

ORIGINAL REPORT

PERCEPTIONS OF GOAL SETTING IN A NEUROLOGICAL REHABILITATION UNIT: A QUALITATIVE STUDY OF PATIENTS, CARERS AND STAFF

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Objective: To explore perceptions of goal setting from the perspective of patients, lay carers and rehabilitation staff.

Design: Semi-structured interviews analysed independently by 2 researchers using content analysis.

Setting: Neurological rehabilitation inpatient unit for adults.

Subjects: Four samples of 10 subjects each, comprising: (i) inpatients, (ii) patients discharged within the last 2 years, (iii) lay carers, (iv) staff. Patients, carers and staff had participated in at least 2 goal setting meetings, patients had any non-progressive neurological condition causing disability and need for inpatient rehabilitation.

Intervention: Goal setting meeting.

Main outcome measures: Themes identified independently before results triangulated to produce consensus list presented as frequency tables across 4 subject groups. Quotations from narratives used to clarify themes.

Results: All 4 groups considered goal setting to be beneficial, increasing motivation and providing reassurance for patients and carers. Carers found goal setting alleviated some anxieties and assisted active problem-solving coping strategies. Staff believed that goal setting made their practice more focused and collaborative because they were working towards stated and shared goals. Specific improvements were suggested regarding education, nature of goals, conduct of meetings and feedback.

Conclusion: Goal setting appears to provide psychological benefits to patients and carers.

Key words: Goals, rehabilitation, qualitative research.

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INTRODUCTION

The goal setting process has been widely studied in neurological rehabilitation, with positive benefits found in adults with acquired brain injury and spinal injury. The goal setting process assists planning for individual patients (1) and provides structure for team conferences (2, 3). Goal setting and review allows patients' progress to be monitored (2, 3), provides information to patients and families (2, 4) and gives feedback to referrers and funders (1–5).

The goal setting and review cycle encourages reflection and quality improvement, since failure to meet a goal suggests a problem with one or more of: the goal, the intervention offered, or the participation of the patient. Goal setting may provide useful data for audit of programmes (6). Indeed, the proportion of goals successfully achieved has been mooted as an outcome measure in neurological rehabilitation units (7). When formalized in Goal Attainment Scaling, goal setting offers promising measurement properties in brain injury rehabilitation, and has been used for programme evaluation (3) or as a clinical trial outcome measure (2) for randomized controlled trials of new drugs (8) or service innovations (9).

Much of the previous published work on goal setting has concentrated on the benefits it offers to delivery of care, monitoring and evaluation. However, less is known about the perceptions of goal setting by patients, their carers, and staff involved in the process. Our literature search found no studies of carers' views of goal setting. The views of staff have been studied and tend to be positive, with staff finding goal setting a satisfactory team activity, particularly if they chair the meetings (10). There are few studies on the perception of goal setting by patients, although it has been suggested that patients may be unable to participate fully in planning goals because of inequalities of knowledge, both of therapeutic possibilities and of their own impairments and prognosis (11). While this limited information is interesting, the views of participants in the goal setting process are worth studying in more detail. If goal setting is to be useful as a quality indicator and service improvement tool, a proportion of goals must be failed. The collaborative approach to goal setting and review between patients and teams means that such failure may well be evident to patients and carers. Failure of a patient to reach a goal should lead to staff reflection as to whether the goal was unrealistic, the intervention in some way lacking, or the patient unable or unwilling to participate. Thus goal setting, while useful to the process of care, may carry negative as well as positive connotations to the patients, carers and staff.

METHODS

In order to study perceptions of goal setting from a number of perspectives, we carried out qualitative interviews with no preconceived hypotheses (12, 13). We studied 4 cohorts who had some experience of goal setting: inpatients in a neurological rehabilitation unit carrying out goal setting; patients who had been discharged from that unit;

carers of past and present patients; and staff involved in goal setting. The inclusion of past patients and carers of past patients was important for 2 reasons. We wished to explore whether views changed over time and perspectives altered once people were no longer inpatients. Secondly, we wondered if goal setting in itself might be a skill that patients and carers learned as part of the rehabilitation process, and which they continued after discharge. The choice of research design, namely qualitative interviews, was driven by the desire to explore perceptions of goal setting, whether positive or negative. A quantitative study, such as a questionnaire, would be premature, as it might bias responses towards the items included.

Context

The Neurological Rehabilitation Unit (NRU) at the Walton Centre for Neurology and Neurosurgery is a 16-bed unit for specialist rehabilitation of neurological disability in patients aged 16–55 years. It is a self-contained and freestanding rehabilitation unit in the grounds of the Walton Centre, a tertiary neurosciences centre in the north-west of England, serving over 3 million people. The NRU receives patients with a wide range of neurological impairments from brain, spinal cord and peripheral nerve pathologies. These pathologies may be both progressive and non-progressive. The rehabilitation team consists of doctors (consultants, and doctors in training), nurses, occupational therapists, physiotherapists, psychologists and speech and language therapists. This service is provided by the National Health Service.

Since 2000, a systematic goal setting process has been provided for all inpatients other than those admitted to a short stay bed. Patients undergo regular goal setting and review meetings. The first goal setting meeting is held with the patient, carers (if agreed by the patient) and members of the multidisciplinary team after a 1–2 week assessment period. Goals for the next 4 weeks are agreed in conjunction with the patient, and at each subsequent meeting feedback is shared about progress towards previous goals, new or revised goals chosen, and the next review date set. The goals are dependent upon the patient's disabilities, anticipated progress and aims. As in Goal Attainment Scaling, better or worse outcome levels are entered on the goal setting charts. The meetings are chaired by the patient's key-worker and written information on the agreed goals is offered to the patient. The Functional Independence Measure (FIM) (14) is assessed by the rehabilitation team as part of the initial assessment and then again at discharge.

Procedure

Patients, carers, and staff for this study were recruited from the NRU over an 8-month period. The protocol for this study was approved by the Walton Centre Research Governance Committee and Sefton Ethics Committee.

We wished to recruit a sample with a wide range of views and experience of goal setting. Therefore our only entry criteria for patients and carers were informed consent, attendance at 2 or more goal setting meetings, and that the patient should have had any non-progressive neurological disorder. Both current inpatients and recent outpatients, i.e. patients discharged within the last 2 years, were interviewed. For this initial study we excluded patients with progressive conditions as their progress through the goal setting review cycle is more complex. Within these parameters, a researcher independent of the treating team (GM) approached consecutive patients, or carers, until the quota for that category was filled.

Carers of patients fulfilling the stated criteria were interviewed as they are an integral part of the rehabilitation process, and it was felt they might give a different perspective on goal setting. Carers were not necessarily matched with either inpatients or discharged patients, i.e. a carer could participate although their patient relative had declined or not been approached. Staff were recruited arbitrarily, provided they had experience of goal setting and gave informed consent, by a researcher independent of the treating team (GM).

Semi-structured interviews were conducted face to face by 2 researchers (GM and JW), and recorded for later transcription, after

which tapes were destroyed. Interviews lasted up to 25 min. Each participant, whether patient, carer or staff, was asked if they would define goal setting, comment on its strength and weaknesses (if any) and offer any suggestions for improvement if they thought goal setting should continue. Questions were open ended and non-directive to encourage free discussion. The interviewers were a physician in training (JW) and a final year medical student (GM). Neither had involvement in goal setting on the NRU or previous experience of goal setting in healthcare. All patients were informed that the study report would include their age, sex, diagnosis, number of goal setting meetings, admission FIM and possibly excerpts from their transcripts.

After the transcript had been checked by the interviewer against the tapes, data was analysed with content analysis. This is a systematic research method for analysing textual information in a standardized way that allows evaluators to make inferences about that information (15, 16).

In order to improve the quality of the study, we interviewed a diverse selection of respondents, the interviewers did not have current or previous experience of goal setting, and this lack of involvement was known to respondents to encourage them to speak freely. In addition the interviewers carried out an audit trail (17) of decisions and interpretations made.

The transcripts, audit trails and analyses were reviewed independently by 2 researchers with 2–15 years experience in rehabilitation medicine (JW and CY) and themes identified. The analyses were compared and a list of themes relating to goal setting mutually agreed. In order to explore the relative importance of the themes and differences between the 3 groups of informants, quantitative data such as how often each theme was endorsed were generated by independent frequency counts for each theme across all 40 transcripts (JW and CY), with any discrepancies resolved by later consensus. Illustrative quotes for each theme were listed by each researcher and a smaller number selected by consensus to clarify aspects of the theme and avoid repetition. Participants were invited to check their transcripts with any proposed excerpts highlighted if they wished to confirm the researchers' interpretation of themes and illustrative quotes. The transcripts were analysed as the study progressed and appeared to have reached saturation by 6–9 interviews. The researchers continued to 10 interviews for each group because participants might already have consented but not yet had their interview, and to be sure that no additional themes arose.

Additional data were collected on the characteristics of our informants, such as demographic information (age, gender, social class according to the Registrar General class scores), diagnosis, number of goals setting meetings attended at time of interview, and FIM at admission for patients. For carers, we recorded age, gender, relationship to patient and number of goal setting meetings attended. For staff, we collected age, gender and discipline. These data explore whether this was a maximum variation sample likely to incorporate a diversity of views on goal setting in non-progressive neurological illness.

RESULTS

None of the patients or carers invited to enter the study declined. Two physiotherapists refused participation because of work pressures. One patient and one carer wished to see their transcripts and no participant wanted transcripts or excerpts altered.

There were 10 subjects in each of the 4 groups: inpatients (P); discharged patients (D); carers (C); and staff (S). The mean age was 39.1 years for inpatients and 43.4 years for discharged patients at time of interview. Inpatients had an average admission FIM of 61, and had attended an average of 3.3 goal setting meetings when interviewed. Discharged patients had an average admission FIM of 76.1 and had participated in a mean of

3.9 goal setting meetings during their stay. Carers were older, mean 51.8 years, 5 women, and had experience of mean 3.9 goal setting meetings when interviewed. The most common diagnoses were stroke and traumatic brain injury, but a variety of other non-progressive conditions were represented.

The most succinct description of goal setting given by a participant – “setting an achievement for the patient that requires their participation, the therapists’ participation, a measurable outcome, and a time in which they achieve it” – recognized that the aim had to be defined, in a measurable way, and reached by joint effort, in a set time. This definition omits medical, nursing and psychology inputs, and there was considerable variation in the definition of goal setting, including among staff. Most participants indicated that goal setting involved setting objectives but a significant proportion failed to acknowledge that there was a time limit (P 3/10, D 4, C 4, S 3).

Perceived benefits of goal setting

For each group, the majority of participants believed goal setting to be beneficial (P 8/10, D 10, C 9, S 10) (Table I). A variety of positive benefits was described. Patients and carers valued having specific aims within a set time frame and felt their motivation was increased. Patients assumed that staff would agree realistic goals for the next month’s meeting and used goal setting as a prognostic measure, “*what my potential was*”. Some viewed the goals as providing a baseline of anticipated recovery which they might try to exceed, “*the goals that they gave me I beat them every time*”. All reported that goal setting had an important role in fostering realistic expectations, “*I had my own goals but I did not know if they were achievable*”.

Concern has been expressed that goal setting may be threatening for people with an uncertain long-term outlook. In this study, goal setting was seen positively by both patients with an optimistic and with an uncertain prognosis, but for different reasons. One inpatient with cervical abscess causing quadriplegia observed “*they just set short-term goals, which is a lot more positive*”. Others who were more confident about eventual recovery viewed the process as a series of milestones, “*I was able to look forward to it finishing as it were*”.

Goal setting was seen as having a role in charting progress as well as providing future aims, “*to be able to look back and say well at that point you were doing that and now you’re doing something different*”. For staff, there was a process of commitment in goal setting in that they declared an aim to be reached in a set time, “*allows us to be much more specific about what we are aiming to achieve together*”. Carers also

believed that regular goal setting meetings motivated staff, “*it obviously makes them achieve these goals as well*”.

Both staff and carers valued the interactive format of the goal setting meeting, “*it was nice..., opened it all up*”. They liked the feeling of working towards shared goals, “*I felt like me and the therapists were pulling together*”. They felt the process increased confidence and provided reassurance, “*I really thought people cared and they really wanted (my relative) to get better*”.

Some carers indicated they used goal setting meetings as a useful coping mechanism. One used them to vent anger and negative feelings, “*formal way of emptying your frustration*”. Another described how she used it to compartmentalize problems, “*I hold questions back to those (goal setting) meetings*”.

Participating in regular goal setting meetings helped patients appreciate that rehabilitation is a gradual, stepwise process. The initial aspirations of patients were usually dramatic and unachievable in a 4-week time-frame, so more modest short-term goals had to be agreed. “*The major goal has been unobtainable...it was explained in the first meeting that it would be broken down*”. It appeared critical that goal setting was sufficiently accurate that some, if not all, of that month’s goals could be achieved as failure was demoralizing. “*It is useful but not good for me... ‘cause I couldn’t achieve them*”. Conversely, goals should not be so modest they were always easily passed, “*He passed them so well they could be set a bit harder next time*”.

Patient participation in goal setting

Almost all participants specifically stated that the patient’s views on choice of goals were solicited (Table II). Despite this, current inpatients, carers and staff often felt their role in determining goals was passive, because of their lack of expertise in rehabilitation or prognosis, “*how I wanted to be is different from how the body responds. So it is not that people did not listen to me*”.

Whilst staff members generally considered goal setting as beneficial for patient care and useful in improving clinical practice, there were some concerns about the process of goal setting meetings. Among staff interviews, 9/10 felt that account was taken of the views of the patient and any lay people invited by the patient, usually family. However they were concerned that patients might lack confidence to express their viewpoint. They might feel intimidated, “*some patients ... have never sat in a formal meeting*”.

Staff were concerned that patients might feel under pressure to accept goals, and were worried that certain topics

Table I. *Benefits of goal setting process described by participants*

Themes	In-patients (n=10)	Discharged (n=10)	Carers (n=10)	Staff (n=10)
Goal setting beneficial	8	10	9	10
Valuable for motivation, guidance, prognosis	8	10	8	10
Staff required to make specific commitment	1	3	3	6
Useful for confidence, reassurance, interaction	7	9	7	6
Carers can use goal setting for coping, release anger, etc.	1	0	4	0

Table II. Observations on goal setting process described by participants

Themes	In-patients (n=10)	Discharged (n=10)	Carers (n=10)	Staff (n=10)
Definition of goal setting including aim and time	7	6	6	7
Goals set should be accurate and not too easy	3	2	3	6
Meetings are more multidisciplinary than interdisciplinary	2	3	1	7
Patients views are solicited	9	10	9	9
Patients do not really control goals	4	0	5	6
Goals should be meaningful, valuable, explicit	3	1	2	5

might be particularly difficult to discuss, such as continence. However, patients and carers approved of self-care goals and patients used specific examples of very personal goals in their interviews, "to wipe my own bum. That was one I asked to set myself".

Goal setting in non-rehabilitation settings

Informants were asked whether they had previously used goal setting and whether they anticipated using it after discharge. Personal goal setting, i.e. separate from and not shared with the rehabilitation team, did not occur among inpatients or their carers in this sample. Some subjects had extensive previous experience of personal goal setting against a time frame, for work or private reasons, such as completing an Open University degree. However they felt unable to use these skills because of distress and lack of knowledge, "when you have had something like this you are so traumatized and you just go one day to the next".

Rehabilitation should teach participants new skills and the majority of interviewees felt goal setting was a useful technique they would continue. Many specifically stated they had or would adopt goal setting for their ongoing rehabilitation, but it seemed this process differed from the goal setting process studied in that it might be a personal rather than collaborative activity, "I do secretly set goals".

Potential improvements to the goal setting process

Several interviews included concrete suggestions on ways to improve goal setting.

Education about goal setting clearly needed to be improved. Patients, carers and staff could not explain the goal setting process as a reiterative activity involving regular reviews. The monthly time frame was appropriate providing goals were not consistently being reached early so patients felt they were losing time.

Goals needed to be explicit, comprehensible, and something the patient could aspire to, "you tailor your goals ... to something meaningful for the person". Having a range of disciplines, including doctors, was viewed very positively, but when staff specified goals in turn by discipline, patients and carers categorized them as physiotherapy goals, occupational therapy goals, and so on. The professional contribution was seen as multidisciplinary, rather than inter-disciplinary or trans-disciplinary, "They all ... said what they expect to do so they were individual really". From a practice viewpoint, if goals are categorized as discipline-specific, joint working seems less likely.

Changes in the composition and running of the meetings were suggested. Therapy disciplines were represented in goal setting meetings by trained staff but some patients who had developed close links with assistants would have preferred them to be present. The key-worker was always present and led the meeting. However, patients' comments indicated the key-worker sometimes did not seem to know the patient well, referring to case notes for information. The key-worker should become familiar with the record in advance and if not frequently in contact with the patient, schedule a pre-meeting talk.

Staff bringing a list of goals to the meeting was viewed as prescriptive and inhibiting discussion. However, in the meeting patients liked documentation to occur, it confirmed to them their views were valued and that the conclusion of the meeting had been reached with their input rather than being predetermined. Following the meeting patients wanted written information on the agreed goals as well as feedback on how well they had met goals. This varied from being pass/fail, to pass+/-, fail+/- to requests for gradings 1-10. It seems the level of detail should be specified by the patient.

DISCUSSION

This study of participants' views of goal setting provides useful insights into acceptability and benefit from the users' perspective. It provides qualitative data on participants' perceptions and quantitative data on how commonly various themes were endorsed between different groups of informants. The analysis also yielded suggestions for improving goal setting meetings.

The study has both strengths and weaknesses. The informants included patients with a range of diagnoses and at different stages after the onset of their non-progressive disabling condition, carers of various ages and relationship to the patient, and 5 disciplines of rehabilitation staff. The interviews were conducted in private by researchers not involved in goal setting, and analysed independently by 2 researchers who triangulated views. An audit trail was maintained and sufficient interviews were carried out to achieve saturation.

Weaknesses were that the interviews were conducted in a hospital setting, which may not be a relaxing venue, and which may explain why informants talked for less than 30 min. Psychologists might have been more skilled at probing for informants' views. Staff may have been inhibited from speaking and thinking freely, as their smaller numbers made them more easily identifiable and staff subscribe to goal setting.

There were no physiotherapists in our staff sample, so we do not know if their views are similar to other clinicians.

Despite these limitations, this study provides highly interesting and novel information that enhances our understanding of goal setting. Goal setting has previously been studied from a pragmatic, process-centred approach; as a means to an end. It has been researched as a key procedure in rehabilitation treatment, as an organizational template for sustained team input, and as an outcome measure. However, this study indicates that the goal setting process itself has intrinsic benefits for patients and carers.

It has been argued that humans find psychological well-being through fulfilment of basic needs for autonomy, competence and interpersonal relatedness (18). Autonomy refers in part to a desire to self-regulate and organize experiences, relatedness to establishing a sense of connection to others, and competence to seeking challenges and increasingly mastering them.

In these interviews the goal setting process was seen as a collaborative endeavour between the patient and the clinical team. Patients felt that their views were taken into account, but that the staff had the knowledge and experience to chart a series of steps between the patient's current state and a higher level of independence. Appropriately conducted goal setting gave participants a sense of autonomy, shared endeavour (relatedness) and competence.

The rehabilitation literature stresses goals and goal setting as critical to progress in rehabilitation programmes (19). This current study offers new insights that goal setting may be important for the individual's retrospective analysis, where patients review their previous successes to affirm their competence and increase their sense of mastery. They cease to be only passive recipients of treatment, whether medication compliance or consenting to surgery. Instead they collaborate in physical or psychological programmes working towards an agreed specific objective. Appropriate goal setting is likely to be important in increasing self-efficacy, or the individual's belief that they have the ability to perform a particular behaviour to achieve a particular outcome.

Goal setting may also be important for the psychological well-being and future role of carers. The patients participating in this study had all developed significant neurological disability as a consequence of a non-progressive neurological disorder. In such situations, carers have considerable anxiety about the future, and little involvement in acute phase treatment. The goal setting process benefited carers as well as patients by fostering relatedness with the clinical team and providing some achievable short-term treatment aims. In addition, carers used the goal setting meetings as a coping strategy, allowing them to compartmentalize and defer future anxieties. The impact of goal setting on carers has not been studied hitherto, but these potential effects merit further investigation. There is a need for further study of the relationship between goal setting, motivation and self-efficacy, and those aspects of the rehabilitation experience other than goal setting that influence self-efficacy.

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