

## International Journal of Palliative Nursing

### Title page

**Title:** Patient centred goal setting in a hospice setting: A comparative case study of how healthcare practitioners understand and use goal setting in practice.

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#### **Abstract:**

**Aim:** To investigate healthcare practitioners' understanding and practice of patient centred goal setting in a hospice.

**Methods:** A comparative case study of 10 healthcare practitioners in one hospice. Nonparticipant observations (n=28), semi-structured interviews (n=10) and case-note analysis (n=67) were undertaken. Data were analysed using framework analysis.

**Results:** Participants viewed goal setting as part of routine practice. However, goal setting focused around what was seen as important from the health practitioner's perspective rather than being person centred. Participants' goal setting practice was implicit and opportunities to support patients to pursue goals were missed. Participants emphasised problem solving and alleviating symptoms rather than focusing on patient priorities and establishing patient centred goals.

Conclusion: While goal setting is valued, it is practiced in an implicit, practitioner centred and inconsistent manner. An explicit person centred goal setting process may support practitioners consistently help patients to identify their priorities and enhance their quality of life.

**Key words:**

Palliative care; end of life; goal setting; case study; patient centred care.

**Introduction**

One of the central aims of palliative care is to help people to live as actively as possible until death (WHO, 2007). Traditionally, medical care has focused on *either* living *or* dying (Steinhauser, Hendrix and Tulsky, 2011). The key aim of palliative care challenges this duality. There are difficulties for both patients and the palliative care professionals who care for them as they attempt to deal simultaneously with the process of affirming life whilst preparing for death (Bye, 199;, Jacques & Hasselkus, 2004). Since its inception, the palliative care philosophy has influenced and changed practice (WHO, 2004), but there is still a tendency to fall back on the traditional way of thinking, with practitioners lacking the focus of supporting people who are dying to maintain meaningful life roles (Hockley, 1993; Hammell; 2004, Pearson, 2008). There is evidence that patients with life threatening illness become engaged in a complex, often contradictory business of “survivorship and limited mortality” (Steinhauser, Hendrix and Tulsky 2011, p.1). A longitudinal study (Nissim, Rennie et al, 2012), which studied the experiences of people who were dying, found that interviewees were concerned with living, but always in the context and knowledge of imminent death. Practitioners in palliative care find it challenging to engage with this tension (Haraldsdottir, 2011). As a result, there has been little focus on helping people who are dying to maintain meaningful life roles and to continue to participate in activities that are important to them.

The philosophy of palliative care has consistently emphasised a holistic, person centred approach. A recent national palliative and end of life research prioritisation exercise (James Lind Alliance, 2015) identified the 10 most important research priorities for people at the end of life. These include finding ways to listen to and incorporate patients' choices and preferences into care. In addition to this, another review has recognised that patients want to be involved in and have control over decisions about their care at the end of life (Henry, 2015).

NICE states that people at the end of their life should be "offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible" (quality statement 5, NICE, 2011). However, patients' unpredictable trajectories (Murray & Sheikh, 2008; Murray et al, 2012; Reed, Corner, & Simmonds, 2013) and individual expectations at the end of life make it difficult for professionals to address patients' choices and preferences in a consistent and meaningful way.

Goal setting is recommended as a method of enabling choice and participation and as an intervention that can help people to live a meaningful life in the face of death (NCPC, 2000; NICE, 2004; Timberini and Richardson, 2015). Goal setting is also recognised as a key skill for patient centred care (Doll, Packard et al, 2013).

While the potential value of goal setting in palliative care is evident in literature and policy, we know very little about how it is understood and delivered by health care practitioners in everyday practice. This omission requires to be addressed, as research in other healthcare specialisms has demonstrated that goal setting is not always understood or followed in practice (Siegert and Taylor, 2004; Wade, 2005; Playford, 2009; Wade 2009, Rosewilliam et al, 2011).

In order to understand how goal setting is understood and delivered in palliative care, we undertook a comparative case study in one setting. We aimed to investigate practitioners' understanding and practice of patient centred goal setting in patients who were admitted to a hospice.

## **Methods**

### *Design*

We used a mixed methods comparative case study design in one palliative care setting to enable us to explore goal setting within the context in which it happens. Case study design is an empirical enquiry that is particularly suited to research focusing on 'why' or 'how' questions in a setting where the researcher has "little control over events" (Yin 2009, p.19). Cases were multidisciplinary team members. We collected multiple sources of data for each case. We sought to ensure reflexivity through regular team discussions throughout the project. We reflected on our different roles as part of the research team and how our various experiences and worldviews might impact on how we might interpret our findings. The study is reported in keeping with recognised standards for reporting qualitative research (O'Brien, Harris et al, 2014).

### *Setting:*

A 24 bedded in-patient hospice in Scotland which provides specialist palliative care on an in-patient, day and community basis for people living in the surrounding urban and rural areas.

### *Participants:*

The cases were 10 multidisciplinary team members (referred to from now on as participants) who worked with people admitted as in-patients to the hospice. We purposively recruited a representative sample of professionals: two doctors, five nurses, one physiotherapist, one occupational therapist and one social worker.

### *Ethical and R & D approval*

Ethical approval for this study was obtained from the local NHS Research Ethics Committee (REC Reference number: 08/S0501/98), the University of Stirling's departmental ethics committee and NHS Forth Valley R&D department. All participants gave informed consent to take part in this study.

### *Data collection:*

Multiple sources of data were collected. Participants were observed on a maximum of three occasions in patient interactions where they expected goal setting to take place. Detailed field notes were taken during each observation. Semi-structured interviews with participants were audio-recorded and transcribed verbatim. A six-month retrospective analysis of all patients' case notes written by each participant was undertaken to examine documentation of patient centred goal setting (Figure 1). Participants and patients were given pseudonyms to preserve anonymity. All data collection was carried out by SB.

*\*Insert Figure 1 here\**

Patients were not interviewed as part of the case studies as there were concerns that they may not have been able to maintain their anonymity and this would have limited recruitment and potentially biased the data that was collected. Instead, a separate sample of 15 patients were interviewed to find out about their experiences and perceptions of goal setting whilst in the hospice. Findings from these interviews will be reported on fully in a separate paper.

### **Analytical approach**

We used a Framework approach (Ritchie and Spencer, 1994; Ritchie and Lewis, 2003) to organise and analyse all data. Transcripts of interviews, field notes and case note analyses, were read and re-read. An initial thematic framework was identified by SB and discussed and revised by all authors until consensus was reached. Having agreed the framework, a third of transcripts and field notes were initially coded (by SB) using NVivo (Version 10). All authors checked, compared and discussed the coded data to ensure that coding was consistent and rigorous. The remaining data was then coded using the same framework. Charts of data were then created. Data were organised thematically, and patterns and associations between and within cases were identified. Charts were organised so comparisons could be made between what participants said, what they did, and what they wrote about.

The final thematic framework is shown here:

**1. What goal setting is:**

- a. Goal setting is important but implicit.
- b. Goal setting: discovering limitations or discovering possibilities?

**2. Challenges to/what affects goal setting:**

- a. Deterioration versus realism.
- b. Balancing risk.
- c. Focusing on significant goals.
- d. Missed opportunities

**Results:**

Data were collected through 28 observations (mean three per case: two professional were only available to be observed on two occasions due to shift patterns and illness), 10 semi-structured interviews (one per case) and analysis of extracts of 67 case notes that had been written by the participants (mean 23 per case). Findings are presented in line with the developed thematic framework.

What goal setting is

**a. Goal setting is important, but implicit:**

The majority of professionals agreed in the interviews that goal setting was an important part of palliative care:

*“Well I think in palliative care it’s very important to let patients goal set’ (Alison, interview).*

*“I think it’s hugely relevant” (Becky, interview)*

However, there was a predominant belief that the process should be implicit rather than explicit:

*“I think sometimes you say a goal today will be – but maybe we don’t use that language – you know, you say maybe 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."*

Hazel (interview)

*"And for us that is the goal setting but we maybe don't use the word 'goals are'"* (Alison, interview).

*"I don't think it's as formalised as that. I'm thinking at some of the multidisciplinary team 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"* (Becky, interview).

This informal approach to goal setting was also reflected in practice. Only two participants used the word 'goal' during the participant-patient observations. In interviews, other participants alluded to setting goals when they said they would ask patients what they wanted to 'do'. Documentation of goals was mainly general and problem-based in nature and focused on symptom control as part of goal setting, for example: *'Hopes to improve vomiting'* (Case note 6).

Whilst this informal and symptom focused rather than person centred approach to goal setting was most common in practice, one participant (Janet) appeared to have a different approach to goal setting compared to others. She openly talked about goals with patients and appeared to go through an explicit process to negotiate goals and action plans with them:

*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 sitting room, 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.'*

Janet also clearly 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 spite of the predominant belief favouring an informal, implicit approach to goal setting, Janet's practice suggested that it was possible to use a more direct approach and the use of action planning appeared to help the patient to take a more active role in the process.

#### **b. Goal setting - discovering limitations or discovering possibilities:**

Participants talked about goal setting as a process of negotiation, which involved 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, participants asked patients for their opinions and gave patients multiple opportunities to raise issues. A commonly used phrase by all participants during observations was, *"is there anything else?"* This enabled participants to ensure that all issues relevant to patients had been covered. It was used several times during patient interactions.

Although interactions with patients often involved participants checking patient's perspectives, these discussions were predominantly symptom and problem based, rather than focused on what patients wanted to be able to 'do', achieve or participate in:



*'I ask them what they've been doing at home. What's been difficult for them.'* (Alison, interview)

*'Debbie immediately starts the conversation saying she wants to "get a feeling for what's been most problematic" (Debbie, observation 1).*

This was also reflected in the case note analysis, which was characterised by a focus on symptom management and problem resolution:

*"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)

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 all sources, which were characterised by a focus on symptom management and problem resolution.

## 2. Challenges and what affects goal setting

### **a. Deterioration versus realism**

At times it was clear that illness and deterioration took priority over identifying person centred goals with patients. Participants and patients were often engaged in a complicated business of assessment, diagnosis, and planning within unpredictable and limited time scales. Consequently participants felt that goal setting could sometimes be difficult.

*'If you've got time to do that. Sometimes you don't – because somebody's condition deteriorates unexpectedly – very quickly'* (Elaine, 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 care pathway' (Frances, interview).*

This was further complicated by the fact that participants perceived some patients to be unrealistic about their future. This was a source of frustration for many.

*'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 two years time – so I'm gonna plan this big family holiday abroad. Next year.'* (Elaine, 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.'* (Frances, interview).

#### **b. Balancing risk:**

Participants were working with patients who were very ill and at the end of life. Consequently participant-patient interactions sometimes appeared to be protective and risk averse. This was evident throughout the data, although not everybody who talked about this demonstrated it in practice (Table 1).

#### **\*Insert Table 1 here\***

The issue of risk was important; particularly for the allied health professionals 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 participants and their patients, whose own problem solving ideas were sometimes disregarded.

*Alison [participant] quickly follows up her question by saying that she will need to be able to 'do stairs' in order to get home. Betty [patient] 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. (Observation)*

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 were 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.

**c. Focusing on ‘extraordinary’ goals:**

Whilst most participants stated in interviews that goals could be about ordinary, everyday things, such as sitting up in a chair or having a bath; these were rarely talked about in detail, observed in practice, or documented in case notes. When asked to talk about a particular goal that participants had helped a patient to achieve, they typically talked about more significant goals. For example, Alison talked about a lady who wanted to watch her grandson perform in his Christmas nativity play. Janet recalled how she and the team had helped organise a man’s wedding just before he died. The 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. More ‘ordinary’ everyday goals were documented in general terms (for example “improve pain, improve mobility”). The general nature of these written goals made it difficult to know whether or not they were a patient’s own goals, or if they had been achieved during a patient’s admission.

**d. Missed opportunities:**

There were occasions when goals were initially identified by patients but because there was not a clear process for taking goal setting forward as a team, opportunities for picking up and working towards these goals with patients were missed, as this example from an observation shows (Katie working with Eric who has been admitted to the hospice for pain control):

*Katie: "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 Eric identified several specific, concrete goals, which Katie acknowledged as being important. However, 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. Even though Katie had heard what Eric's goals were, there was no clear procedure or specific action planning process to guarantee that the team would work together to support him to achieve his goals. This issue of missed opportunities was discussed at length by a separate sample of patients who were interviewed. This will be reported on fully in a separate paper, but an example is given below which illustrates some of the frustration felt by patients who felt at times they were not being listened to:

*"I'd like to wash myself, which I can do in the bed but they insist that they'll wash me" (Ruth, interview participant)*

*'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, interview participant)

The goals described by participants who were interviewed were predominantly ordinary goals based around activities that they wanted to participate in, rather than based around symptoms or problems. Given that professionals tend to focus on symptoms and problems, it is not surprising that patient's goals were sometimes missed.

## **Discussion**

This study sought to investigate how goal setting is understood and delivered in practice by healthcare practitioners in a single hospice setting. Participants viewed goal setting as important, but treated it as an implicit, informal process. Consequently, goal setting was not routinely or consistently undertaken. Overall this informal, implicit approach to goal setting in the hospice resulted in missed opportunities for staff to work with patients to identify and work towards goals that were important to them. It also meant that many of the goals that were set with patients focused on the healthcare practitioner's expertise rather than being led by what the patient themselves wanted to work towards or achieve.

Goal setting in healthcare has a well-developed theoretical base (Bandura, 1997; Gum and Snyder, 2002; Locke and Latham, 2002; Scobbie et al, 2009) and research in other healthcare settings such as paediatrics and stroke rehabilitation suggests that the theoretical underpinnings of goal setting can help structure healthcare practitioners' understandings, delivery and adherence to using goal setting interventions (Kolehmainen, MacLennan et al, 2012; Scobbie, McLean et al, 2013). Goal setting within palliative care is less well developed (Boa, Duncan et al, 2014). Within this hospice, goal setting appeared to be largely carried out in an atheoretical manner, with many participants appearing unaware of theory underpinning the process. A few were able to discuss theories they believed underpinned goal setting, but there was little evidence that their practice was theory based. One participant (Janet) stood out as an individual whose goal setting beliefs, practice and documentation were all linked to goal setting theories. She explicitly set goals *with* patients and worked in partnership with them to identify action plans, and this appeared to help sustain a focus on goal setting as well as encouraging patient participation in the process.

Delivering consistently high quality, person centred palliative care at the end of life is essential and of increasing importance. In spite of the palliative care movement's early endeavours to focus on quality of life and dignity as part of the dying process, it has become increasingly medicalised (Clark, 2002). This was evident in the current study, particularly in relation to how participants focused on patients'

symptoms and problems, rather than what was important to them at that moment. A different approach which actively encourages patients to become involved in identifying, planning and working towards goals in palliative care settings would help to shift professionals' focus away from professionally demarcated boundaries and back to the patient, increasing their choices and participation in their care (Sandsdalen, Hov et al, 2015; Timberini and Richardson, 2015).

Theory based goal setting interventions have already been developed for use in paediatric (Kolehmainen et al 2012; 2013) and stroke settings (Scobbie et al 2009; 2013; 2014), with promising results. These may provide a starting point for developing a goal setting intervention for use in palliative care. This could improve patient choice and participation and in doing so it would help hospices and other environments which care for the terminally ill to deliver consistently high quality end of life care. There is, therefore, a clear need to develop and evaluate a theory-based structured goal setting intervention for palliative care settings.

### **Limitations**

The single study site and sample size mean that our study findings may not transfer to other palliative care settings. However, a representative range of healthcare professionals took part in the study, multiple data sources were used, and the data were transparently analysed and reported. In the absence of a structured and well adopted evidence and theory based goal setting intervention for palliative care (Boa, Duncan et al, 2014) it is likely that goal setting practice will also be highly variable, and therefore potentially suboptimal, across palliative care settings internationally. Patient interviews were not included in the study. These would have been a valuable addition to the data. However, patient recruitment linked to study participants was felt to be inappropriate as it may not have been possible to maintain patient anonymity from study participants. A series of patient interviews regarding their views and experiences of goal setting were conducted separately, and will be reported elsewhere.

### **Conclusion**

Despite its founding principles and enduring rhetoric, this study suggests that palliative care practice may be missing everyday opportunities to support their patients to live as actively and meaningfully as possible until death. Goal setting is an immediately recognisable concept that practitioners in this study felt was an implicit part of their practice. But effective goal setting is a highly complex and theoretically based intervention that requires knowledge, skills, commitment and aptitude. Palliative care should look to established goal setting theory and evidence from wider healthcare research to support the development of theory and evidence based goal setting in palliative care.

### **Acknowledgements**

We are grateful to the staff and patients of Strathcarron Hospice who gave their time to participate in the data collection process.

### **Funding**

This study was financially supported by Strathcarron Hospice and The University of Stirling Strategic Research and Knowledge Transfer Development Fund.

### **Declaration of conflicting interests**

ED, EH and SW declare no potential conflicts of interest with respect to the research, authorship, and or publication of this paper. SB is currently the Head of Research, Education and Practice Development at Strathcarron Hospice, where the study was conducted. At the time of the study being undertaken she was not a member of its staff and had no potential conflict of interest.

### **Supplementary materials**

Underlying research materials can be obtained from the first author. Contact details provided.

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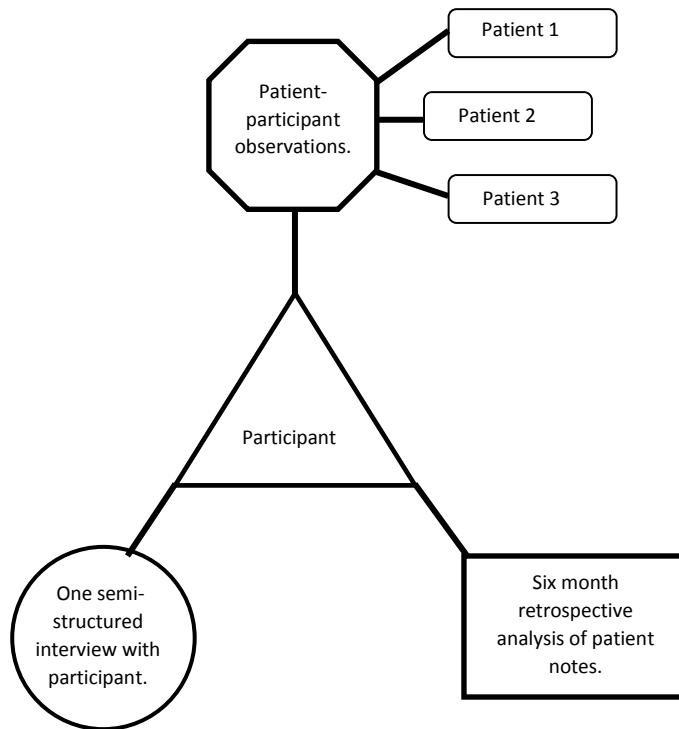
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Figure 1: Summary of data collection for each case.



**Table 1. Balancing risk.**

<b>Balancing risk (interview data)</b>	<b>Balancing risk (Observational data)</b>	<b>Balancing risk (case note data)</b>
<p><i>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’</i></p>	<p><i>Iris: “we’re focussing on how safe you are. We don’t want you falling”</i></p>	<p><b>Iris:</b> wrote notes that related to care she had given. She did not refer specifically to risk.</p>
<p><b>Katie:</b> “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.”</p>	<p><b>Janet:</b> “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 knackered [tired].” She also says that “safety’s important”.</p>	<p><b>Hazel:</b> ‘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.’</p>