported them to use G-AP PC)*

At the beginning of the pilot, the Yellow team recognised that they might need a mechanism in place to notify all members of the team that the goal setting process had been started with a patient. In order to do this, the team used the white board where the names of all patients were written in the duty room. Yellow team patients had the initials *G-P* written in red beside their names if they had goals. This served as a reminder to participants to check goal folders, but did not always appear to be enough to ensure that everybody remembered to do this. Some participants (particularly nursing staff) felt that it would be better to have the goals as part of the nursing care plans:

"I know we had it on the board – G-P beside their names and things, but because it wasn't integrated into the care plan, it was quite difficult." (Lisa, Qualified Nurse)

Others felt that goals should be integrated into the medical notes so that they could be more readily discussed at the MDT:

"But you know, I think, actually, the documentation would need to come [to the meeting] *if it was going to be part of the MDT, the documentation needs to come to the MDT so that then – goal setting – you just open up the file – and yes – it's du du du - just like we do with the forms – what forms have they got? What goal setting have they got?"* (Jane, Doctor)

Participants recognised that, in order to sustain use of G-AP PC, they needed to work together to remind and encourage each other to complete all stages of the process:

"I think – I would have to be prompted to remember to do it as well. I think you know, it's important, to have somebody there reminding you to do it cause otherwise it can get forgotten about. You have to have somebody there that's really saying – we have to do this. Really be on people's radar. Otherwise it definitely gets forgotten about." (Jane, Doctor)

Others felt that, if one person had identified goals with a patient then they should take responsibility to ensure that these were pursued and that relevant people were asked to help support the patient with goal achievement:

"The person that set the goal with them should keep an eye on it. So that they feel happy with how it's being written up, or happy with how it's going – cause they're the person that set the goal." (Julie, AHP/other)

The paperwork was regarded as an important method of communication between staff, but there was not an obvious solution about where this should be kept:

"I think if you put it in the nursing notes, doctors will think it's a nursing thing. But equally, if you put it into the medical notes, the nurses might think it's a medical thing. Um That's why I suppose putting it by the patient's bedside is the most neutral place – to put it um" (Jane, Doctor)

During the implementation period, members of the Yellow team constantly reviewed the systems and routines which might support more consistent use of G-AP PC. They recognised that at times they forgot to use the process, and individually and collectively tried to put mechanisms in place to remedy this.

Relational integration *(What did people need to know in order to use G-AP PC confidently)*

Participants appeared to value the training which had been provided at the beginning of the pilot study. One participant (Mary) had been off when this happened, and although she had been given a one-to-one catch up, she felt that she had missed out by not attending the workshop:

"The only thing I would say I felt I missed out on was the training. The proper training. I wasn't here - I was on annual leave, and you're not going to have everyone here all the time. But I think it was different because it was a study whereas if it was going to be in the hospice then a full time thing then we would have to have a little bit more training." (Mary, Qualified Nurse)

Another participant reflected that she might benefit from further discussions about how to support people who were deemed to be unrealistic:

"how to make possibly unrealistic goals achievable. I found that - I found sometimes it's quite difficult when somebody came up with a goal which is quite obviously unachievable and it's how to scale that back and suggest things that were perhaps more appropriate."

(Lisa, Qualified nurse)

Another found it difficult to know precisely what to write in which part of the documentation, which might have implications both for future training and for clearer paperwork:

"when you're in a hurry - when you're busy busy, then I think 'oh God - what do I write here.' You know, then that puts people off." (Sarah, AHP/other)

This was picked up by others who thought it would be beneficial to have examples to guide staff about what and how they should document goals:

"I think the fact that it's flexible, that it's not prescriptive, but just trying to encourage people to fill the paperwork in really. And maybe giving examples as well. Just examples – for rolling it out to other teams. Having cases of what happened and what the goals were, so people can see – you know, how it can work." (Jane, Doctor)

Participants agreed that although G-AP PC appeared to be a simple process, staff needed training in order to use it consistently.

<u>Skill set workability</u> *(Who was responsible for doing what in order to effectively use G-AP PC)*

Participants believed that using G-AP PC should be a joint responsibility across the whole team and that different people might take the lead at different times:

"And then to identify that somebody's got these goals – this pain, nausea, so I think there's certain members of the team may be more important at those times. But I

think it depends – maybe sometimes – which goal it is. But I think they all have a place

in all of them as well –somewhere." (Julie, AHP/other)

Others expressed frustration because the whole multidisciplinary team had not consistently used G-AP PC during the pilot period:

"And trying to get all the multidisciplinary team I think to take part has been quite

challenging. There has been two or three colleagues embracing it really well, and then

others – I don't really know because I haven't actually challenged them on it to find out

why they didn't take more part, because they seemed quite keen at the beginning."

(Wendy, Qualified Nurse)

One participant felt that people needed practice in use of G-AP PC and that this might help people to engage in its use:

"I think people have become more aware of it and more um confident about using the

paperwork. Because it is a new thing, it is sort of frightening – 'what do I do with this bit?

Does it fit with that bit?' That kind of feeling – whereas probably the more you get to use

it, the more confident - the more linguistically you'll be able to - you know - find the right

things really." (Sarah, AHP/other)

From the interview transcripts, it appeared that people had engaged in using G-AP PC to different extents. More explicit guidelines and discussions about roles and responsibilities at different stages of G-AP PC might help produce a more consistent, whole team approach to using it.

Contextual integration *(What resources, protocols and procedures need to be put in place for*

G-AP PC to be used)

During the implementation period, staff in the Yellow team worked together to identify procedures to help them to use G-AP PC more effectively. For example, they identified the need for a signal to help all staff know when goals had been set with a patient (through the use of the initials 'G-P' on the white board in the duty room). This was useful in helping to raise awareness and remind staff to look at goal folders, but it did not guarantee that everybody did this.

> *"I didn't even remember to look and see if someone had the sheets there."* (Mandy, AHP/other)

A predominant theme from the interviews was the documentation and where it should be kept. The perceived availability of goal setting paperwork was seen as crucial in supporting the use of G-AP PC by the whole team:

> *"I think right now, it's difficult finding paperwork sometimes. I think, sometimes, when we go for nurses notes, it's either in the room or it's with the drug sheet – tray or it's up in reports or it's with the doctors on ward round or it's at the nurses' station – and lately it seems to have got harder."* (Julie, AHP/other)

One participant felt that if a key person was responsible for setting goals and championing the use of goal setting, that might help to embed it in practice:

> *"It's almost like you need a goal setting – a goal setter. Instead of a nurse, it should be a goal setter! Going round and setting goals for people (laughs). Cause that would be that one person, and she's be asking in the same way and she's really – be asking. You know, there'd be no dubiety."* (Sarah, AHP/other)

This links back to the need to have roles and responsibilities more clearly signposted, which I highlighted under 'skill set workability' (Section 7.9.1).

One participant talked about the challenges of using G-AP PC with people who had communication or cognitive difficulties.

> *"Yes, I think patients with cognitive impairment, it was quite difficult. Um – patients with dementia or patients with – some patients who had brain tumours as well – had a degree of cognitive impairment and weren't able to sort of understand the question – so these patients it's quite difficult to use with."* (Wendy, Qualified Nurse)

During the pilot, no adjustments were made to G-AP PC to enable this group of patients to take part in the goal setting process, but additional resources and training could be developed in order to include this patient group.

During the implementation period, it was evident that, although staff had been initially enthusiastic to use G-AP PC, not all had consistently used it. Staff felt that training for the whole team was an important part of the implementation process. They also identified a need to simplify the paperwork and emphasised the importance of agreeing where it should be kept and who should complete it. Although this was a predominant theme, there was no agreement about the best solution.

iv. Reflexive monitoring

(How do we know if the intervention is effective, who will it benefit, what outcome measures could we use, and would it be feasible to use these?).

<u>Systemization</u> *(What type of information needs to be collected to show effective use of G-AP PC)*

Participants agreed that it was important that all parts of the paperwork should be completed, but recognised that the 'appraisal and feedback' stage was not always completed. This was evident in the case note analysis which I discuss in detail in section 7.9.3. Participants

believed that they were reviewing patients' goals in practice, but that they did not always document them:

> "I think it's been happening. I think people have asked – you know, have you got any other goals – you know, is that OK? Or have you got any other goals that you want to achieve or whatever. That has certainly been said. Verbally. So maybe it's just people not remembering that that's a part of the process." (Sarah, AHP/other)

Another participant felt that at times, documentation was not completed at all, even though staff were asking patients about their goals:

> "Because you hear staff saying – this patient wants to do that – like the other day when you were round, I don't think the staff member took the time to write it out again – d'you know? So that's how the patients are aware of it but it's not always getting followed up. The written side of it." (Wendy, Qualified Nurse)

In spite of this, documentation was seen as a really important part of G-AP PC, and something that was valuable for providing evidence of patient centred goal setting within the hospice:

> "I would say so. I think it's a good thing to do – and I know it is another bit of paper to fill in and everybody's busy, but I think it's really good for evidence – and I think it's good to show that sometimes, some patient's goals allow us to show that we're different. It allows us to show – palliative care in a hospice – it's what's – different." (Julie, AHP/other)

Staff recognised that, in order to demonstrate that G-AP PC is being used in practice, there needed to be written evidence in the case notes that this had been done.

<u>Communal appraisal</u> *(How do people work together to evaluate the worth of G-AP PC)*

At the beginning of the implementation period, senior staff (a group comprising doctors, AHPs and the nurse team leader) decided to meet on a weekly basis to discuss how use of G-AP PC was progressing. They recorded any issues that came up during these meetings and put them in a book which I checked each week. Figure 27 shows examples of the questions which came up after one of the initial meetings.

Figure 27 Example of written questions from the weekly meetings

1. *How/if to use G-AP PC with patients with cognitive impairments*

2. *Challenges in initiating G-AP PC/?Appropriateness for some patients*

3. *If a goal appears quickly/ad hoc and there is little time to document*

4. *Quite a lot of paperwork (can lead to duplication if forms regarding certain goals already exist).*

5. *Are night staff aware of the goal setting pilot?*

6. *There is no list of patients who have gone onto G-AP PC and those who haven't*

I met on a regular basis with the team leader and provided written feedback regarding the questions in the comments book each week. The types of questions staff asked at this early stage suggest that they were working together, anticipating potential problems and evaluating the implementation of G-AP PC. After the first three meetings, the group decided not to continue to meet (Figure 28).

Figure 28 Notes from final group meeting

Present: (Team leader, Physio, Physician and Consultant)

- *Documentation a bit too wordy/long/duplication between similar questions*

- *Nurse on ward round writing down goals/filling out goal setting documentation worked well this week*

- *Overall: goal setting pilot well established – only meet when required (i.e. not weekly on a Wednesday at 11am anymore)*

Individual appraisal *(How did individual staff appraise use of G-AP PC – what did it add or take away from their work)*

During interviews, participants reflected on their use of G-AP PC. Although participants did not consistently complete the appraisal and feedback sections of the documentation (section 7.9.3), this was regarded as a valuable component of the goal setting process which could help patients achieve even more than they expected:

> *"I think what's next is good. Because sometimes, if patients improve, they've not thought about that – they've not thought about what else they might do now – and seeing they've achieved something – and even if you've done it in a different way, it'll maybe open the door for other things."* (Julie, AHP/other)

Lisa found this quite difficult to do:

> *"I always found it quite difficult to - to go back and get the feedback from - from the patient."* (Lisa, Qualified Nurse)

Wendy talked about some of the challenges of asking patients how confident they felt about achieving their goals:

"This is the bit that I think gets missed out quite a lot to be honest because the patients don't really engage with that or really understand it at times either. They either say – 'oh I think I'll be able to manage that', but they're not able to score it." (Wendy, Qualified Nurse)

Following discussions with the task group before the implementation period, we agreed that goal setting documentation should be in a form that could be used and held by patients themselves. In practice, participants found that patients were not keen to be involved in working through paperwork with staff and in fact, documentation was completed with minimal involvement from patients:

"certainly I had no feedback from the patients of having had any input actually to their documentation of it." (Evie, Doctor)

"Yes. I think it sounds really nice to give ownership to the patient but – whether that would come with practice – in the three months I don't know of any patients that have picked it up" (Wendy, Qualified Nurse)

However, some participants did believe that the paperwork should be available for patients and their relatives to look at:

"In the nursing notes. In the nursing notes – because the nursing notes we say you know – the patients can see it. At any time." (Mary, Qualified Nurse)

Participants individually reflected on their use of G-AP PC and made comments about the different stages of it. There was agreement that use of G-AP PC enhanced patient centred goal setting but not every stage made sense to each professional or was perceived as useful in practice.

<u>Reconfiguration</u> *(What did staff do to try and change G-AP PC to make it more workable)*

During interviews, participants told me that they had found some of the questions in G-AP PC repetitive. There was agreement that the 'what's important to you right now?' and 'what do you want to do in the next wee while?' questions should be merged:

> *"I mean I think, as I've said, I think, you know – drop - I didn't feel the need for the second question."* (Jane, Doctor)

The purpose of having the two questions was to provide patients with an opportunity to express what was important to them before negotiating a more specific goal. However, in practice, this did not appear to 'make sense' to professionals, and seemed to lead to confusion:

> *"what you want to do in the next wee while' - is a bit misleading for some patients. They kind of think – well, they've just told you. So they feel they've got to think up something different to say – when you say the next wee while."* (Julie, AHP/other)

Professionals also found it difficult to distinguish between *'what I need to do'* and *'what I need help with and who I need to ask for help'* in the action and coping plan. They suggested that these questions could also be merged:

> *"The 'what do I need to do' and 'what do I need help with'. I feel that they could probably be put together sometimes as well. Because sometimes patients were saying – well I need to ask the physio to help me or I need to ask the complementary therapy to give me something to help with relaxation – and then we would move on to 'what I need help with'"* (Mandy, AHP/other)

One participant suggested an IT solution to the problems which many people identified around documentation:

"For me I see no reason why the system that we have as a paper exercise could not be incorporated very easily onto a. Into an I.T. um programme – and it might even. It might even demand that people fill it in. you know, on the frame that comes up."

(Fred, AHP/other)

Another participant suggested that the appraisal and feedback could be recorded from the family's as well as the patient's point of view:

"I just wonder about the appraisal and feedback. I know it was from the patient's perspective, but it might be quite nice putting in – what the families feel as well – I mean that's not something I've thought about doing – but that brought home to me. When I was speaking to that family yesterday. Um – how it had been really important to them. It had made them feel so much more relaxed when they came in when they knew that b was being looked after well – not just physically but emotionally too. Maybe it would have been nice to write that in. Whereas we just sort of put it in from the patient's point of view." (Wendy, Qualified Nurse)

During their interviews, participants suggested changes which could be made to G-AP PC which might enhance the process and make it easier to use in the context of the hospice.

v. Additional themes

Some themes arose which could not be categorised under the NPT headings. These were: *what patients understand about goal setting; deterioration; organisational barriers and use of the confidence rating*.

<u>What patients understand about goal setting and what options are available:</u>

Two participants told me that some patients did not understand what goal setting meant:

"I think some people don't know what goal setting actually means." (Julie, AHP/other)

On these occasions, participants felt they had to work hard to suggest possible options for patients:

> *"Then we would suggest – and trigger their memory - not trigger their memory but kind of give them a few triggers. And they would go – well Ok, yeah, that would be nice. So sometimes I felt am I putting words in someone's mouth here."* (Mary, Qualified Nurse)

Some participants found that discussing action and coping plans could be difficult because patients were not always aware of the options available or what individual team members could do. At times, suggestions had to be made to help patients think of alternative ways of doing things or plan for future, unknown eventualities:

> *"but until you know you can't do something, and you see it, it's very difficult to plan a 'what if', so it's – to me, asking a patient that at the time – isn't so easy for them to answer."* (Julie, AHP/other)

Others agreed that they had to ensure that patients were aware of all the options that were available to them:

> *"It's also probably highlighted as well for us - how many people often don't know about our service. There have been several people who haven't known about our service."* (Sarah, AHP/other)

Although some of the staff who I interviewed raised this as a problem, this did not appear to be an issue for the patients who I interviewed (section 7.9.4).

<u>Deterioration:</u>

Participants identified deterioration as one of the main barriers to successfully setting goals with patients. Lisa talked about the pressure of time for those who were rapidly deteriorating:

> *"I found it quite difficult with people who - people who deteriorated quite quickly. And I think they're probably the people who would have wanted to - to - to try and develop goals and things."* (Lisa, Qualified Nurse)

For some patients, goals became less important as their condition worsened, and this made it difficult to review progress:

> *"I think -well, I know a few times people just shrugged their shoulders really. Because - I think the other thing is – if people then move on - certain people move on to - you know, they become iller. Their goals are changing because of their illness."* (Sarah, AHP/other)

One participant suggested that this needed to be captured in the documentation, which was another reason why goal review should be documented:

> *"But it allows you to read – the dip – and we're always going to have that in palliative care. That your goal may only be achievable for a certain time – and then it changes – so - I think that's really fine that we've got that in. So you've the evidence of progressive disease sometimes."* (Julie, AHP/other)

Setting, reviewing and documenting goals when patients were deteriorating appeared to present particular challenges for participants. This is an area which could be addressed by providing mechanisms to remind staff to carry out the review process and also through training.

Participants talked about several organisational barriers that affected the goal setting process. Sarah found that at times she would visit patients to help them achieve their goals, but they would not be available:

> *"any time I went to see her – she had relatives or her grandson there or next time I went a bunch of friends who used to work with her – it was – it just happened that I – and then she went home."* (Sarah, AHP/other)

My own experience of trying to find the right moment to interview patients was similar. The ward routine was such that, in the morning, personal care tasks and the ward round took priority. In the afternoon, patients were resting or had visitors. It may have been useful to have considered this in the action and coping plan stage of G-AP PC. Choosing the right time to work towards goals may have helped clarify the type of support patients wanted from staff.

Other participants talked about their own time pressures, which affected their ability to take part in the goal setting process:

> *"we're trying to do two jobs basically, in one amount of hours – and so we're just always chasing our tails and trying to juggle far too many things – so any extra paperwork is a challenge for us. Not because we're resistant to doing it"* (Mandy, AHP/other)

Some participant's working patterns made it difficult to engage fully in the process:

> *"So sometimes you see someone and by the time you come back they're away home. Because you've been off you know. But it's just the way it goes."* (Sue, Nursing Auxiliary)

Some patients were moved from one team to another during the implementation period, and this affected the continuity of the goal setting process:

> *"I think it's been a wee bit harder when patients have been transferred from other teams because they have been in for a wee while and they're sort of set in their ways, and you're getting to know them – going over ground that they've been on before so it's sort of not been so easy."* (Wendy, Qualified Nurse)

The other barrier which participants talked about was the availability of the paperwork. This needs to be addressed at a local level if G-AP PC is to be successfully implemented in any setting.

Confidence rating

Participants talked about their use of the confidence rating scale with patients. One person felt that this was a difficult question to ask and that it gave mixed signals to patients:

> *"I sometimes felt that they thought I was questioning you know their realism with it - when you said - well how confident are you and it was 'maybe she thinks I can't do it?' um and perhaps it was just the wording of the question."* (Lisa, Qualified Nurse)

Others found that patients could be overly confident:

> *"I think it's was quite variable really. Um – some people would be absolutely fine about it and maybe a bit over confident – you'd be thinking – I'm not sure if this is achievable – you know – becoming independently mobile again –'oh, yeah, yeah, yeah, I think I can do that'."* (Jane, Doctor)

But it did give staff the opportunity to talk about goals and break them down into manageable steps:

"it was kind of separating, and it was giving you a window to speak about em – how appropriate these goals were." (Mary, Qualified Nurse)

One participant found this question particularly valuable in helping patients to discuss action and coping plans:

"Yep, because I think actually, that would open up into the next two questions – how confident do you feel about it? Well, I'm worried about – saying how my pain's going to allow me to do that or I'm worried I might have a fall or – or – and then we'd say, well what can we do to try and prevent that from happening – and then you would turn it round to try and you know, make it achievable." (Jane, Doctor)

The extent to which professionals valued and used the confidence rating scale varied between professionals.

7.9.2 Staff questionnaires

Fourteen out of a possible 25 questionnaires (Appendix 16) were returned by Yellow team staff. I report on results for each question (Figures 29 and 30) and have categorised any comments which were made using the NPT constructs. Although 14 people returned questionnaires, one person only made comments at the end and did not answer any of the questions, so for most questions there are a maximum of 13 responses (not everyone answered all the questions).

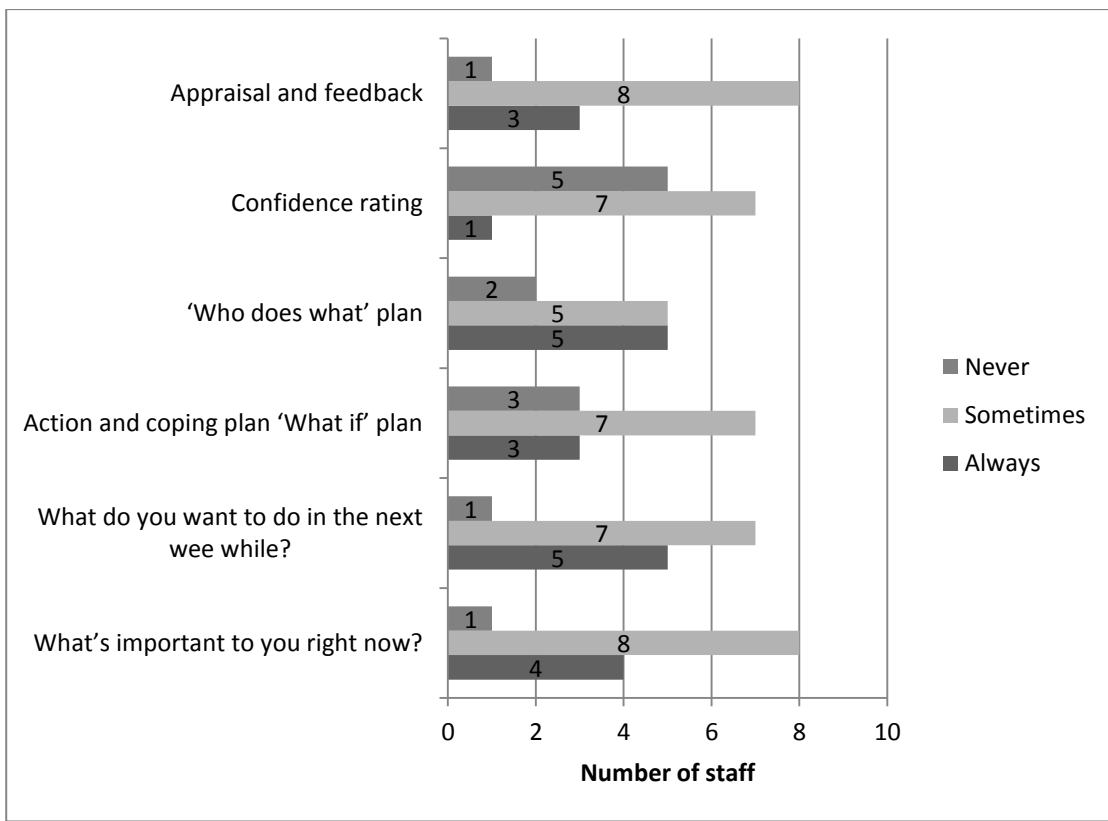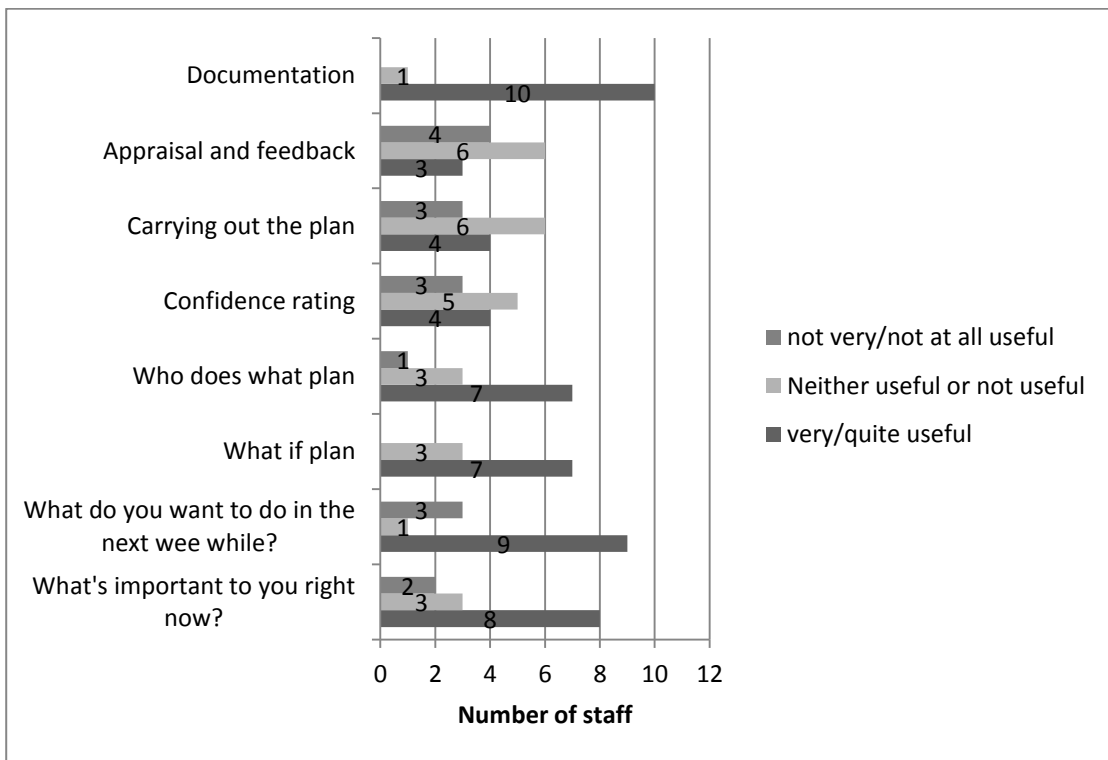Figure 29 How often staff used each G-AP PC question

Figure 30 How useful staff found each stage of G-AP PC

Responses from the questionnaire suggest that most of the questions asked at different stages of G-AP PC were used and valued by participants, with the exception of the confidence rating scale. According to respondents, this was the least used part of the process and people appeared to find it the least useful component in the process. This is in line with some of the comments from the staff interviews (section 7.9.1), although data extracted from the case notes (section 7.9.3) shows that in practice, during the implementation period, staff did complete the confidence rating part of the documentation. Respondents also had the opportunity to make comments at the end of the questionnaire. I have categorised comments under the relevant NPT headings (Figures 31, 32 and 33).

Figure 31 Comments categorised under 'coherence'

> *"As stated in our interview the whole idea of goal setting is highly important. Sincere thanks for motivating staff towards increased involvement in this area" (AHP/other)*
>
> *"Thank you for stimulating us to focus on this area of our involvement with patients and their families" (AHP/other)*
>
> *"There was repetition with the first two questions. Great tool which should be implemented into practice" (Qualified nurse)*

Figure 32 Comments categorised under 'collective action'

> *"generally very good. Patients sometimes find it difficult to rate confidence and to think about 'what if'. Not always appropriate to ask what if dependent on patient's state of mind. Good way of bringing goal setting to staff attention. Staff should involve all appropriate staff/volunteers in achievement of goals." (AHP/other)*
>
> *"I think the goal setting is excellent, but we are not consistently in the ward, making things more difficult for us to continue to update." (AHP/other)*

Figure 33 Comments categorised under 'reflexive monitoring'

> *"Thought it was repetitive at times. Would probably be effective if used as a care plan. Limited use for very poor patients. Effectiveness depending on criteria of the patient and stage of illness" (Qualified nurse).*
>
> *"I found the section on what to do in the next wee while a bit more of the same as page 3. I found page 3 very good. All in all it really makes us think about goal setting. Keeps us focused on each goal we may be involved in so that we do not 'lose the plot'." (AHP/other)*

Only 56% of questionnaires were returned. However, those responses match with findings from the staff interviews (section 7.9.1) and can also be compared with findings from the case note analysis (section 7.9.3). Staff appear to have used most elements of G-AP PC and have found them useful, with the exception of the confidence rating scale. I discuss this in more detail in section 7.9.3.

7.9.3 Case note analysis

Thirty one G-AP PC folders were used with patients during the pilot study. A total of 42 goals were set with patients (some had more than one goal) and of these, 21 were achieved, four were partially achieved, ten were not achieved and goal outcomes for seven goals were not documented. In this study, G-AP PC was implemented in order to improve the *process* of goal setting in the hospice rather than focusing on outcomes, so analysis of the case notes focuses on how G-AP PC was used rather than use of goal setting to measure outcomes. (Table 54)

Table 54 Elements of G-AP PC documentation completed (from the 31 completed G-AP PC folders)

Patients priorities established	Short term, meaningful goals	'What I need to do'	'What I need help with'	'What if' plan	Confidence rating	Evidence of appraisal and feedback
28	31	29	30	29	29	27

Responses from the interviews and the questionnaires suggest that participants did not feel that they had used the confidence rating scale or carried out appraisal and feedback with patients. However, the case note analysis results suggest that professionals did complete all steps with most patients. Sixteen of the 27 'appraisal and feedback' entries were written in the continuation notes of the goal folder rather than on the form on the final page of the folder. This might explain why professionals felt that they had not always gone back and reviewed patient's goals with them.

When I carried out the case note analysis, it was much easier to find goals than it had been during the initial phase of the research (see chapter 4.4.5). This was because goals were written in a separate document and each goal setting 'story' could be traced from beginning to end. The way in which goals were written varied. Some were very personal and patient centred (Figure 34). Others appeared to have been written from the perspective of the professional, and reflected the tasks which they as professionals were most concerned about (Figure 35).

Figure 34 Example of a personal, patient centred goal

What's important to you just now?	'Increasing mobility so I can get in a bath and relax with a whisky'
What do you want to do in the next wee while?	To have a bath
What are the steps to achieving that?	To transfer from bed to chair, then bed to bath.
Confidence rating	9
What I need to do	improve strength to transfer
What I need help with and who I need to ask for help	nurses and physio to improve strength. Nurses to assist to transfer and bathe.'

| ‘What if’ plan…. (think of things that might get in the way, and how they might be overcome) | fatigue – resting as much as possible. Pain – Analgesia before going for bath.’ |

Figure 35 Example of a professionally led goal

What's important to you just now?	Nothing recorded in this section
What do you want to do in the next wee while?	To walk better and maintain my independence
What are the steps to achieving that?	mobility and safety
Confidence rating	7
What I need to do	take advice
What I need help with and who I need to ask for help	Medical, nurses , physio
‘What if’ plan…. (think of things that might get in the way, and how they might be overcome)	If I don't take advice I put myself at risk of falls

In the first example (Figure 34), staff and the patient identified the goal of having a bath, which for the patient went hand in hand with relaxing with a whisky. In order to achieve his goal, the patient and professional identified tasks. These involved other professionals (for example, the physio for help with mobility and transfers, and medical staff for help with pain relief) as well as the patient himself who agreed to take responsibility for getting as much rest as possible so that he had enough energy to have a bath. Progress towards achieving this goal was documented in the continuation sheets of the goal folder (Figure 36).

Figure 36 Continuation notes/appraisal and feedback

> *'…he did transfer from his bed to the wheelchair in the afternoon as practice for getting to the bath.'*
>
> *'Patient declined a bath this morning stating he was too tired but was keen to pursue this tomorrow. He would like to stay in bed today to try and conserve energy.*
>
> *Two days later: 'patient was too uncomfortable when he stood up to transfer onto a chair for a bath, tried the shower chair, still uncomfortable, agreed may benefit from pain relief prior to movement, but patient had the whisky in bed.'*
>
> *Next day: 'pain relief given. Patient managed 6 steps and tolerated sitting in shower chair. Enjoyed shower. Enjoyed his whisky after shower with lunch.*
>
> *Next day: patient very poor today. Commenced on LCP.*

Although he did not manage to achieve the goal of having a bath with a whisky, there was evidence of discussion around the action plan. Both the patient and professionals seemed to work together to adapt and work out ways around the problems which arose. Most importantly, staff maintained a focus on the overall goal which was for the patient to feel relaxed and to enjoy a whisky, which he did manage to achieve, even though it was not in the bath.

In contrast, in Figure 35, the professional appeared to have missed out the first stage of G-AP PC and went straight on to set a very professionally-led goal. There was no evidence of discussion with the patient and the professional seemed to use the paperwork to state that the patient needed to take advice in order to reduce their risk of having a fall. The appraisal

and feedback was also written from the professional's perspective, with a focus on risk and safety (Figure 37).

Figure 37 Appraisal and feedback

What went well	walking with delta frame instead of crutches. Feels safer
What didn't go so well	not completed
How do you feel	Happy to use the delta frame
Is it still important to you?	Yes
What next	not completed

Examples such as the one shown in Figures 43 and 45 were in the minority, but further training may be needed in order to help the whole team engage to use each stage of G-AP PC to help ensure that goals are patient centred rather than professionally led.

Although there was some variation in the way in which goals were documented, the majority of goals were patient centred and showed evidence that participants had used each stage of G-AP PC. I now look at examples of documented goals in relation to each theory.

i. Social cognitive theory (Bandura 1997)

The two key constructs in G-AP PC from Social Cognitive Theory (Bandura 1997) are self-efficacy and outcome expectancies.

Self-efficacy

In G-AP PC, a patient's self-efficacy is measured using the confidence rating scale. Interview and questionnaire data suggest that some people found this difficult to understand and were not sure of its value. It was consistently used during the pilot but there was not a strong link between a patient's level of confidence and their level of goal achievement. There are several

possible reasons for this. One professional had misunderstood the rating scale and wrote down a patient's confidence as '3' whilst noting that the patient had said *'I'm sure this is achievable'*. Some patients rated their confidence as low, but then managed to achieve their goals. For several patients, there was evidence that the confidence rating had been done for an initial goal which was then scaled back to something more manageable. For example, one patient initially set a goal of going on holiday with her husband. Her confidence rating for this was a 1 or 2. The goal was then scaled back to going for a drive on a Saturday night and then out for a meal. The patient was much more confident that this could be achieved, and rated it as an 8. Use of the confidence rating scale appeared to work hand in hand with the action and coping plan, and when used together, this appeared to be a mechanism to help professionals work with patients to scale back goals and discuss ways to make them more achievable. More training in the use and value of the confidence rating scale may help it to be used and understood more consistently.

<u>Outcome expectancies</u>

According to Bandura (1997), in order to be motivating, goals should be relevant to the person, with a perceived benefit for them. Goals which were documented in the case notes were consistently more personal to individual patients than those which had been documented in the first phase of this research. For example, common goals prior to using G-AP PC are shown in Figure 38:

Figure 38 Goals from previous phase of research

Patient 6: 'Hopes to improve vomiting'

Patient 7: 'to address pain, support self , husband and family, to revise will'

Patient 27: 'wishes to get home soon'

Patient 58: 'Wants to improve his mobility and jaw pain then get home.'

This contrasts with documented goals using G-AP PC (Figure 39).

Figure 39 Documented goals using G-AP PC

> **Patient 21:** 'To get into wheelchair and go outside with grandchildren'
>
> **Patient 30:** 'To be able to improve breathlessness enough to be able to walk to the toilet and back' and 'To get home to watch the horse racing'
>
> **Patient 33:** 'To make a card for my husband for our golden wedding anniversary'
>
> **Patient 38:** 'To go out for lunch with my family.'

The goals written using G-AP PC focussed less on symptom control and were more specific and personal (and theoretically, more motivating for patients). The case note analysis did not show evidence that patients were more motivated to pursue their goals, although there is evidence that this was the case from patient interviews (see section 7.9.4). However, the personal nature of goals did appear to effect staff motivation to support patients in their pursuit of goals. Staff seemed to be more aware of patients as people, and there was evidence that they followed up personal aspects of goals. For example, patient 30 had stated that he wanted to get home so he could watch the horse racing. Staff picked up on this and arranged for the patient to place bets on the horse racing over the phone while he was in the hospice. During appraisal and feedback, the patient appreciated that he had been supported to do this and stated *"it felt good that I could continue my interest".*

ii. Goal setting theory (Locke and Latham 2002)

Locke and Latham (2002) state that in order to maximise motivation, goals should be sufficiently difficult and specific and that people should be provided with feedback about their performance. Using G-AP PC, staff were asked to document the goal negotiation process,

going from general goals *('what's important to you right now')* to more specific goals (*'what do you want to do in the next wee while?').* In practice, staff were sometimes confused by the distinction between the two steps and there were some examples of this seen in the documentation, where goals were simply repeated (Figure 40, patients 2 and 21). There were other instances where professionals had understood the process and successfully negotiated broad goals into more specific ones (Figure 40, patients 5 and 8):

Figure 40 Examples of confusion between broad and specific goals

What's important to you right now?	What do you want to do in the next wee while?
Patient 2: *'To see the priest and receive sacrament of the sick'*	Patient 2: *'To see the priest and receive sacrament of the sick'*
Patient 21: *'Getting home, putting on shoes'*	Patient 21: *'Getting home, putting on shoes'*
Patient 5: *'Filling my day with something'*	Patient 5: *'I would like to do some painting'*
Patient 8: *'To have pain better controlled. To improve quality of life'*	Patient 8: *'Take an interest in my hobbies again: photography, model aircraft, reading on kindle'.*

It was not possible to gauge the difficulty of goals from the case note analysis, apart from through the confidence rating, which unfortunately was not always a good predictor of whether or not goals were achieved.

The feedback and appraisal part of the G-AP PC documentation was intended for use by professionals to help them provide feedback to patients about their performance in relation to goals and in planning next steps. Professionals did not consistently complete this part of the paperwork, but most did write about progress in the continuation sheets within the goal folders. This appeared to provide a useful opportunity for both patients and professionals to reflect on goal achievement (or lack of achievement) and also provided reasons why goals might not have been achieved.

In Table 55, we can see how the appraisal and feedback section helped a patient reflect on what he had achieved and begin to plan some goals for himself.

Table 55 Appraisal and feedback

Patient details and goal	Appraisal and feedback
Patient 8 (80 year old man with cancer – related disease). His goal was to: *'To have pain better controlled. To improve quality of life.'* **Specifically, he wanted to:** *'Take an interest in my hobbies again: photography, model aircraft, reading on kindle.'* **Steps to achieving that:** *'Pain to be better managed to allow me to concentrate and enjoy hobbies.'*	**What went well?** *'I'm feeling more relaxed, improved management of pain, advice on moving and changing position safely. Now have improved concentration to be able to continue with my hobbies I really enjoy.'* **What didn't go so well** *'nothing'* **How do you feel about it?** *'I feel really good.'* **Is it still important?** *'Yes'* **What next?** *'I'm looking forward to going to a cottage in September on holiday with my wife and friends.'*

Where goals had not been achieved, staff documented what had happened and why the goal had not been achieved (Table 56).

Table 56 Appraisal and feedback when goal not achieved

Patient details and goal	Appraisal and feedback
Patient 11 (77 year old man with cancer – related disease). His goal was to: *'spend time with family, occupying time whilst in hospice'* **Specifically, he wanted to:** *'Participate in puzzles/jigsaw puzzles'* **Steps to achieving that:** *'Speak to staff and arrange for jigsaw puzzles to be made available. Continue to do puzzles in daily newspaper.*	In continuation notes: *'Patient's condition has shown little improvement with his mood deteriorating as a result. Spoke at length today and he feels fed up. Explored goals again although he doesn't feel up to anything today. Encouraged to get up in wheelchair and go for a walk tomorrow if weather permits as he states he has been in same room for weeks. Unable to do jigsaw due to fatigue/mood but read his newspaper in the*

Patient details and goal	Appraisal and feedback
	morning.'
	Later:
	'patient too sleepy and fatigued to discuss this. Perhaps if reviewed at an earlier date would have been able to do this.'

In the example above, although the patient did not achieve his goal, there is evidence that staff tried to support him to pursue it, and they also reflect on the fact that, perhaps if his goal had been reviewed sooner, he might have been more able to discuss his priorities.

Although appraisal and feedback was not always formally carried out, because goals were documented in one place, it was much easier to track goal progress in the continuation notes.

iii. Health action process approach

Within G-AP PC, an action and coping plan is made in order to bridge the gap between what people intend to do and what they actually do in practice. Professionals were asked to discuss the following with patients:

- What I need to do

- What I need help with and who I need to ask

- 'What if' plan

In the case notes, there were examples where discussion had clearly taken place with patients to proactively think about what might get in the way of goal achievement and to agree on who should do what (Figure 41).

Figure 41 Example of patient centred action and coping planning

Goal	'Go out for lunch with my family'
What I need to do	*Arrange a time for my daughter to take me*
What I need help with	*Nurses – arrange pain medication*
What if plan	*I might get tired – need to arrange for my daughter to bring my wheelchair*

In the example above, the patient and professionals appeared to work together to plan what needed to be done, by whom, in order for the goal to be achieved. In practice, once staff were aware of the goal, they did their best to make it happen, as documented in the continuation sheets (Figure 42):

Figure 42 Excerpt from continuation sheets

'when discussing transport options for hospital appointment tomorrow, it was suggested that patient's daughter could take her. Plan to take her to appointment then out for lunch.'

Then: 'Patient was ready early this morning for appointment. Medication and breakthrough analgesia given to daughter with instructions. Patient's own wheelchair brought from home in case she got tired. Patient appeared very happy as she left.'

Then: 'Patient returned just before 4pm today, she attended her appointment then went for lunch. She enjoyed herself so much she decided to go shopping in town for the afternoon. She admitted she wouldn't have managed this without her wheelchair but had a wonderful day. Although very tired now she plans to get out again this week.

Then: 'sadly patient's condition has deteriorated considerably over the last few days, she has been commenced on LCP and will be unable to achieve further goals although she was thrilled at her achievements earlier this week.'

In this example, the action and coping plan was followed through. Having the breakthrough analgesia and wheelchair were instrumental in helping the patient achieve her goal. The patient died shortly after the goal had been achieved, which underlines the importance of the whole team working together to support patients to make the most of opportunities as they arise.

There were some examples where professionals did not seem to have any discussion about the action and coping plan with patients (Figure 43):

Figure 43 Example of professionally led action and coping plan

Goal	'return home with pain better controlled'
What I need to do	*Spend time in hospice to allow doctors to review and assess pain management'*
What I need help with	*Doctors and nurses*
What if plan	*Not completed*

This example appears to have been written from the point of view of the professionals and results in an action plan where the patient is minimally involved and other people's roles and responsibilities are not clearly outlined.

iv. Hope theory (Snyder 2002)

There are three constructs from Hope theory (Snyder 2002) which are important in G-AP PC: *recognising one's worth*; *agency thinking* (initiating a goal and believing that it can be achieved) and *pathways thinking* (planning how a goal might be achieved). *Agency thinking* as a construct overlaps with self-efficacy, and *pathways thinking* is closely linked to Health Action Process Approach, although the emphasis in Hope theory is about recognising that

goals can become blocked and that people may need to find alternative ways to achieve goals, or set different goals altogether.

The question 'what's important to you right now' relates to *recognising one's worth*, and most professionals were comfortable about asking this question and documenting it, although, as I have said, some professionals found it difficult to distinguish between broad goals and more specific ones. There was evidence in the case notes that professionals and patients were involved in adapting goals and sometimes developing new ones as their situation changed (*pathways thinking*). This tended to happen during the action and coping stage of G-AP PC. Having a conversation about confidence (which relates to *agency thinking* as well as self-efficacy), who had responsibility for what, and anticipating what might get in the way of goal achievement seemed to help patients and professionals to think about adapting goals and sometimes agreeing on new goals (*pathways thinking*). Appraisal and feedback was also important for giving the patient and professional information about what was and was not possible. One patient wanted to be able to get into a wheelchair so that he could go outside with his grandchildren. In the action plan, pain was identified as something which might get in the way of him standing to transfer and tolerating sitting up. Plans were put in place to ensure that he was given analgesia before transferring from bed to wheelchair, and initially the patient achieved his goal. However, his condition deteriorated and later on he was unable to go outside, but it was documented that staff had moved his bed so that he could watch his grandchildren playing outside while he watched from the window. Having really listened to what was important to the patient from the beginning (*recognising one's worth*), staff were able to maintain this aspect of the goal so that, even when he was too ill to go outside, he could still enjoy watching his grandchildren having fun from his window (*pathways thinking*).

In palliative care, patients are often simultaneously engage in getting on with the practicalities of life whilst preparing for death. Several patients were concerned with both living and dying at the same time, and identified goals which were about 'affirming life' (e.g. 'getting back home', *patient 1*) whilst also planning for the future when they were no longer alive (e.g. 'support/help for wife when I die', *patient 1.*). Not all patients appeared to do this, but the process of asking patients what was important to them provided an opportunity to identify a range of different types of goal. Within G-AP PC, no explicit distinction is made between goals that affirm life and those that are about preparing for death. During implementation of G-AP PC, this appeared to happen naturally, but opportunities for preparing for death may have been missed, so a more explicit link might be useful in a future version of the framework.

7.9.4 Patient interviews

Data from patient interviews was analysed under three categories: *patient's goals; experiences of goal setting* and *evidence of G-AP PC constructs.*

i. Patient's goals

All patients interviewed were able to tell me why they had been admitted to the hospice and what their goals were. This had been the case in the first phase of this project (see Chapter 5.5.1) but last time, many needed prompting before they were able to tell me about goals. This time, patients spoke readily about the goals which they had discussed with hospice staff without any prompting from me:

> *"the goals- when I came in was – I was immobile when I came in and then they got me – sorted out. Pain free - and then we started to set goals after that."* (Pete)

Some of the goals were personal and based around activities that patients wanted to be able to do. Others were symptom or problem based (Table 57).

Table 57 Patient's goals

Symptom/problem based goals	Goals based around activity
"Well the main reason I came in was to get stabilised. Right. So – I think by the time I come out – I'll be stable." (Norman, 64 year old man)	*"they know I want to get back and see the dogs – and walk the dogs"* (Henry, 67 year old man)
"the main reason I came in was to get pain relief. And they seem to be pretty much getting on top of that now you know." (Sam, 80 year old man)	*"My goal has been to get some – err mobility back. To get back with the family. Get back home"* (Bob, 67 year old man)

There was evidence from the case note analysis that patent's goals had been pursued by the whole team, and patients talked about this during their interviews. For example, Henry's goal in his G-AP PC folder was to: *'get outside. To be able to get out to field next to house to watch dogs running around'.* During his admission, staff worked with Henry to help him with his mobility. He had practiced walking outside on uneven ground in preparation for going into the field behind his house. Whilst working towards his goal, staff had documented some safety concerns about him managing to walk his dogs as he was at risk of spinal cord compression. In spite of their concerns, staff still helped Henry to pursue his goal. During the process of practicing walking outside and discussing what might get in the way of goal achievement, Henry seemed to scale back his goal, as this excerpt from his interview suggests:

> *"I know I won't be walking like I used to. But I'll still be able to take them out into the field behind us – which is great –I'll be able to sit and let them run –um – and just get back, amongst the family."*

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Although able to tell me about his goals, one man (Alan) had not managed to convey to staff how important gardening was to him. He became upset during his interview, and showed me photographs of his award winning garden. When I asked him if he had been able to explore this during his admission, he told me that staff had been focusing on his mobility and in particular his ability to walk up and down stairs, which was limiting his options for going home. He told me:

"And I'd like to get walking in the garden. To have a look in the garden."

In Alan's case, opportunities for exploring what was really important to him appeared to have been missed. He seemed to be aware of the potential barriers for getting home, but also had his own action and coping plan:

"I'd like to go home – for even a day. – and see if I could – walk - up the stairs. I've got a bathroom up the stair and a bathroom down the stair. So I'm just wondering if I could do with that."

In Alan's case, use of G-AP PC had not led staff to identify and support him to work towards personal goals which were important to him. Acknowledging the significance of his garden may have resulted in a different outcome for Alan, such as a visit home to see his garden. Instead, staff focused on steps towards achieving a safe discharge which included being able to use the stairs. Although Alan wanted to go home, during his interview, his reasons for doing this appeared to be primarily linked to seeing and walking in his garden, which he may have been happy to just do just for a day. When I looked at Alan's case notes, his action and coping plan was professionally led, as it focused on practicing walking up and down stairs, with 'breathlessness' identified as something which might get in the way. This was a missed opportunity which seemed to have come about because staff had focused on Alan's goal from their own perspective. The importance of listening to the patient's point of view throughout

the goal setting process needs to be taken into account in training staff to use G-AP PC. A focus on Hope theory (and *recognising one's worth*, in particular) could help staff to reflect on this.

ii. Experiences of goal setting

Patients who took part in interviews talked about their experiences of goal setting within the hospice which they were able to relate their own experiences of goal setting, for example within their working lives in industry. They also talked about their attitudes to goals in everyday life.

Experiences within the hospice

When I interviewed patients before G-AP PC was piloted, patients felt that staff consulted with them prior to making decisions (Chapter 5.5.2), and this was also the case during the pilot study:

> *"I mean I've just had a conversation there with the doctor – about err – the level of medicine I should be taking, and yes, you are involved in it. You know – and you're quite happy. This extra bit. If you said no then they wouldn't do it. If you said yes, they'll go ahead. They're very good."* (Henry)

In addition to this, patients told me that, during their time in the hospice, they were at the centre of care rather than having to fit in with the routines of the hospice:

> *"It was very much patient focussed rather than – what would you say, organisational focused"* (Sam)

This is in contrast to last time when some patients felt that they had to 'fit in' with the hospice routines (Chapter 5.5.2), which some had felt restricted what they could and could not do.

Patients also felt that staff communicated very well between each other and that each member of staff seemed to know what they as patients were working towards:

Sally: "And do you feel that all the staff know what your goals are?"

Pete: "Well I haven't came across one that doesnae. Cause I think they have, I think they have meetings. Err handover meetings. I think they're well-versed, even if it's day shift, backshift or – they're just well-versed."

One patient commented on the informality of the goal setting process but also felt that there was a structure underpinning what was happening:

"Oh, there's a structure alright! - but they're very informal about everything. Um – there's a very strong structure actually." (Henry)

Another patient (Norman) felt that the extent to which staff talked to him about his goals depended on their status within the staff hierarchy:

"The senior ones asked you. Staff nurses and that. Nursing auxiliaries they just talked to you in general. But err – the doctor, she would come and talk to you." (Norman)

He also commented on how well staff seemed to communicate with each other:

"But the good thing I think is they've got a very efficient handover. I've not seen it – I don't know what they ask but they're up to speed. Because anything that's happened prior to them coming in – they know about it." (Norman)

I asked patients if they were aware of G-AP PC documentation and of paperwork being worked through and completed by staff. None of the patients had worked through the G-AP PC folders either themselves or with members of staff, but they did acknowledge the importance of keeping paperwork up to date:

"I think they do fill in bits of paper. I would imagine they would have a record of where I am. I would imagine – I would do that. If you've got ten people - you'd never remember." (Jack)

However, nobody felt that having and working through a goal folder would have been particularly helpful to them, and one person felt it might be counter-productive, given that things might change quickly:

"No I don't think so. Because you're involved - anyway. You know what the plan is – and the only reason for having a written plan is that – if they're deviously going to do something else rather than what they're saying – no, you don't need a plan. And apart from everything else, things can change so quickly – you know – you know so, no."
(Henry)

From the interviews it is evident that patients were aware that goal setting was happening in an informal but structured way within the hospice. Patients appeared to like this approach and did not see any benefits to using a goal folder and having goals written down so that they could refer back to them.

<u>Attitudes to and 'real life' experiences of goal setting</u>

Several of the patients I interviewed believed that goals were very important within their everyday lives, regardless of their illness. Sam told me how he had been a 'goal setter' all his life:

"So, you know, goal setting – I think it's essential in life for God's sake, you know. Um. It's something we've always done." (Sam)

He told me how he had continued to set goals during his illness:

"when I was first diagnosed, we knew there'd be an operation and that sort of thing. And each year we set a goal. And the most recent one was to – in March I was entering my 81st year. So – that had been a goal and other bits before." (Sam)

Others related their experiences of goal setting in the hospice to their working lives. Jack told me that he was aware of the importance of handovers to support communication between members of staff:

"I was an engineer and a works manager. Onsite - You had to be on the ball, and everything had to be spot on. I had good handovers. I would do handovers to three or four people. They had to be on the ball. And at the handover you had to make sure they all understood what was expected of them. That's what the handover was" (Jack)

Pete had used goal setting when he had worked in industry and he compared this with the goal setting he had experienced during his hospice admission;

"I think the system they've got's an excellent system. And I've worked through all these systems all my life anyway. When I worked in the refineries and err - you've got all these – goals - It's similar, it's similar, but this is in the medical setting. It's a similar thing." (Pete)

Norman had thought about the connection between goal setting in his working life and goal setting in healthcare in some detail prior to our interview. He explained that he felt that the whole team should be involved in supporting patients to achieve their goals:

"it's – taken me a wee while to think about what I was going to say but you tend to – when you're talking about goals, you tend to think about you and your boss. If you think about you and your doctor. But, to be able to achieve or look for the support – that's where the auxiliaries come in." (Norman)

Norman was able to explain goal setting theory, and the 'just right' challenge to me:

> *"And if they're too easy to achieve, folk switch off. So the secret is getting one that's*
>
> *challenging. That's what I think anyway."*

He also believed that goals should be achievable, but that the process of setting goals should involve an element of negotiation which should motivate people to try harder in relation to goal pursuit. Norman described Goal Setting Theory to me (Figure 44).

Figure 44 Norman's account of Goal Setting Theory

"Aye. I think they should always be achievable. Cause if you think they're not achievable, and you're not getting the success at the beginning, they're a waste of time. You get into that negative mindset. Right. And I've seen it. I've seen guys – they'll say 'this'll never work'. Or 'we did this twenty year ago – what are they coming away with now?' So you've got to prove to them. The best way to prove to them – is to actually sit down and talk to them and say – 'look, what do you think?' Great seeing you achieved something that was set. Do you think you can do better? 'Aye, I could do better if I had more time.' 'I could do better if I got' 'I could do better if you do it a different way. Instead of wasting my time doing this.' Then it's up to you to say – well, if I did this, would you achieve more? And then you put the measure in - Cause what you're doing is you're taking away one of the negatives. Which they're suggesting."

Norman used information about his symptoms to constantly appraise where he was in relation to his illness. As the person experiencing the symptoms, he felt that he was an integral part of the team and he was able to use information to work out possible solutions to problems that he encountered. He told me how he had worked out a different eating pattern to help him with problems that he had with breathing:

"Cause it puts pressure on my diaphragm. And with my diaphragm being so weak –

that's a major issue. So if I eat - my breathing goes a bit heavier and if I drink, that's

the same thing too. But what we've discovered here, and I'll take this home. If I eat

more at lunch time, and take some medication in the afternoon and have a lighter

evening meal, it makes it a lot easier for me at night."

Several of the patients I interviewed had direct experience of goal setting in their working lives, and use of a goal setting framework appeared to be something which they could understand and actively engage with.

iii. Evidence of G-AP PC constructs

Some comments which patients made during interviews can be mapped to the individual constructs which underpin G-AP PC. For example, Sam talked about a change in his attitude which he believed had come about during his stay in the hospice:

"it's sort of motored me to get off up my backside and get going again. You know

before, at home, only since about May – life was pretty active up until then. Err – M

was saying – are you going to get showered and I would say 'after lunch time'. And

that regime's finished – when I get home I'll get showered at a normal time. And err –

sitting about on your backside can cause muscle pain – you've got to exercise the

muscles, so as I say, I'm already working out my – I've done a tactical evaluation of

the situation, of what I'm going to change….working out what I'm going to do then

you know." (Sam)

Whilst in the hospice, Sam had worked towards goals which were initially symptom based (to reduce pain), but later focused on him being able to enjoy his hobbies such as reading and photography. By the time he was discharged, Sam's motivation seemed to have increased and he was ready to take charge of his own goals:

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"It's essential I do – because if I don't nobody else is going to make them for me – you know. And it's also essential that with a very good motivation here, I use it. If you sit back and feel sorry for yourself, - I would have died about 40 years ago!"

I asked patients if staff had asked them how confident they felt about achieving their goals. Not everybody remembered being asked about this:

Sally: Did – has anyone sort of asked you how confident you feel about achieving the goal of getting things a bit stable – a bit more stable?

Norman: Pause. I don't think I've had that question.

However, when I asked one patient (Bob) about this, he reflected on it and told me that there was a difference between what he thought he could achieve and what staff felt:

Sally: Has anyone asked you how confident you're feeling about your mobility goal?

Bob: Well Dr XX – she understands what I'm after. What I'm after may not be obtainable – sort of, attainable. But what I want to do – what I can do – might be two different things.

He also said: "*They're probably more realistic than myself*"

When he spoke to me, Bob was aware that he was less realistic than members of staff and the 'confidence' question prompted him to talk about this. His goal was to be able to walk again, and staff felt that this was unrealistic. In spite of this, they did support Bob to work towards his goal of walking. He later scaled this back and accepted use of a wheel chair:

"Disappointed I won't walk again but relieved pain better controlled now." (from appraisal and feedback section in case notes)

Patients appeared to be aware of action plans that were made with staff to help them achieve their goals. Henry seemed to be happy to go along with plans that staff made, preferring not to get involved in planning himself:

> *Henry: I've no plan.*
>
> *Sally: No?*
>
> *Henry: No. I'm not the planning type. They've got a plan. They've got a plan! Oh aye, they've got a plan to get me out of here.*

He was happy to go along with plans that professionals made:

> *"they have a plan and err and whatever their plan is, is fine with me."*

Pete took more of an active part in his plan and told me how the plan was developing as he made progress:

> *"I was aware of the plan. Well, when they were talking about - the first stage of the plan was to try to get me a little bit of mobility. Which I've now - I've now achieved. Obviously the next part of the plan is to get me back to my own environment. Which is better off for me and for everybody." (Pete)*

There was evidence that patients used information gained from feedback about goal achievement and that they adapted their goals in light of this. Alan appeared to be rethinking his plans for going home:

> *"But it's the getting home. I would have to have a lot of people helping me at home – I would need someone to get me up in the morning early – and get me dressed – That's a different story. When you're on your own, yourself." (Alan)*

Pete told me how he had talked to staff at the hospice and had not only thought about how he was managing just now, but had also made arrangements for the future, after he had died, which he appeared to be satisfied with:

> *"But the positive side is that we can try and make life a wee bit easier – until the time comes. She made me realise all that. She also made me realise – to get things done – all set up. To look after my family, when I'm no here. So I've managed to do all that."* (Pete)

Patients told me that staff regularly reviewed their goals, but that this happened in an informal way:

> *"Well – people do actually, you know, but not always in a direct way. Quite often, you could have a conversation with one of the staff and all of a sudden you realise that it wasn't a chance conversation. It had been a detailed way of questioning."* (Henry)

Patients appreciated the fact that staff spoke to them on a daily basis and kept them informed about what was happening. One patient felt that this made him feel valued:

> *"A doctor comes in, not only to tell me what's going on, and also, to pass the time of day. Oh and that makes you feel a human being rather than a piece of what would you say – goods. So – I think that's where the great success lies."* (Sam)

Patients valued being part of the goal setting process and as a result felt they were at the centre of the care they received. Although the process was informal on the surface, patients were aware that there was a structure underpinning it which included goal negotiation, action planning and review. Patients used their own experiences of goal setting in their everyday lives to engage in the process and this seemed to motivate them to work towards goals.

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7.10 Limitations

The aim of this phase of the study was to implement and evaluate the acceptability and feasibility of use of G-AP PC in one hospice setting. I endeavoured to obtain the views of a range of staff and patients through the use of semi-structured interviews and a questionnaire for professionals. One of the main limitations of this study is that I only managed to interview male patients and I did not reach my target of ten interviews. This means that I have a restricted range of views from the patient's perspective. A larger number of interviews, including women may have provided different opinions, and this should be considered in future evaluations of G-AP PC. It would also be interesting to find out what families of patients involved in goal setting at the hospice think about the process, and again, this should be considered in future evaluations. I interviewed a representative group of staff in this study, but only one auxiliary was included in the sample. Having carried out my analysis, it would be useful to get the views of other auxiliaries, as this group seem to be the most resistant to actively using G-AP PC in practice.

7.11 Discussion

In this section I revisit the research questions and discuss my findings in relation to them. I then discuss the nature of goals set using G-AP PC, referring to the WHO ICF framework (WHO 2001).

RQ 1 How feasible is it to use G-AP PC as part of routine care in a single hospice setting?

a.   Which patients can G-AP PC be used with?

Over the three month implementation period, data was collected about who G-AP PC could and could not be used with. G-AP PC folders were completed with 31 patients. An additional four patients reportedly had folders, but these were unaccounted for. Originally I had anticipated that G-AP PC would be most suitable for use with patients who were admitted for

symptom control, and were therefore most likely to go home. In practice it was used with patients who were actively dying as well. Using G-AP PC, professionals asked patients what was really important to them. This opportunity to *recognise ones worth* (Hope Theory, Snyder 2002) prompted professionals to focus on patient's priorities and helped them to support patients to do the things that really mattered, even when they were very ill. An example which illustrates this is the woman who went out for lunch, then shopping with her daughter, two days before she died (Chapter 7.9.3, Figures 41 and 42). In this example, professionals found out what was important to the patient and her family, then used the action and coping plan to identify possible barriers to goal achievement, and put plans in place to overcome them. This combination of finding out what was important and proactive coping and planning increased everybody's goal related behaviour and meant that the patient, the family and the multidisciplinary team all worked together to support goal achievement. The original purpose of including constructs from behaviour change theory in G-AP PC was to increase patient's motivation and goal related behaviour. However, in practice, the process of identifying what mattered to patients prompted the whole team to direct their energies towards goal achievement. Explicit discussion of possible barriers and solutions (HAPA, Schwarzer 2001) gave staff, patients and families clarity about who was doing what and resulted in plans being put into action, often within very short timescales.

Although G-AP PC could be used with a wider range of patients than anticipated, professionals found that they could not use it with people who had severe communication or cognitive problems, as it was difficult to engage them in discussions about goals. This is an area which could be explored in a future study, as potentially, adaptations could be made to the framework to help this group of patients participate in goal setting.

b.   *How is G-AP PC documented in practice?*

In practice, the majority of professionals who engaged in G-AP PC used the paperwork successfully. Because goals were written down in one place, it was easy to find and track each patient's goals, and this supported a team approach to patient centred goal setting. However, some problems with the documentation were identified, and adaptations could be made to make it easier to use. During the implementation, each patient was given a goal setting folder which was kept by their bedside. The original intention was that patients would look at and refer to this during discussions with staff. In practice, this was never done. Patients did not feel that it was important to have written goals to refer to, partly because they already felt very involved in the goal setting process and partly because they were aware that things might change rapidly. In practice, professionals found having a separate goal setting folder problematic. The folder was often moved which meant that people could not always find them when they wanted to write in them. Some professionals felt that writing in the folders was duplication, as they wrote their notes somewhere else. This meant that not all staff evidenced work that they were doing to support patient's goal achievement. Given that patients did not see any benefit in having a separate goal folder, it might be better to integrate the G-AP PC documentation into the main case notes.

Some professionals felt that they needed to be reminded to write in the goal folder, and said that they would benefit from having formal triggers to prompt them (for example, having goal setting on the agenda at each handover meeting). There was evidence that some staff were confused by some of the questions in the goal setting paperwork, particularly the first two questions (*'what's important to you right now'* and *'what do you want to do in the next wee while?'*). It may be possible to merge these two questions in order to avoid confusion, but training will be needed to ensure that people negotiate wider goals into more specific ones (and thus incorporate Hope theory, Social Cognitive Theory and Goal Setting theory) when using a modified question.

G-AP PC was successfully implemented and used over a three month period by a range of professionals in the hospice, suggesting that it is feasible to use in practice. This success relied heavily on Anne, the team leader, who became the champion for goal setting during the project. The role of local champions as agents for change and innovation has been promoted in the healthcare literature over the last decade (Ploeg et al. 2010, Thompson 2006). According to Thompson, "*champions adopt programmes, ideas or projects as their own and relentlessly promote them*" (Thompson 2006:695). During the implementation period, Anne embraced this role and she took responsibility for encouraging all members of the multidisciplinary team to use G-AP PC. Identification and recruitment of local champions would need to be prioritised in a future evaluation of G-AP PC.

RQ2 How acceptable is G-AP PC as a method of eliciting patient's goals, from the professional's perspective?

Use of NPT (May 2010) provided a structure for thinking about how G-AP PC was implemented in practice. Professionals involved in this project were able to make a distinction between use of G-AP PC and 'usual practice' and could see benefits of using this framework in relation to:

- Supporting a team approach;

- Shifting their attention from *symptoms/problems* to patients *goals*;

- Providing the team with a focus which helped them to act on what patients wanted to achieve;

- Providing written evidence of what they were doing with patients.

Although there was a high level of agreement that G-AP PC 'made sense' to professionals (coherence), some staff believed that it was something that they already did or they did not believe that using G-AP PC was part of their role. In a future implementation project, it would

be worth examining the role of each member of the team and exploring their attitudes and values in relation to patient centred goal setting and use of G-AP PC in particular.

Some staff reported that they found the confidence rating question difficult to ask, although in practice, this part of the paperwork was filled in. However, there appeared to be little correlation between a patient's confidence rating and goal achievement. In palliative care it can be difficult for patients and professionals to predict how well they are going to feel in the next hour or day, therefore making it difficult to rate confidence in relation to goal achievement. It may be more appropriate to ask patients to rate goals in relation to 'importance'. This is an area which requires further investigation. Apart from the confidence rating scale, the majority of professional's found G-AP PC acceptable to use in practice and reported that it increased their ability to work as a team and resulted in positive outcomes for patients and their families, including those who were imminently dying. In spite of this, G-AP PC was not used by the whole multidisciplinary team. This is an issue which would need to be addressed in a future implementation study, and could be done through training (cognitive participation) and putting mechanisms in place to support goal centred discussions with the whole team (collective action).

RQ 3 How acceptable is G-AP PC as a method of eliciting goals, from the patient's perspective?

Patients were aware of and were actively involved in the goal setting process during the implementation period. In interviews, patients readily told me about the goals that they were working towards and knew the part that they had to play in the process. Patients commented that they felt they were at the centre of their care and were aware that professionals were using a structured approach to goal setting which involved goal negotiation, action planning and review. They felt that this informal yet structured approach worked well and that

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professionals listened to their views and encouraged them to work towards their goals, even when there was a difference in opinion about what was and was not realistic. In spite of this, one patient implied that opportunities had been missed to find out what was really important to him, which resulted in his goal being at odds with the professional's goal. Patients did not feel that they needed a separate goal folder and were happy for professionals to document goals in their clinical notes. Patients felt that setting and achieving goals helped to increase their involvement in their care and also increased their own motivation to do things. The patients I interviewed were all familiar with the process of goal setting (they either set goals as part of their everyday lives or had used goal setting in their working lives). They felt that the goal setting process used in the hospice was applicable and useful in this setting.

Use of G-AP PC and WHO ICF

In chapter two, I provided an overview of the WHO ICF framework (WHO 2001), an illness model which underpins rehabilitation (Wade 2005). Currently, this framework is not widely used in palliative care. Given that it provides a framework to help professionals work holistically with patients to think about the impact of illness and disability on everyday life, it could be used to underpin rehabilitation in palliative care settings. In chapter 2.4.1, I described how the WHO ICF (WHO 2001) provides a structure to help people to consider goals and interventions at different levels (for example, they may be targeted at the level of impairments, activities, participation or the environment). Personal factors can also be taken into account.

In the first phase of this research (Chapter 4.6), professionals predominantly supported patients to work towards impairment based goals which were around managing patient's symptoms and problems. Patients themselves (Chapter 5.5) worked towards both impairment based goals (for example, trying to reduce pain) and goals based on activity (for example, walking) and participation (using the computer to have a conversation via Skype with a

brother in Australia). Patients did not always talk to professionals about their goals and as a result, opportunities for supporting patients to work towards activity and participation-based goals were missed. The process of using G-AP PC, particularly the goal negotiation stage, helped professionals to find out what was important to patients, thereby making goals more specific and personal. Having an explicit, formal approach to goal setting helped them not only to focus on impairment-based goals (such as getting pain under control) but also to focus on activity-based goals (for example, *what do you want to be able to do if we can control your pain better?*), as this excerpt from the case notes illustrates:

'Pain to be better managed to allow me to concentrate and enjoy hobbies.' (Patient 8)

As patients deteriorated and became less able to take an active part in working towards goals, professionals took on a more proactive role in supporting them to participate in activities. For example, Wendy told me about the patient who wanted to hear his friend play the bagpipes, a goal which he achieved. As he deteriorated, staff took time to adjust his environment by putting music on for him in his room. Even when he could no longer actively participate in achieving his goal, the patient and his family were made to feel that they mattered and that they had been listened to. The process of finding out what was important to the patient and his family helped staff to consider him as an individual and resulted in person centred care, even when he was dying.

7.12 Summary

G-AP PC has been successfully implemented in an in-patient hospice setting where it has been used by staff to engage patients in setting and working towards personal goals which are of importance to them at the end of life. During this evaluation I have identified practical challenges which were encountered when staff used G-AP PC in practice and have pinpointed changes which could be made to the framework to make implementation more successful in

the future. Since the implementation project, use of G-AP PC has been taken up by the whole in-patient unit within the hospice. I have continued to work with a group of staff to help them take this forward and a programme of education has been set up to help ensure that staff understand and use the intervention. There are plans for use of G-AP PC to be rolled out to other parts of the hospice (day care and home care).

In the next chapter I bring together findings from the literature (Chapters 2 and 3), the first phase of the study (Chapters 4 and 5) and the implementation of G-AP PC (Chapters 6 and 7). I discuss these in relation to the MRC framework for developing and evaluating complex interventions (Craig et al. 2008) and the implementation literature in order to inform future development, use and evaluation of G-AP PC.

Chapter 8 Discussion and conclusions

8.1 Introduction

I embarked on this project as a practicing speech and language therapist, interested in research that could be used in clinical practice to help address the issues that arise in day to day clinical settings. Inspired from my clinical work with people with rapidly deteriorating conditions such as MND, Multiple Sclerosis and brain tumour, I have used a real world research approach (Robson 2011) to investigate and develop goal setting practice in palliative care. I have experienced first-hand the challenges of balancing the goals of patients, families and professionals and am aware that, as illness progresses, it can become increasingly difficult to genuinely listen to and act on the wishes of the patient.

Dame Cicely Saunders' original vision of palliative care was that it would enable people to *'live until you die'* (Saunders 2006:xxiii) and these values continue to underpin palliative care today (WHO 2007). However, in modern palliative care, the practicalities of balancing treatment and supporting people to live whilst dying can be difficult to do. Rehabilitation and goal setting are seen as important mechanisms to help people do this (National Cancer Action Team, 2009, NICE 2004, NCPC 2000), but to date, little attention has been paid to how they are understood and delivered in practice in palliative care. The research presented in this thesis has been designed and undertaken with the express aim of reducing this knowledge gap, and implementing an evidence and theory-based goal setting intervention in palliative care.

8.2 Aims, objectives and summary of main findings

The studies within this thesis are placed in the 'development and feasibility' phases of the MRC framework for developing and evaluating complex interventions (Craig et al. 2008). My overarching aim was to investigate, inform and develop goal setting practice in palliative care.

I conducted the research in three stages, each of which had its own specific objectives; in stage 1 I conducted a structured literature review in order to:

1. Find out the range and quality of the published literature on patient-centred goal setting in palliative care;

2. Identify the main themes contained within this literature in relation to patient centred goal setting;

3. Identify the conceptual or theoretical basis underpinning goal setting in palliative care.

The review showed that goal setting is an important and relevant aspect of palliative care but there was little agreement on what goal setting is, what it does or how it should be delivered. It was widely acknowledged that one of the main challenges for patients and professionals working in palliative care is that they are dealing with deterioration and unpredictability. I identified Hope Theory (Gum and Snyder 2002) and Bye's framework of Affirming life: Preparing for death (Bye 1998) as possible theoretical/conceptual underpinnings that were relevant to goal setting in palliative care settings and had the potential to be integrated with existing goal setting literature.

In stage 2 I used two approaches to investigate current goal setting practice in one hospice setting. This stage had three specific objectives:

1. Find out how goal setting is delivered in practice to patients in a hospice setting;

2. Find out multidisciplinary staff team members' experiences and perceptions of goal setting as an intervention for patients who are admitted to the hospice;

3. Find out the expectations, experience and perceptions of patients who are admitted to the hospice with regard to goal setting.

I found that goal setting in palliative care was regarded as important by both professionals and patients alike, but the process was an implicit, unstructured one. There was no agreement about how goal setting could be structured and delivered within the hospice where this research took place and documentation of goals was variable. As a result, opportunities were sometimes missed to help patients identify and work towards goals which were important to them. Professionals tended to focus on symptoms and problems (impairment based goals) rather than what patients want to 'do' (goals based around activity and participation). Professionals and patients both linked goal setting to hope and tried to strike a balance between working towards goals which are about living as well as those that are about dying.

In stage 3 I developed and undertook a preliminary evaluation of a goal setting and action planning framework for use in palliative care. I had two specific objectives:

1. Based on findings from stages one and two of the study, develop a theory based Goal setting and Action Planning framework for use in Palliative Care (G-AP PC);

2. Investigate the feasibility and acceptability of using G-AP PC as part of routine care in a single hospice setting, from the point of view of:

   a. Professionals

   b. Patients.

I used Scobbie et al's G-AP framework from stroke rehabilitation (Scobbie et al. 2011, Scobbie et al. 2009) and the findings from stages one and two as my starting point for the development of the Goal Setting and Action Planning in Palliative Care (G-AP PC) intervention.

I used a participatory approach to engage with the task group and Normalisation Process Theory to structure and analyse discussions (May 2010). There was strong agreement that the theoretical underpinnings of G-AP 'made sense' (coherence) to palliative care professionals.

They also felt that Hope theory (Gum and Snyder 2002) and Bye's framework of 'Affirming life: preparing for death' (Bye 1998) were important additional theories for use in palliative care. G-AP PC (see section 6.5.1, Figure 22) was developed and presented to the group who provided critical comment on how it could be used in practice. At this stage, discussions focused on documentation and procedures for making the framework workable in practice (cognitive participation). Task group members also drew on their clinical experiences and use of G-AP PC in practice and within role play scenarios to agree on what should be included in training prior to implementation of G-AP PC over a three month period within the hospice (collective action). The task group informed the evaluation of G-AP PC, in particular suggesting that it should be used by a whole team and that all patients (if able) should have the opportunity to use the framework to identify and work towards goals.

Findings from my initial evaluation of the implementation of GAP-PC (see Chapter 7) show that patients and professionals found the intervention both acceptable and feasible. It helped professionals to:

• Work together as a team;

• Shift their attention from symptoms/problems/risk to patient's goals for living (or doing);

• Have a focus which helped them to act on what patients wanted to achieve within short timescales;

• Provide written evidence about what was important to patients, what they wanted to achieve and how they were going to do it.

Patients appeared to value being part of the goal setting process and felt they were at the centre of the care they received. Although the process was perceived as and appeared

informal, patients were aware that professionals were using a structured approach that included goal negotiation, action planning and review. Some patients used their own experiences of goal setting in their everyday lives to engage in the process and this seemed to motivate them to work towards goals.

Implementation of G-AP PC was not without its problems. The organisation and location of paperwork proved to be a particular challenge for staff. In addition, not all staff engaged with use of the framework, some because they felt goal setting was not part of their role, and others because they felt they already delivered it in practice. During implementation of G-AP PC, a senior member of the ward nursing staff took the project forward and became the 'champion' for implementing G-AP PC within the ward (Campbell et al. 2006). Her participation as an intervention champion was fundamental to the success of the implementation within the ward setting.

8.3 Reflections on implementation of a complex intervention into a 'real world' situation

The MRC framework for developing and evaluating complex interventions (Craig et al. 2008) provided a structure for the logical development of this intervention, which was successfully implemented and used in the hospice. This, combined with use of NPT before and during the implementation meant that potential barriers to implementation could be identified. I suggest that use of these two frameworks contributed to the successful implementation of this intervention for the following reasons:

1. I was able to explain to staff why the intervention had been developed (using evidence from the literature review and the research carried out at the hospice). The majority of staff were convinced by this research evidence and agreed that goal

setting was important but that a theoretically based framework would help support more consistent patient centred goal setting by the whole team.

2. Having identified candidate theories/frameworks to underpin the goal setting process, I was able to provide staff with explanations about each theory and gave them examples of how each theory might work in practice. I used vignettes from the hospice research project to make it applicable in practice and also gave staff the chance to try using G-AP PC through the use of role play. I felt that this was important as it helped staff to understand the basis of what they were doing and why.

3. Staff had the opportunity to discuss and contribute to the development of G-AP PC. They agreed that the constructs included in the framework 'made sense', and made suggestions about how it could be used in their particular setting (for example, use of the prompt card, wording of the questions for each stage of G-AP PC). Use of NPT made it possible for me to look at different aspects of the implementation process systematically in relation to coherence, cognitive participation, collective action and reflexive monitoring.

In addition to this Anne, the 'champion' for G-AP PC was instrumental in sustaining its use during and after the implementation project. Since the implementation project, I have carried out training with other teams in the hospice and G-AP PC is now being used by all three teams within the in-patient unit.

8.4 Methodological issues

8.4.1 Strengths

In this study I have developed, implemented and evaluated a research base goal setting and action planning framework for use in palliative care. I have used a flexible, pragmatic approach, using a range of qualitative research methods at different stages, depending on the

research questions. G-AP PC has been rigorously developed and implemented and an initial action-oriented evaluation of its implementation has resulted in a complete reorganisation of direct clinical practice throughout the in-patient unit in the hospice where this research took place. Consequently the hospice is now moving away from its focus on problem and symptom management, to a truly patient-centred agenda which places an emphasis on supporting patients to achieve what is important to them in the final period of their life, thus fulfilling its aim of supporting people to live their life to the full whilst dying.

In October 2013, I was nominated by the hospice for the Scottish Healthcare Innovation Award (Scotland's most prestigious health care award ceremony) for which I was shortlisted as a finalist. This reflects the value that the hospice places on this research and suggests that G-AP PC has brought a change in practice and knowledge that is valued by clinicians and patients alike.

Throughout this research, I have endeavoured to make the processes I have used as transparent and rigorous as possible. In the *literature review*, I used a structured approach to try to ensure that the process of searching and identifying the literature was transparent and replicable (Petticrew and Roberts 2006, Arksey and O'Malley 2005). In my *investigation of current goal setting practice* in the hospice, I used a case study approach (incorporating observation, semi-structured interviews and case note analysis, (Yin 2009). This allowed me to collect data from different sources and make comparisons between what professionals did in practice, what they said they did and how they documented goals. Having collected data from different sources, my challenge was to analyse and synthesise them. Framework analysis (Ritchie and Lewis 2003, Ritchie and Spencer 1994) provided me with a structure that was systematic and allowed me to refer back to the original data sources. This helped me to continuously check that my themes had arisen from the data rather than being influenced by my own thoughts and judgements. My supervisors also checked and discussed my coding

during this process and always questioned 'how I knew what I knew'. In addition to the case studies, I conducted semi-structured interviews with patients to find out about their perceptions and experiences of goal setting during their in-patient admission. Gathering and analysing data from different sources meant that I could find out about goal setting from the perspective of patients and professionals alike. This enabled me to consider goal setting in different ways, which informed the development of the intervention. For example, in their interviews, patients predominantly talked about activity based goals, whereas staff focused on symptoms and problems. This difference became an important focus when I developed the intervention, and may not have been identified if I had not interviewed both patients and staff.

I used an existing goal setting framework (Scobbie et al. 2011, Scobbie et al. 2009) as a starting point to *develop the intervention* for use in palliative care. During this stage I used a participatory approach (Froggatt and Hockley 2011) so that I could work closely with staff to find out about issues that were relevant to them. This approach allowed me to integrate information from theory/frameworks with experiential knowledge from experienced palliative care practitioners, thereby increasing the likelihood that the intervention would be useful in a clinical setting. Use of NPT (May 2010) to structure and analyse discussions helped me to identify potential barriers to implementation, which was crucial preparation for the implementation and evaluation stage of the research. During the *evaluation of G-AP PC* I endeavoured to obtain the views of a range of staff and patients through semi-structured interviews with patients and professionals and a questionnaire for professionals. I also analysed and extracted data from patient's goal folders. This again provided a range of perspectives and data about the acceptability and feasibility of using G-AP PC in practice. These insights from different data sources provide information which can be used to inform future iterations of G-AP PC.

8.4.2 Limitations

There are, of course, limitations associated with the different methods which I have used. In the *literature review*, it was particularly challenging to identify, analyse and synthesise a very diverse body of literature. Much of the challenge lay in integrating insights from a few good quality studies with several poor quality ones or brief conceptual articles which still provided some insight into goal setting in palliative care. I overcame this by using a structured approach to analysing themes from the literature. I acknowledge that this process is quite subjective and that other researchers may have drawn out different themes. Again, as in all qualitative research, I tried to minimise this potential weakness by including others in the process of analysis.

One of the major limitations of the research is that it was undertaken in only one hospice and the framework was developed by mainly keen professionals committed to trying a new approach to goal setting. There is no way we could assume G-AP PC is appropriate for use in other settings without further research.

Having said that, I hope that further research will be possible because, having presented my work at palliative care conferences (Palliative Care Congress and European Association of Palliative Care Conference), I have received feedback from delegates that suggests that the findings resonate with them. Furthermore, the intervention is based on general psychological theories. There is reason therefore to believe that this research is potentially transferable to other hospice settings. The next logical step would be to evaluate G-AP PC in other settings (see section 8.5).

Whilst evaluating G-AP PC from the perspective of patients, I only managed to interview male patients and I did not reach my target of ten interviews. A future evaluation of G-AP PC in another setting should aim to address this, ensuring that interviews are conducted with a

larger number and a more diverse group of patients and also that outcome measurement is attempted. It would also be interesting to find out more about the perspectives of auxiliary staff, who I found particularly resistant to using G-AP PC in practice.

8.5 Adaptations for future iterations of G-AP PC and implications for further research

During the evaluation of G-AP PC, I encountered some practical difficulties and changes were suggested which will make the intervention more useable in practice. Professionals found it difficult to distinguish between the first two stages of G-AP PC (goal negotiation and goal setting). They really valued use of the question *'what's important to you right now'* but found that asking the next question (*'what do you want to do in the next wee while?')* led to confusion and repetition. A future version of G-AP PC should merge these two questions to avoid this, but training would need to emphasise the importance of using Hope Theory (recognising one's worth, Snyder 2002) and Goal Setting Theory (setting specific, difficult goals, Locke and Latham, 2002) during the goal negotiation process.

Many professionals reported that they omitted the 'confidence' question when they were delivering G-AP PC. They did not feel that it added value to the process, partly because patients were unsure of their own capabilities and what the future held for them. Although some professionals did ask patients to rate how confident they were about achieving goals, in practice there was not a good match between a patient's confidence rating and goal achievement. It might be better to ask patients to rate their goals in relation to *importance* (based on Hope Theory, Snyder 2002). This might have the effect of increasing the whole team's (including the patient's) motivation to support goal achievement.

Although Bye's framework for affirming life and preparing for death (Bye 1998) was incorporated into G-AP PC, professionals did not always think about this explicitly when

setting goals with patients. More emphasis on this in training sessions may help professionals to support patients to consider goals which are about living as well as goals that are concerned with preparing for the future after they have died. In addition to this, during the implementation, it was not possible to use G-AP PC with all patients, particularly those with severe communication or cognitive difficulties. Including this group of patients is an area which should be considered in a future iteration of G-AP PC. Communication support materials could be developed to help this group of patients take part in discussions around goal setting. A starting point for this work would be to explore use of an established communication framework (Talking Mats: Cox et al. 2008, Murphy et al. 2007) alongside G-AP PC. Talking Mats is a communication framework which uses sets of symbols on a mat or digital space to help patients consider issues one at a time and prioritise areas of importance. This framework is widely used in clinical practice by a range of rehabilitation professionals to help patients with a range of cognitive and communication difficulties identify problems as part of the goal setting process. Symbol sets have been developed, based on the WHO IFC framework (WHO 2001, Murphy and Boa 2012). Use of these symbols would provide a basis for exploring the feasibility of using G-AP PC with this group of patients.

G-AP PC was successfully implemented in the hospice where this research took place, and is now being used by all three teams within the in-patient unit. This study has shown that it is acceptable and feasible to use G-AP PC in an in-patient hospice setting, from the perspective of professionals and patients alike. The next logical step is to test its use in other palliative care settings. G-AP PC could be implemented by several diverse teams. Each team would need to undergo training in use of the intervention and its theoretical underpinnings. Local alterations regarding the 'form' (Hawe et al. 2004) of delivery of the intervention would need to be made (for example how the documentation is organised, the mechanisms put in place to help staff work together as a team to go through each stage of the process). However, the

'function and 'process' (Hawe et al. 2004) of the intervention and associated components (the G-AP PC framework itself and the theories that underpin it, the elements of the training and the local champion) would remain the same.

Prior to a future evaluation of G-AP PC in other settings, reliable and valid outcome measures should be identified so that the effects of using G-AP PC can be evaluated. Given that use of G-AP PC seems to improve patient centred care and participation, potential outcome measures which could be explored are:

a) the Consultation and Relational Empathy (CARE) measure (Mercer et al. 2004). This is a patient reported measure which measures empathy in professional-patient consultations. Use of this measure would provide information about how much patients feel they are listened to in interactions with professionals;

b) a patient reported Health Related Quality of Life measure. A wide range of these measures exist, so time would need to be spent to identify the best one to use with a palliative care population;

c) the Therapy Outcome Measure (TOMs) (Enderby et al. 2006), a measure completed by professionals which measures the impact of disease on a person's impairment, activity, participation and well-being.

8.6 Conclusions

In this project I have worked closely with patients, hospice staff and my PhD supervisors to develop an innovative yet practical research and theory-based intervention that supports patient centred goal setting practice. I drew on existing theories and research on goal setting in rehabilitation and actively collaborated with a multidisciplinary group of professionals at the hospice to develop G-AP PC. The intervention was found to be feasible and acceptable to both hospice staff and to patients. Using this intervention, professionals changed their focus

from symptom and problem management to finding out what patients wanted to be able to 'do' if their symptoms were better controlled. The nature of goals became less focused on impairment, more personal and focused on activity and participation, so that patients were more able to live actively until they died. The act of finding out what was important to patients seemed to work as a mechanism to motivate professionals to work together as a team to support patients to achieve their goals, often within very limited time scales. When patients were rapidly deteriorating, professionals were able to retain a patient's sense of identity so that, even when they were no longer able to actively work towards goals, their original wishes and hopes were still considered. In essence, use of a theory based goal setting and action planning framework helps professionals to achieve Dame Cicely Saunders' original aspirations for palliative care:

> "You matter because you are you. You matter to the last moment of your life and we will do what we can not only to help you die peacefully but to live until you die"
>
> (Saunders 2006:xxiii)

Epilogue

Six months after the G-AP PC implementation project, staff in all three teams in the in-patient unit at the hospice continued to use G-AP PC. Over the six months, I have worked with staff and set up a training programme which was taken on by the education department of the hospice after I left. I had regular meetings with a team of 'goal setting' champions and they told me some of the goals which patients were achieving on a daily basis. I would like to finish with an example of a goal that one of the champions told me about.

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Figure 45 Goal setting using G-AP PC

Background:

Rowena, a woman in her forties with advanced metastatic disease, was admitted to the ward on a Friday. She was reluctant to come in, preferring to stay at home so she could be with her teenage children and husband, but agreed to be admitted 'just until Monday'.

Goal setting:

On the Saturday, Katie, the nurse working with Rowena asked her "what's important to you in the next wee while?" Rowena told her that she hadn't been able to have a bath for over 9 weeks, and that she and her mum had been trying to achieve this unsuccessfully at home. Katie felt very hesitant. She knew Rowena was very unwell and may not survive the bath. However, she also knew that this was really important to her and her mum, so she and the auxiliary put a plan together and helped her to have a bath. Rowena's mum came in and was able to spend time washing her back and helping her to relax. Throughout the time, Katie popped in and out of the bathroom, checking that everything was OK.

Once out of the bath, exhausted but elated, Rowena said she would like to go out into the grounds in a wheelchair with her daughter. Katie again had reservations and discussed these with Rowena –but she could see how important it was. Rowena and her daughter went out into the grounds for 52 minutes (Katie was timing it – such was the risk). They came back in and Rowena said goodbye to her daughter. Later that evening, Rowena said she was content to stay in the hospice. She knew that she was dying.

The next day Katie asked Rowena if her daughter was coming in. Rowena said that Saturday's excursion in the grounds had been her 'good bye' to her. Rowena died the next day.

Katie's reflections:

Katie used G-AP PC as she worked with Rowena. Because she had asked her the question 'what's important to you in the next wee while', she really had to listen and act on what she heard. Katie told me that, before G-AP PC, Rowena would have been tucked up in bed. She would not have had her bath or her trip outside because it would have been deemed too risky. Asking the 'what's important' question and then thinking through the action and coping plan meant that Katie listened to Rowena, made a plan, discussed the risks and made plans to address these. Knowing that these things were really important to Rowena meant that Katie was prepared to take risks. As a result, Rowena was able to spend quality time with her mother and daughter and was also able to live actively until she died.

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Appendix 1 (Example of observational field notes)

19.11.09

Janet phones me from the ward, as she is ready to speak to Dave, who has agreed to take part in the study. Dave is a 55 year old man with advanced metastatic disease. He was admitted to the hospice for symptom control or perhaps terminal care.

I go onto the ward (the same one that I was on this morning) and the curtains are closed around Dave's bed. I let Janet know that I have arrived, and pull up a chair. *Once again, I am on the other side of the curtain, so I cannot see what is happening. In some ways, not being seen frees me up to write as furiously as I can, even when the conversation becomes difficult. As far as Janet is concerned, there is no question that I should be an 'unseen' observer – I think she sees it as part of preserving the patient's privacy and dignity. I find it interesting that Janet is the first person who has done this automatically for her patients.*

As I sit down, it sounds as though Janet is carrying out some care with Dave. She asks Dave how he has been getting on. He tells her that he has had a lot of visitors. Janet asks "is it getting too tiring?" Dave says that it is "OK – I do sometimes nod off a bit". He also says that sometimes he tells his visitors that they can only stay for a short time. Janet indicates that she thinks this is a good idea "I'm sure they appreciate that". She then asks "How are you enjoying getting up to the sitting room?" Dave says that he likes the "change of scenery. I like the greenery – any greenery, it doesn't matter if it's wet greenery" *(it is pouring with rain outside today).* Janet agrees that she also likes green spaces, and then asks "how are you feeling?" Dave replies "not too bad – sometimes a bit knackered." He adds "it's just part of getting better. I'm not saying I'm super duper fit." He then talks about the pain that he is in "if they could control it". Janet asks "you saw the doctors this morning?" Dave says that he missed seeing them as he was in the sitting room with a visitor. Janet tells him that they have had a look at his drugs – "they're going to put the medicine in your pump up" (as Dave has

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been requesting a lot of break through pain relief). Dave says "thank goodness for that". He seems pleased that there is an option for his pain relief to be increased, and then says "A problem is – I seem to have this fixation with playing with my hearing aids." He says that he thinks this annoys the night staff as they keep taking his hearing aids away. Dave thinks this is because, when he fiddles with the hearing aids, they make a 'squealy noise'. He talks about the importance of having his hearing aids handy, in case he needs to talk to someone, but he is very aware of the fact that his 'fiddling' might be annoying staff and patients. Janet asks "Where would you prefer them to be?" She adds that she thinks the staff are worried that his hearing aids might get lost and that this might be a possible reason for staff taking them away. She says "I wonder if we got a wee box and put them here?" – I assume she is referring to putting them on his bedside cabinet, so Dave can still reach them if he needs them in the night. Dave says "right, OK". *He sounds pleased with this solution.* Janet assures him that she will pass the information on to the night staff, so they know what to do.

One of the other nurses comes up to the cubicle. She needs to pass the keys on to Janet, as she is about to go off duty. She is reluctant to interrupt the conversation, but I think Janet hears the jangle of the keys, so she excuses herself and gets the keys from the other nurse. They have a very quick conversation before the nurse leaves to go off duty. Janet goes back into the cubicle. Dave is talking about other symptoms that are troubling him. He indicates that he is constipated, so Janet asks "how long has it been?" Dave says it's been about two days. Janet suggests that they could increase Dave's lactulose, and explains that, as his morphine is increased, he is more likely to become constipated. Dave hadn't realised this, and sounds pleased that something can be done to ease his constipation.

Janet asks "how are you feeling since your transfer over?" *She is referring to the fact that Dave was transferred to the hospice from hospital – I later find out that this is because there are no longer options to actively treat Dave's cancer.*

Dave says "the staff and the food are superb". He adds that "someone was talking about half days out". Janet asks "is that something you'd like?" Dave says that it would "be a good idea – to get back with familiarity". Janet picks up on this, saying this is "something we could work towards – a spell at home". Dave says that he was only "thinking about a half day". He wonders "what's available". *I am interested in Dave's use of language here, and wonder where he feels the control over what he does lies.*

He adds "it depends on what I can cope with" Janet agrees, saying "it depends on how you are, and what support you need." She adds "you've been doing really well. We don't want you to be too knacked." She also says that "safety's important". Dave says that he would like to "get to the house. Have a challenge, see what I can achieve." Janet agrees with this saying that they need "to think about your goal". She talks about the steps towards achieving that, suggesting that Dave could try going along to the canteen, to see how he gets on. Dave asks if that would be "under your own steam?" He thinks this would be a good plan. *Once again, Dave seems surprised and pleased with the possibilities being suggested.*

Dave then says "one thing we haven't talked about – the panicking". He says that this has lessened since he has come into the hospice, but he is unsure as to why he gets panicky. Janet explains that "a symptom like breathlessness goes hand in hand with panic". She goes into more detail, saying that sometimes when less oxygen is getting to the brain, people have difficulty thinking, and that this can lead to panic. Dave agrees that he is now more relaxed and is therefore less panicky. Janet says "what we want is what you want". Dave says "I want to be fit and healthy". He adds that he is "never going to be – I just want to get about". He talks about the fact that he wants to "build up what I can do – a lot more than I was expecting to be honest". Janet picks up on this, revisiting the fact that Dave had mentioned a visit home. She suggests that they should "pick a good day" and that he should pace himself by having "no shower". She talks about all the things that will need to be organised in order to get Dave

home for a short time, such as thinking about "getting in and out of the house" and "organising oxygen". She says "we can start aiming for that". Janet asks some questions about Dave's home environment: "do you have stairs and that?" Dave explains that he has ramps at the front and back of the house, but that there is a stair case up to the first floor. Janet suggests that equipment could be put in to help Dave: "There are aids out there". She adds that they will need to take it "a step at a time", and asks "have you spoken to S about it?" *(she is referring to Dave's wife).* Dave explains that his wife had asked him to bring up the subject of a visit home. He adds "S wants to push for things. She doesn't like to see a cup half empty, it's always half full". Janet asks "how do you feel about that?" Dave replies "no problem". Janet asks "Not pushed?" *She is checking how Dave feels about his wife's attitude.* Dave replies "no – encouraged". Janet says that she is "just checking".

Dave summarises the conversation saying "that's the situation. This is the weekend. I'll look forward to next week". *I think Dave is implying that things quieten down at the weekends.* Dave talks about the fact that the tall chimney at the old paper mill (near the hospice) is going to be demolished this weekend. Lots of visitors are expected to watch the chimney going down. Janet suggests that Dave should "speak to S – see how you're placed" *(here, I think she is referring to the home visit).* She adds that Dave is having "a blood test this morning. We need to check your calcium levels. Can cause you to be nauseated and muddled". Dave says "Just my speech can be a bit fatigued". Janet explains that, because he is breathless, his speech will be difficult as he needs "breath to get speech out". She goes back to talking about Dave's calcium levels, saying that there is a "possibility of having treatment for calcium if it's bothering you. If you've no symptoms, there's no need to treat." *I am surprised that Janet is talking about Dave's calcium levels, as he has not complained about symptoms. Perhaps she is trying to warn him that some treatment may be required once he has the results of his blood test.* Janet goes on to talk about the treatment saying "that maybe will hold you back this

weekend – you may be on a drip." She adds "we'll aim to get you best as possible for next week so you can go home" *She is talking about a trip home rather than discharge, I think.* Janet talks a bit more about the steps towards a visit home, saying that they will "need to show S how to transfer". She adds that Dave will need to "stay downstairs while you're at home". Dave explains that that will not be a problem as he has a downstairs toilet. Janet suggests that "over the weekend – you can gauge how much time you're spending in the sitting room – it will help you decide how long you can go home for". She adds "it's about pacing your self". Dave agrees with this, saying that talking tires him out. He talks about all the visitors he has, saying "it fairly bucks you up. Takes it out of you". Dave says that he has "lots of good friends" and adds "I still do business. I had the accountant in today – got the monthly accounts done. Need to get the audits done for the year". *I gather that Dave runs his own business, and is obviously still trying to keep this going.* Janet asks: "What's your goal there, with work?" Dave replies "I don't have a goal. I don't want to disappear either". He adds that his "employees are taking the strain". He talks about how his wife feels about him continuing to work: "she was very anti me picking up the phone. She sees the benefits. I can go along time, not doing very much. I'd rather not throw in the towel altogether. Is that silly?" Janet replies "not at all – you've worked hard." Dave talks about how his insurance will help him while he is not working, and how there is government aid to help him out. Janet asks "I know when you first came in, the doctor said – would you want information on your illness – you're focusing on the cup half full, but would you want to know what's next?" Dave replies "I want to get better. I'm sure that's what S feels." Janet asks "have you spoken to her?" "no, no time. Why bring things up that aren't a problem?" Janet pursues her line of enquiry: "would you want us to tell you what's going to happen – if we know?" Dave replies that he "wouldn't like it. It's not something I'd like." He goes on to say that he is "going to see the professor – it might be fatal – it might be treatable". Janet asks "are there any questions you want to ask?"

Dave replies "no. I'm not sure why people talk about terminal. Nobody knows. Maybe it's the head in the sand idea". Janet comments "the only worry is, if things are further on – and you weren't given the chance to tie up loose ends." Dave says "it's a chicken and egg" and then abruptly tries to bring the conversation to a close, saying "righty ho. Thank you very much". Janet continues to clarify with Dave how much information he wants,, saying "we won't wade in with information. But we have an obligation – if we feel you're not up to speed. I'm not sure, to be honest, about far ahead". Dave says that he will speak to the professor. Janet says "I'm not sure – I thought you didn't have an appointment with him. Thought he wasn't offering active treatment." She adds that they "can help with symptoms – not the cancer". Dave says "I've no idea"

Janet says "you know we're here. You can come back - and if things change – is it OK to talk to you?" She talks about "tying up loose ends". *This part of the conversation feels very uncomfortable. I feel that Janet knows that Dave's time left is limited. She wants him to know this, so that he can focus on saying his goodbyes and tying up loose ends. There seems to be a dissonance between Janet and Dave, possibly in terms of their shared understanding of the illness or in terms of what they want to focus on.*

Janet says "there are things we can do to make things easier. Maybe S has got her own thoughts". Dave replies "I just keep my head down. Look on the best side. The tumour's removed. The next challenge – no idea. I'm supposed to go and see the doctor – from Stirling. Not sure." Janet reiterates again that the doctors in Stirling will not be doing any "active treatment". Dave focuses on trying to remember the doctor's name. Janet again says they will "probably not be treating". Dave replies "it's just one of those things. I'm staying as positive as possible".

Janet summarises, saying that they will "work towards these goals – we may have to rein back and look at plan B, or set another one". She reminds Dave of the immediate plan: "this weekend. Sitting room". She reminds Dave that he should see how long he can manage in the sitting room, and that will help him gauge how long he should go home for. She adds that they will have to organise Dave's oxygen. She also suggests that she will speak to Dave's wife and the doctors. Dave wraps up the conversation saying "excellent. Can I have a bottle before you disappear?"

Janet gets a bottle organised for Dave and comes out from behind the cubicle. She suggests that we have a 'debrief' after this session. I wait for Janet in the duty room. While I am there, one of the doctor's gets some scan results from the man who is due to go home today. The news is not good – as he has suspected brain metastases, and will need another scan to investigate this. The doctor's initial reaction is that the man cannot go home today. There is some heated discussion when Janet comes in. She feels that the man's goal is to go home – and that the results of the scan should not change whether or not he achieves this. The doctor agrees, but is also worried about what the man's family will say, and the timing of giving the man the bad news just before he goes home. *I am interested in this conversation – it seems to sum up all the complexities of goal setting and achieving goals in palliative care. Even the professionals within the team have different opinions about what should happen. I will be interested to find out what happens.*

Janet and I go into the Chapel area to have a chat about the session I have just observed. Janet tells me that she found it really difficult, as Dave seems to have a different perspective about his illness from the professionals who are working with him. She feels that she has to keep the lines of communication open with Dave so that he can prepare for the future with as much information as possible. She understands that Dave wants to remain optimistic, but also wants him to be informed about the possibilities.

When I return to the hospice the following Monday, I find out that the man who was due to go home on Friday did, in fact, go home. He has had another scan which has confirmed that he has brain metastases, but he is still managing at home.

When I go back to the hospice on the 30th November, I learn that Dave has died. He deteriorated very quickly and died last week.

Appendix 2 (Staff interview topic guide)

- I am interested in finding out about your views on goal setting in a palliative care context. Can you tell me what the term 'goal setting' means to you?

- How relevant do you think goal setting is to patients who are admitted to the hospice?

- How do you work with patients to find out what their goals are?

- How are goals documented in patient notes?

- Think of an example when goal setting has worked well. Can you tell me about that with a specific patient? What were the benefits to the patient? What were the benefits for you as a professional?

- Can you think of an example when goal setting has not worked well.   Can you tell me about that with a specific patient? What were the problems in setting goals with this patient? What were the problems for you as a professional?

- Can you think of any specific situations when you wouldn't set goals with a person?

Assessment (General - written in admission notes) Were patient's difficulties established?	
Yes Note what is written in the patient goals and immediate plan of admission notes	No
Were patient's priorities established?	
Yes Use of quotes to indicate patients own words	No
Treatment (professional specific) Were goals of admission established?	
Yes Assessment completed and specific goals written down, e.g. patient wants to in less pain. Patient wants to be able to walk to the toilet.	No General goals such as 'maximising potential', symptom control.
Review Were the goals reviewed with the patients?	
Yes Is there any evidence of discussion with patients – e.g. patient reports that pain is now much reduced, patient reports that they walked to the bathroom	No
Discharge Were the reasons for discharge established?	
Yes Reasons must be stated clearly in the discharge letter. This must be more than a	No

summary of the medication, but must state explicitly which areas have been focussed on during the admission and what the outcomes are.	

Appendix 4 (First version of the data extraction form)

1. Case code (Professional):

Demographic data (Patient):

2. Birth year: Month:
3. Medical diagnosis code: 1 = Cancer 2= Non-malignant life limiting disease
4. Gender: F   M

Outcome data:

5. Date of admission: Year: Month:
6. Date of discharge: Year: Month:
7. Discharged to: Home ☐   Nursing Home ☐   Hospital ☐   Other ☐

Professional's decisions and behaviour:

ASSESSMENT
8. Were patient's difficulties established?   Y   N
9. Were patient's priorities established?   Y   N
10. ECOG[3] score on admission:
TREATMENT
11. Were goals of admission established?   Y   N
12. If goals were established   - How many goals were set?

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[3] ECOG (Eastern Cooperative Oncology Group performance scales) *These scales and criteria are used by doctors and researchers to assess how a patient's disease is progressing, assess how the disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis. (Oken et al. 1982)*

- Were they written in the patient's own words?   - Were they time limited?
13. Were goals agreed with patients?   Y   N
14. Was progress monitored against patient's goals?   Y   N
REVIEW
14. Were the goals reviewed with the patients?   Y   N
DISCHARGE:
15. Were the reasons for discharge established?   Y   N
16. Was there a discharge summary/letter?   Y   N
17. ECOG score on discharge:

Appendix 5 (Second version of the data extraction form)

1. Case code (Professional):

Demographic data (Patient):

2. Birth year: Month:
3. Medical diagnosis code: 1 = Cancer 2= Non malignant life limiting disease
4. Gender: F   M

Outcome data:

5. Date of admission: Year: Month:
6. Date of discharge: Year: Month:
7. Discharged to: Home ☐   Nursing Home ☐   Hospital ☐   Other ☐

Professional's decisions and behaviour:

ASSESSMENT (general)	Details
8. Were patient's difficulties established? Y N	
9. Were patient's priorities established? Y N	

10. ECOG score on admission:	
TREATMENT (professional specific)	
11. Were goals of admission established? Y N	Examples:

12. If goals were established
 	
      - How many goals were set?
 	
      -Were they written in the patient's own words?
 	
      - Were they time limited?
	Examples:

13. Were goals agreed with patients? Y/N/NA	Evidence:
14. Was progress monitored against patient's goals? Y/N/NA	

REVIEW	
14. Were the goals reviewed with the patients?　　Y/ N/NA	
DISCHARGE:	
15. Were the reasons for discharge established?　　Y　　N	
16. Was there a discharge summary/letter?　　Y　　N	
17. ECOG score on discharge:	

Appendix 6 (University of Stirling ethical approval)

LD/TS

UNIVERSITY OF STIRLING

10 October 2008

DEPARTMENT OF
NURSING AND MIDWIFERY

Email: nursingmidwifery@stir.ac.uk
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Len Dalgleish, PhD
Chair, Dept Research Ethics Committee

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Sally Boa
R.G Bomont Building
Department of Nursing & Midwifery
University of Stirling
STIRLING   FK9 4LA

Dear Sally

An investigation of goal setting and rehabilitation in palliative care

Thank you for submitting to me, the Chair of the Departmental Research Ethics Committee, the amended documents for your submitted proposal, entitled as above, on Friday 10 October 2008.

I am pleased to advise you that your proposal has been approved.

Many thanks

Len Dalgleish, PhD
Chair

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Appendix 7 (NHS ethical approval)

NHS
Fife

NHS
Forth Valley

NHS
Tayside

Fife, Forth Valley & Tayside Research Ethics Service

Fife & Forth Valley Research Ethics Committee
Research Ethics Office
Residency Block, Level 2
Ninewells Hospital & Medical School
DUNDEE
DD1 9SY

Mrs Sally E C Boa
Clinical Research Practitioner
Strathcarron Hospice
Randolph Hill
DENNY
Stirlingshire FK6 5HJ

Date:	21 January 2009
Your Ref:	
Our Ref:	FB/**08/S0501/98**
Enquiries to:	Miss Fiona Bain
Extension:	Ninewells extension 32701
Direct Line:	01382 632701
Email:	fionabain@nhs.net

Dear Mrs Boa

Full title of study: **An Investigation of Goal Setting and Rehabilitation in Palliative Care.**
REC reference number: **08/S0501/98**

Thank you for your letter of 08 January 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to the research sites listed on the attached form.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

With regard to your undertaking an MPhil, it is noted that you were not asked for this to be made clear within the first paragraph of the Participant Information Sheets in our letter of 23 December 2008. However, it would be appreciated if you could make this change and submit the amended documentation as soon as possible.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Data Extraction Form	1	06 November 2008
Letter from department ethics	1	06 November 2008
Statement of Indemnity Arrangement		30 October 2008
C.V for Sally Wyke		31 October 2008
Participant Consent Form: Observation	1	06 November 2008
Participant Information Sheet: Interview	1	06 November 2008
Participant Information Sheet: Observation	1	06 November 2008
Interview Schedules/Topic Guides	Appendix 2 Version 1	06 November 2008
Letter from Sponsor		30 October 2008
Summary/Synopsis	Executive Summary Version 1	06 November 2008
Covering Letter		03 November 2008
Protocol	1	06 November 2008
Investigator CV		03 November 2008
Application	1.1	03 November 2008
Patient Interview Guide Appendix 3		06 November 2008
Appendix 4	1	06 November 2008
Poster (Observation)	2	08 January 2009
Response to Request for Further Information		08 January 2009
Participant Consent Form: Staff Consent Form	2	08 January 2009
Participant Consent Form: Patient Interview Consent Form	2	08 January 2009
Participant Information Sheet: Staff Information Sheet	2	08 January 2009
Participant Information Sheet: Patient Observation Information Sheet	2	08 January 2009
Participant Information Sheet: Patient Interview Information Sheet	2	08 January 2009
GP/Consultant Information Sheets	GP letter - 1	08 January 2009

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

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DEPARTMENT OF
NURSING AND MIDWIFERY

Strathcarron
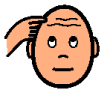HOSPICE

An Investigation of Goal Setting and Rehabilitation in Palliative Care

Would you like to take part in a research study?

Before you decide, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information.

The research is looking at how staff and patients work together to identify and meet your goals and objectives.

I am interested in finding out how goals are set at Strathcarron Hospice.

The study is part of a research project for my MPhil qualification.
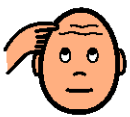
It is up to you to decide whether or nor to take part.

If you say 'yes' you will be asked to sign a consent form.
If you change your mind at any time about being involved, you can tell me to stop without having to say why. Stopping will not effect your care.

This is what it would mean for you

I am interested in observing the staff who work at Strathcarron Hospice, to find out how they set goals with patients. I therefore need to observe a consultation between a patient and a member of staff. I will not take part in the consultation, but will make notes as you talk. I will make sure that you cannot be identified from any of the notes I take. You can ask me to leave at any point during the consultation.

Results of the study

The results of the study will be gathered together and written in a report which will be ready in 2010.

No one will be identified in the report, although some direct quotes will be included.

I hope that this study will improve the process of goal setting for people at Strathcarron Hospice.

Funding and Organisation

The research is funded by Strathcarron Hospice and is part of a project for my MPhil qualification which I am doing at the University of Stirling.

The research ethics committees of NHS Fife and Forth Valley and the Department of Nursing and Midwifery at the University of Stirling are happy for me to carry out this study.

I am a speech and language therapist.
My name is Sally Boa

I can be contacted in any of the following ways:

📧 **by letter**: Sally Boa, Strathcarron Hospice, Randolph Hill, Denny, FK65HJ

☎ **by telephone**: 01234 826222

💻 **by email**: sally.boa@nhs.net

If you would like to talk to someone about the study, please contact Sally Wyke on 01786 466381 or Marjory McKay on 01324 826222, who will be happy to discuss it with you.

If you have any concerns about the study, please contact Irene McKie on 01324 826222.

Please take time to think about this. If you would like to take part please fill in the attached form and return it to a member of staff.

✂---

I am interested in being involved in the study and would like more information.

Name:

……………………………………………………………………………….

Address:

……………………………………………………………………………….

Telephone number:

…………………………………………………………………..

Appendix 9 (Patient interview guide)

Question guide (on admission):

Can you explain to me what was happening to you before you came into the hospice which led to the decision for you to come here as an in-patient?

How involved were you in making the decision about coming into the hospice?

How many of the issues that were important to you were covered in the discussions which led to you coming in here?

How well do you think you were listened to during the discussions?

How well were you able to express your views during the discussions?

Who else was involved in that decision?

What are your expectations about your stay in the hospice? Do you expect anything to change while you are here, and if so, what?

Can you think of any ways that staff have helped you make decisions about what happens to you while you are here?

Does the term 'goal setting' mean anything to you – and if it does, what does it mean?

Question guide (on discharge):

Can you think about why you came into the hospice. To what extent have your expectations been met?

What has changed for you while you have been here?

How many of the issues that were important to you have been covered while you have been here?

How well do you think you have been listened to while you have been here?

How well were you able to express your views during your stay here?

How have staff involved you in making decisions about your care?

Can you give me an example of how one of the staff members did this?

Has anyone spoken to you about setting goals while you have been here? Can you tell me a

bit about how staff found out what your goals were?

Appendix 10 (Adapted version of the patient interview guide)

I am interesting in goal setting and as part of a study I have been observing how staff work with patients in meeting their goals.

I would be interested in hearing from you whether you have specific goals in your mind related to coming to the hospice?

- Can you tell me what was important to you when you came into the hospice?
- Have you spoken to staff about these goals?
- Who/where/how etc.

How involved were you in making the decision about coming into the hospice?

- How well do you think you were listened to during the discussions?
- How well were you able to express your views during the discussions?
- Who else was involved in that decision?

What are/were your expectations about your stay in the hospice?

- Do/did you expect anything to change while you are here, and if so, what?
- What has changed for you while you have been here?

Can you think of any ways that staff have helped you to make decisions about what happens to you while you are here?

- How have staff involved you in making decisions about your care?
- Can you give me an example of how one of the staff members did this?

Does the term 'goal setting' mean anything to you – and if it does, what does it mean?

- Has anyone spoken to you about setting goals while you have been here?
- Can you tell me a bit about how staff found out what your goals were?

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Strathcarron
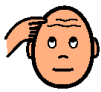HOSPICE

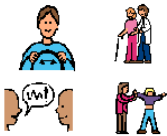## An investigation of goal setting and rehabilitation in palliative care

Would you like to take part in a research study?

Before you decide, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information.
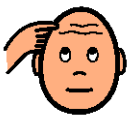
The research is looking at how patients and staff work together to decide on and work towards goals and objectives.

I am interested in what goal setting means for you while you are involved with Strathcarron Hospice.

The study is part of a research project for my MPhil qualification.

You have been chosen because I am interested in your views about goal setting.

It is up to you to decide whether or not to take part.
If you say 'yes' you will be asked to sign a consent form.
If you change your mind at any time about being involved you can tell me to stop without having to say why.
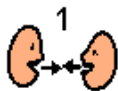
Stopping will not affect your care.

This is what it would mean for you

Visits:

I will visit you at home or in the Hospice.

Visit 1- I will tell you about the project.
I will ask you if you want to help. If you decide that you would like to help, I will ask you if I can contact your GP to let them know about your involvement in the study.

Visit 2 - I will visit you again at the beginning of your stay at the Hospice and will ask you questions to find out your thoughts about goal setting.

Visit 3 – I will visit you again at the end of your stay at the hospice and will ask you questions about your experience of goal setting while you have been on the ward.

If you like, you can ask a relative or friend to be present during the interviews.

Both interviews will be recorded so that I can listen to your views and take notes about what you are saying. The recordings will be destroyed when the study is finished. The interview will last for about 45 minutes. You are free to stop the interview at any time without having to say why.

All personal information will be treated as confidential and will be stored in a locked filing cabinet.

Results of the study

The views of you and other patients at Strathcarron Hospice are important

I am also listening to the views of Strathcarron Hospice staff.

All these views will be gathered together and written in a report which will be ready in 2010.

No one will be identified in the report, although direct quotes from the interviews will be used.

I hope that this study will improve the process of goal setting for people at Strathcarron Hospice.

Funding and Organisation

The research is funded by Strathcarron Hospice and is part of a project for my MPhil qualification which I am doing at the University of Stirling.

The research ethics committees of NHS Fife and Forth Valley and the Department of Nursing and Midwifery at the University of Stirling are happy for me to carry out this study.

You will be given a copy of the information sheet and a signed consent form to keep

I am a speech and language therapist.
My name is Sally Boa

I can be contacted in any of the following ways:

📧 **by letter**: Sally Boa, Strathcarron Hospice, Randolph Hill, Denny, FK65HJ

☎ **by telephone**: 01234 826222

💻 **by email**: sally.boa@nhs.net

If you would like to talk to someone about the study, please contact Sally Wyke on 01786 466381 or Marjory McKay on 01324 826222, who will be happy to discuss it with you.

If you have any concerns about the study, please contact Irene McKie on 01324 826222.

Please take time to think about this. If you would like to take part please fill in the attached form and return it to a member of staff within 1 week.

✂---

I am interested in being involved in the study and would like to discuss it with the researcher.

Name:

………………………………………………………………………….

Address:

………………………………………………………………………….

Telephone number:

………………………………………………………………….

Appendix 12 (G-AP PC Sample documentation version 2)

What's important to you just now?

Goal setting (a):

What do you want to do in the next wee while?

Goal setting (b):

Short-term goal:

380

Action and Coping plan:

Agreed goal	What I need to do	What I need help with	'What if' plan….

Appraisal and feedback:

How did it go?

What went well?	What didn't go so well?	Agree new pathways or new goals

Appendix 13 (GA-P PC Reflection sheet)

Patient ID:

Male/female

Age

Diagnosis

Use of GA-P PC

Stage 1 (What's important):

To what extent did this stage 'make sense'?

To what extent did the paper work help/hinder this stage?

What could be improved?

Stage 2 (Goal negotiation):

To what extent did this stage 'make sense'?

To what extent did the paper work help/hinder this stage?

What could be improved?

Stage 3 (Action and coping plan):

To what extent did this stage 'make sense'?

To what extent did the paper work help/hinder this stage?

What could be improved?

Stage 4 (carrying out the plan):

How did it go?

Stage 5 (Appraisal and feedback):

To what extent did this stage 'make sense'?

To what extent did the paper work help/hinder this stage?

What could be improved?

Anything else?

Appendix 14 (Reasons for not using G-AP PC)

If you have decided not to use G-AP PC with this patient, please complete the following:		
Demographic data	*Birth year:*	*Gender:* *M* ☐ *F* ☐
	Diagnosis: Cancer ☐ *Non-malignant life limiting disease* ☐	
	ECOG[4] Score on admission: ☐	
Reasons for not using G-AP PC (please tick all that apply)	*Patient placed on Liverpool Care Pathway* ☐ *Patient unable to engage in goal setting due to cognitive impairment* ☐	

---

[4] *These scales and criteria are used by doctors and researchers to assess how a patient's disease is progressing, assess how the disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis.*

	Patient unable to engage in goal setting due to severe communication impairment ☐
	Unable to set goals with patient for other reasons (please specify):

Appendix 15 (Case note analysis data extraction form)

Demographic data (Patient):

1. Birth year: Month:
2. Medical diagnosis code: 1 = Cancer 2= Non malignant life limiting disease
3. Gender: F   M
4. ECOG score on admission:

Outcome data:

5. Discharged to: Home ☐   Nursing Home ☐   Hospital ☐   Other ☐   Patient remains in Strathcarron ☐   Patient died ☐

Use of G-AP PC

	Details
6. Were patient's priorities established? [1] Y N [1] Responses to question: what's important to you just now?	
7. Were meaningful[2] short term goals established? Y N [2] That is: appears to be in patients own words and focuses on participation, not medically focused (e.g. pain management)	
8. Evidence of an action and coping plan? Y N 'What if' plan? Y N	Examples:

'Who does what' plan?	Y	N		
Confidence rating carried out?	Y	N		
9. Evidence of appraisal and feedback?	Y	N	Examples:	

Appendix 16 (Questionnaire for Professionals on use of G-AP PC)

The purpose of this questionnaire is to find out whether using G-AP PC over the last 3 months has helped or hindered patient centred goal setting.

Please tick which group you belong to:

Consultant/Doctor	Qualified Nurse	Nursing Auxiliary	AHP	Chaplain/Social worker

1. *Goal negotiation:*

Did you use the 'what's important to you just now' question?   Please tick the appropriate response

Always	Sometimes	Never

How useful did you find this question? Please circle the appropriate response

Very/extremely useful   Not at all useful

1   2   3   4   5

2. *Goal setting:*

Did you use the 'what do you want to do in the next wee while' question?

Please tick the appropriate response

Always	Sometimes	Never

How useful did you find this question? Please circle the appropriate response

Very/extremely useful   Not at all useful

1   2   3   4   5

3. *Action and coping plan:*

Did you use the 'what if' plan?   Please tick the appropriate response

Always	Sometimes	Never

How useful did you find this? Please circle the appropriate response

Very/extremely useful   Not at all useful

1   2   3   4   5

Did you make a 'who does what plan' with the patient?   Please tick the appropriate response

Always	Sometimes	Never

How useful did you find this? Please circle the appropriate response

Very/extremely useful   Not at all useful

1   2   3   4   5

Did you use the confidence rating scale? Please tick the appropriate response

Always	Sometimes	Never

How useful did you find this? Please circle the appropriate response

Very/extremely useful   Not at all useful

1   2   3   4   5

4. Carrying out the plan

How helpful was G-AP PC in supporting you and the patient to work together to work towards goals? Please circle the appropriate response

Very/extremely helpful   Not at all helpful

1   2   3   4   5

5. *Appraisal and feedback*

Did you ask the 'how did you get on' question?   Please tick the appropriate response

Always	Sometimes	Never

How useful did you find this? Please circle the appropriate response

Very/extremely useful   Not at all useful

        1   2   3   4   5

6. *Paperwork*

How useful was the documentation? Please circle the appropriate response

Very/extremely useful   Not at all useful

        1   2   3   4   5

7. *Anything else?*

If you have any comments you would like to share about the usefulness (or otherwise) of any of the stages of G-AP PC or the process as a whole, please add these here:

Thank you for taking time to complete this questionnaire.

Appendix 17 (Interview topic guide for professionals)

Introduction

You have been involved in goal setting using the G-AP PC intervention which has been developed at the hospice. We want to know your opinions on how it works in practice.

1. Tell me about your experience of using G-AP PC.
   Prompts:
   - How often did you use it?
   - What type of patients did you use it with?
   - Was there any part of the process you found particularly helpful?

2. Can you give me an example of how you used G-AP PC and you felt it worked well?

3. Now give me an example where using G-AP PC didn't work so well.
   Prompts:

   - What could be done to avoid the difficulties you encountered?

4. What do you think about the paperwork to support the G-AP PC process?

5. What differences do you notice about using G-AP PC compared to what you usually do?

6. Can you tell me about any disadvantages to using G-AP PC?
   Prompts:
   - Was there any stage that was particularly challenging to use or unhelpful?

7. Do you intend to continue using G-AP PC in the future?
   Prompts:
   - If not, why not?
   - If yes, can you think of any ways to improve it?

8. Within the multidisciplinary team, which team members do you feel G-AP PC is most useful for?

Introduction

You have been involved in goal setting using a new intervention during your stay at the hospice. We want to find out what you think of it.

Reflections on G-AP PC

Patients will be asked to describe one of the goals that they worked on during their hospice admission. Probing questions will be asked to find out if the stages of G-AP PC were followed and how the patient felt about the process:

1. Goal Negotiation:
   - How easy did you find it to identify what was important to you?
   - How did staff help you with this?

2. Goal Setting:
   How easy did you find it to come up with goals?
   • Did the team use a *scale* to find out how confident you were at achieving your goal?
   - How helpful did you find this?

3. Action and coping plan
   - How easy did you find it to work out how you were going to go about achieving your goals?
   - Did staff help you to come up with an action plan?
   - How helpful did you find the action plan?

4. Carrying out the Action Plan
   - Did your plan translate into something you were actually able to do?
   - How did the team support you with this?

5. Appraisal and Feedback
   - Did anyone ask you if you had achieved what was important to you?
   - How useful did you find that?
   - How easy was it to reflect on what you'd done, and how that tied in with your goal?

How much help or support did you get from the hospice team to go through the process?

Appendix 19 (University of Stirling ethical approval)

JP/SG

13 April 2012

UNIVERSITY OF STIRLING

SCHOOL OF
**NURSING, MIDWIFERY
AND HEALTH**

Sally Boa
PhD Student
NMAHP Research Unit
Iris Murdoch Building
University of Stirling
Stirling
FK9 4LA

Email: nursingmidwifery@stir.ac.uk
Web: www.nm.stir.ac.uk

John Paley
Chair
School Research Ethics Committee

School of Nursing, Midwifery and Health
University of Stirling
Stirling   FK9 4LA

Tel: +44 (0) 1786 466399
Fax: +44 (0) 1786 466333
Email: john.paley@stir.ac.uk

Dear Sally

Development of a research based patient centred goal setting intervention for use in palliative care

Your application was reviewed at the SREC meeting on 11 April 2012. I am pleased to tell you that it was approved.

May I take this opportunity to wish you well with the remainder of your PhD studies.

Best Wishes

John Paley
(Chair)
School of Nursing, Midwifery and Health Research Ethics Committee

Appendix 20 (NHS ethical approval)

2 7 JUN 2012

EoSRES

NHS SCOTLAND

East of Scotland Research Ethics Service (EoSRES) REC 1
(formerly Tayside Committee on Medical Research Ethics A/B)
Tayside Medical Sciences Centre (TASC)
Residency Block C, Level 3
Ninewells Hospital & Medical School
George Pirie Way
Dundee DD19SY

Mrs Sally Boa
PhD Student
NHS Forth Valley and Strathcarron Hospice
Strathcarron Hospice
Randoph Hill
Denny
FK6 5HJ

Date:	26 June 2012
Your Ref:	
Our Ref:	LR/**12/ES/0044**
Enquiries to:	Mrs Lorraine Reilly
Extension:	Ninewells extension: 40099
Direct Line:	01382 740099
Email:	lorraine.reilly@nhs.net

Dear Mrs Boa

Study title:	**Development of a research based patient centred goal setting intervention for use in palliative care**
REC reference:	**12/ES/0044**

Thank you for your letter of 1 June 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

1. The Committee requested a copy of a letter from Dr Mckie at Strathcarron Hospice indicating as Caldicott Guardian he is aware of the project and has given approval to look through patients notes.

2. Regarding the Participant Information Sheet (PIS):

   - Please check spacing and spelling throughout the PIS's.

   - Please change 'professional malpractice practice' to 'professional malpractice' in the staff interview information sheet under 'Deciding to Participate'.

   - Telephone number '01234 826222' should read '01324 826222'

   - Under 'What the research is about' please change 'method' to 'methods'.

Please send revised copies with new version number and full date as a footer.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		23 April 2012
Evidence of insurance or indemnity		23 April 2012
Interview Schedules/Topic Guides	1	26 March 2012
Investigator CV		
Letter from Sponsor		23 April 2012
Other: CV - Dr Edward Duncan		
Participant Consent Form: Pilot	2	01 June 2012

Development and evaluation of a research based goal setting intervention for use in palliative care: Interview information

Would you like to take part in a research study?
Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information.

What the research is about.
The purpose of the research is to pilot and evaluate a research based goal setting intervention (G-AP PC) which has been developed at Strathcarron Hospice. Goal setting is part of routine care at the hospice, and all patients are asked about their goals during admission, if they are well enough. This research aims to evaluate the acceptability and feasibility of using G-AP PC in Strathcarron from the point of view of professionals and patients.

Deciding to participate
It is up to you to decide whether or not to take part. Deciding not to participate will not have any implications for your employment.   If you do not wish to take part, other members of staff will be approached to see if they would like to participate.
If you agree, you will be asked to sign a consent form. If you decide to take part you are free to withdraw at any time without giving a reason. If you wish to withdraw from the project, please let the researcher know. Any data collected prior to you withdrawing from the study will be retained, but no further data will be collected. All data will be anonymised.
If professional malpractice practice is reported while the research is being carried out, this will be reported to senior management.

What it would mean for you
If you decide to take part in the study, this will mean three things for you:

1. You will be invited to attend a half day training session where you will have the opportunity to find out more about the project and practice using G-AP PC.

2. You will be asked to use G-AP PC with patients who are admitted to the Yellow team within the hospice over a three month period. You will only be asked to use G-AP PC with patients who you would normally set goals with.

3. You will be asked to complete a questionnaire about your experiences of using G-AP PC. A sample of Yellow team staff will also be invited to attend one individual interview. I hope that you will find the discussion worthwhile and that you will appreciate the opportunity to discuss this issue with me. The discussion will take approximately 45 minutes and will be audio recorded. It will be held locally within work time.

Clinical notes regarding patients who are admitted to the Yellow team at the hospice will be analysed. The purpose of this is to find out if using G-AP PC makes any difference to how goals are documented in patients' notes. All information from the case note analysis will be anonymised.

All personal information will be treated as confidential and will be stored in a locked filing cabinet. The digital recordings will be destroyed after the study has been completed. Any electronic data held on a computer will be password protected.

Results of the study
The aim of this study is to find out the acceptability and feasibility of G-AP PC as a method of helping patients to set goals. The study is part of PhD qualification and a written report will be ready in 2013. The study will also be written up and published in a paper in an academic journal. Whilst every effort will be made to anonymise the study's findings, on occasion it may not be possible to guarantee anonymity to staff**.**

Funding and Organisation

The research is being carried out by Sally Boa who is employed as a researcher by Strathcarron Hospice. The research is funded and supervised by Strathcarron Hospice and the University of Stirling.

The research ethics committee of the Department of Nursing and Midwifery at the University of Stirling are happy for me to carry out this study. The East of Scotland Research Ethics Committee REC 1, which has responsibility for scrutinising all proposals for medical research on humans in Tayside, has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant records, be made available for scrutiny by monitors from the University of Dundee and NHS Tayside, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

If you would like to talk to someone about the study, please contact Dr Edward Duncan (Senior Research Fellow) on 01786 466286 or Marjory McKay (Director of Nursing) on 01324 826222, who will be happy to discuss it with you.

If you have any concerns about the study, please contact Irene McKie (Chief Executive) on 01324 826222.

You will be given a copy of the information sheet and a signed consent form to keep.

Sally can be contacted in any of the following ways:

⊟   by letter: Strathcarron Hospice, Randolph Hill, Denny, FK65HJ

☎   by telephone: 01234 826222

▭   by email: sally.boa@nhs.net

Thank you for taking time to read this information sheet and for considering taking part in this study. If you would like to find out more about it, please fill in the attached form and return it to Sally within one week.

✂---

(please tear off and return in the envelope enclosed – no need for a stamp)

I am interested in being involved in the study and would like to discuss it with the researcher.

Name: ……………………………………………………………………….

Address: …………………………………………………………………..

Telephone number: ………………………………………………………..

Development and evaluation of a research based goal setting intervention for use in palliative care

CONSENT FORM

Please read the following statements and initial each one to indicate that you have read and understood them:

I have read the information sheet.

I have had the chance to ask questions
and talk about the project.

I understand that it is my choice
to participate in the study.

I understand that I will be invited to attend training
In the use of G-AP PC and will be asked to use it with
patients who are admitted to the Yellow team.

I understand that in the unlikely event of
professional malpractice being reported,
this will be reported to the senior management
team at the hospice.

I understand that I will be asked to complete a
questionnaire at the end of the pilot study.

☐

I understand that notes that I have
written will be analysed.

☐

I understand that I can withdraw
from the project without having to say why
at any time and that if I withdraw, data collected
up to that point will be retained and used, but no further
data will be collected or used.

☐

I agree to take part in the study.

☐

Name ……………………………………………………………………

Signature…………………………………………………………..

Name of person taking
consent…………………………………………………………………….

Signature…………………………………………………………..

Development and evaluation of a research based goal setting intervention for use in palliative care

Thank you for agreeing to take part in this research study. You are being approached to see if you would like to play a further part in this research process.

Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information.

Deciding to participate

It is up to you to decide whether or not to take part. . Deciding not to participate will not have any implications for your employment. If you do not wish to take part, other members of staff will be approached to see if they would like to participate.

If you agree, you will be asked to sign a consent form. If you decide to take part you are free to withdraw at any time without giving a reason. If you wish to withdraw from the project, please let the researcher know. Any data collected prior to you withdrawing from the study will be retained, but no further data will be collected. All data will be anonymised.

If professional malpractice practice is reported while the research is being carried out, this will be reported to senior management.

What it would mean for you

If you decide to take part in this phase of the study, I will arrange a time to interview you to find out your experiences of using G-AP PC over the last three months. I hope that you will find the discussion worthwhile and that you will appreciate the opportunity to discuss this issue with me. The discussion will take approximately 45 minutes and will be audio recorded. It will be held locally within work time.

All personal information will be treated as confidential and will be stored in a locked filing cabinet. The digital recordings will be destroyed after the study has been completed. Any electronic data held on a computer will be password protected.

Results of the study

The aim of this study is to find out how acceptable and feasible G-AP PC is as a method of helping patients to set goals. The study is part of PhD qualification and a written report will be ready in 2013. The study will also be written up and published in a paper in an academic journal. Whilst every effort will be made to anonymise the study's findings, on occasion it may not be possible to guarantee anonymity to staff.

Funding and Organisation

The research is being carried out by Sally Boa who is employed as a researcher by Strathcarron Hospice. The research is funded and supervised by Strathcarron Hospice and the University of Stirling.

The research ethics committee of the Department of Nursing and Midwifery at the University of Stirling are happy for me to carry out this study. The East of Scotland Research Ethics Committee REC 1, which has responsibility for scrutinising all proposals for medical research on humans in Tayside, has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant records, be made available for scrutiny by monitors from the University of Dundee and NHS Tayside, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

If you would like to talk to someone about the study, please contact Dr Edward Duncan on 01786 466286 or Marjory McKay on 01324 826222, who will be happy to discuss it with you.

If you have any concerns about the study, please contact Irene McKie on 01324 826222.

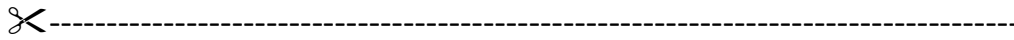You will be given a copy of the information sheet and a signed consent form to keep.

Sally can be contacted in any of the following ways:

	by letter:	Strathcarron Hospice, Randolph Hill, Denny, FK65HJ
	by telephone:	01234 826222
	by email:	sally.boa@nhs.net

Thank you for taking time to read this information sheet and for considering taking part in this study. If you would like to find out more about it, please fill in the attached form and return it to Sally within one week.

✂--

(please tear off and return in the envelope enclosed – no need for a stamp)

I am interested in being interviewed as part of this study and would like to discuss it with the researcher.

Name: …………………………………………………………………….

Address: …………………………………………………………………….

Telephone number: ………………………………………………………..

Development and evaluation of a research based goal setting intervention for use in palliative care

Please read the following statements and write your initials in each box to indicate that you have read and understood them:

I have read the information sheet.

I have had the chance to ask questions
and talk about the project.

I understand that it is my choice
to help with the study.

I understand that I will be recorded
as part of the study.

I understand that direct quotes
from the interviews may be used in the final
report and published papers.
This has been explained to me on page two
of the information sheet.

I understand that I can withdraw from the project

404

without having to say why at any time and that if I
withdraw, data collected up to that point will be
retained and used, but no further data will be collected.

I understand that in the unlikely event of
professional malpractice being reported,
this will be reported to the senior management
team at the hospice.

I am happy to take part in the study.

Name ……………………………………………………………

Signature……………………………………………………..

Name of person taking
consent…………………………………………………………….

Signature……………………………………………………..

Development and evaluation of a research based goal setting intervention for use in palliative care

Would you like to take part in a research study?

Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information about the project.

What the research is about.

I am working with a group of staff who are helping to develop a way of goal setting with patients at the hospice. This will help staff find out about what is important to you just now and work with you towards achieving it. A member of staff would like to try using the goal setting method with you, and after that I would like to interview you, to find out your thoughts and feelings about this process.

The study is part of a research project I am doing for my PhD studies. You have been chosen because we are interested in your views about goal setting and the method that we are developing at Strathcarron Hospice.

Deciding to take part.

It is up to you to decide whether or not to take part.
If you agree, you will be asked to sign a consent form. If you decide to take part you are free to withdraw at any time without giving a reason. This will not affect your care. If you wish to withdraw from the project, please let a member of staff or the researcher know. Any data collected

prior to you withdrawing from the study will be retained but no further data will be collected. All data will be anonymised.

If you report any professional malpractice during the course of the study, this will be fed back to senior management at the Hospice.

This is what it would mean for you

1. If you decide that you would like to take part, I will visit you in the Hospice and tell you more about the project.

2. A member of staff will use the goal setting method with you. This may take place over a number of days during your hospice stay.

3. I will visit you again once you have worked with the member of staff. I will interview you, asking questions about your experience of using the goal setting method.

If you like, you can ask a relative or friend to be present during the interview.

The interview will last for about 45 minutes. You are free to stop the interview at any time without having to say why. The interview will be digitally recorded so that it can be transcribed. All identifiable information will be removed so you cannot be identified. The recordings will be destroyed when the study is finished.

All personal information, including the recordings will be treated as confidential and will be stored in a locked filing cabinet.

Results of the study

The views of you and other patients at Strathcarron Hospice are important. I am also finding out what Strathcarron Hospice staff think of this new goal setting process. All these views will be gathered together

and written in a report which will be ready in 2013. They will also be written up and published in a paper in an academic journal.

No one will be identified in the report or paper, although direct quotes from the interviews will be used.

I hope that this study will improve the process of goal setting for people at Strathcarron Hospice.

Funding and Organisation

The research is funded by Strathcarron Hospice and the University of Stirling and is part of a project for my PhD qualification, which I am doing at the University of Stirling.

The research ethics committee of the Department of Nursing and Midwifery at the University of Stirling are happy for me to carry out this study. The East of Scotland Research Ethics Committee REC 1, which has responsibility for scrutinising all proposals for medical research on humans in Tayside, has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant records, be made available for scrutiny by monitors from the University of Dundee and NHS Tayside, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

You will be given a copy of the information sheet and a signed consent form to keep

I am a researcher and also work as a speech and language therapist.
My name is Sally Boa

I can be contacted in any of the following ways:

✉	**by letter**:	Sally Boa, Strathcarron Hospice, Randolph Hill, Denny, FK65HJ
☎	**by telephone**:	01234 826222
💻	**by email**:	sally.boa@nhs.net

If you would like to talk to someone about the study, please contact Dr Edward Duncan (Senior Research Fellow) on 01786 466286 or Marjory McKay (Director of Nursing) on 01324 826222, who will be happy to discuss it with you.

If you have any concerns about the study, please contact Irene McKie (Chief Executive) on 01324 826222.

Please take time to think about this. If you would like to take part please fill in the attached form and return it to me using the attached envelope within 1 week.

✂---

I am interested in being involved in the study and would like more information.

Name: ……………………………………………………………………………….

Address: ……………………………………………………………………………….

Telephone number: ……………………………………………………………………..

Development of a research based goal setting intervention for use in palliative care

Please read the following statements and initial each box to indicate that you have read and understood them:

I have read the information sheet.

I have had the chance to ask questions
and talk about the project.

I understand that it is my choice to help with the
study.

I understand that I will be recorded
as part of the study.

I understand that direct quotes from the interviews
may be used in the final report and academic papers.
I understand that I will not be identified in these.
This has been explained to me on page three
of the information sheet.

I understand that I can withdraw from the project without having to say why at any time and that if I withdraw, data collected up to that point will be retained and used, but no further data will be collected.

☐

I understand that if I report professional malpractice to the researcher during the interview, this will be reported to senior management at Strathcarron Hospice

☐

I am happy to take part in the study.

☐

Name …………………………………………………………………

Signature…………………………………………………………..

Counter signature (by a person independent of the research)

 …………………………………………………………………………

(To be used if participant is unable to sign because of physical disability)

Name of person taking consent……………………………………………………………….

Signature…………………………………………………………..

Date…………………………………………………………....