

# Fostering hope through palliative rehabilitation

Palliative rehabilitation is key to enhancing quality of life for people living with cancer, say **Caroline Belchamber**, **Mamood Gousy** and **Caroline Ellis-Hill**, who have sought the perceptions of a small group of patients receiving rehabilitation in a day care centre

**C**ancer patients' need for rehabilitation is growing, as more and more people live with the long-term consequences of disease and its treatment due to early detection and improved treatment regimens.<sup>1</sup> There are a number of people living with incurable cancer who have symptoms that need to be managed for many years, paralleling long-term conditions.<sup>2</sup> Beyond clinical management, a sense of hope is vital in enhancing their quality of life, as it plays an integral role in their psychosocial well-being.<sup>3</sup> This paper describes how a small group of patients in a hospice day care centre regained hope through a two-month palliative rehabilitation programme, which included:<sup>4</sup>

- Evaluation/assessment of their symptoms and referral to the appropriate members of the palliative care team
- Physical care; for example, therapeutic interventions to reduce lymphoedema and non-pharmacological management of dyspnoea
- Co-ordinated multidisciplinary care
- Psychological care
- Supportive care

## Key points

- A small group of cancer patients attending a day care centre went through a palliative rehabilitation programme meeting their social, physical, emotional and psychological needs. They took part in a qualitative study exploring the benefits of palliative rehabilitation.
- Palliative rehabilitation provides the support needed to reduce both the physical and psychological isolation commonly experienced by people living with cancer.
- The open and supportive environment of palliative rehabilitation fosters a sense of hope and helps people regain a sense of connectedness, enabling them to live rather than just existing.

## Box 1. Inclusion and exclusion criteria

### Inclusion criteria:

- People living with cancer who had been referred to the palliative day care centre
- People capable of articulating their experiences
- People experiencing one or more of the following symptoms: pain, dyspnoea, fatigue
- People who would have completed palliative chemotherapy and/or radiotherapy at least four weeks before the start of the palliative rehabilitation programme

### Exclusion criteria:

- People who were not fit enough to participate in the two-month palliative rehabilitation programme
- People who required further palliative chemotherapy or radiotherapy
- People who had underlying pathologies such as cardiovascular disease, a history of cardiovascular accidents or a history of myocardial infarctions

- Spiritual care
- Aromatherapy
- Group work, incorporating social care
- Exercise
- Relaxation
- Diversional therapy

All these various aspects of care are considered to be important components of palliative rehabilitation.<sup>4</sup>

## Method

An interpretative phenomenological approach<sup>5</sup> was used to gain an understanding of individual experiences. Box 1 shows the criteria used to select participants. Following ethical approval by the East Dorset Research Ethics Committee, eight participants who attended the day care centre for palliative rehabilitation undertook an in-depth interview that allowed detailed qualitative analysis.

**Table 1. Physical symptoms experienced by participants**

Participant	Cancer diagnosis	Pain	Dyspnoea	Fatigue	Lymphoedema		Cramps	Dry cough
					Lower limbs	Upper limbs		
1	Right breast cancer (recurrence)	Yes	–	Yes	Yes	–	–	–
2	Bilateral breast cancer	Yes	Yes	Yes	Yes	Yes	Yes	–
3	Renal cell carcinoma	Yes	Yes	Yes	–	Yes	–	–
4	Cancer of the oesophagus	–	Yes	–	–	–	–	Yes
5	Cancer of the colon	–	–	Yes	–	–	Yes	–
6	Right breast cancer (recurrence)	Yes	–	Yes	–	–	–	–
7	Prostate cancer	–	Yes	Yes	–	–	–	Yes
8	Cancer of unknown primary	–	–	Yes	–	–	–	Yes

Ages ranged from 45 to 82 years (median 66 years); time since primary diagnosis ranged from one to 17 years (median seven years) and time since the most recent secondary diagnosis from six months to three years (median 15 months); active treatment had been completed between three months and two years ago (median ten months). Seven participants had previously had surgery, four had been treated by radiotherapy and five had received chemotherapy. All were experiencing a number of symptoms, detailed in Table 1. The interviews covered:

- Expectations from the rehabilitation programme at the palliative day care centre before and after attending
- Quality of care received
- Quality of communication with staff
- Quality of life before and after palliative rehabilitation
- Benefits of receiving palliative rehabilitation
- Improvements that could be made to the service
- Most difficult symptoms to manage
- Care that may have helped manage the symptoms.

The interviews were audio-recorded and transcribed verbatim. Transcripts were read, re-read, coded and then compared to determine overall themes, similarities and differences, providing a deep understanding of individual experiences.<sup>5</sup>

### Regaining hope

The qualitative analysis found that the key benefits of rehabilitation reported by

participants were psychological support and hope. Participants reported many deep losses prior to entering rehabilitation, including: loss of bodily health, of energy, strength, mobility, control, self-esteem, role and social support. They described their diagnosis as ‘terrifying’, ‘frightening’ and ‘devastating’ and that they had feelings of abandonment. *‘I’d given up, I’d given up. Yes, that’s the only word for it, I’d given up.’* However, participants were apprehensive about attending, or reluctant to attend, the rehabilitation programme. *‘I wasn’t sure what to expect, because it seems a final thing, the word hospice, so I wasn’t sure about the whole thing.’* These feelings of apprehension changed once the participants commenced rehabilitation. Hope developed in several ways, which are described below.

### Regaining hope through sharing

Group work was seen as enjoyable, important and an encouragement to each other, promoting perseverance as well as a sense of identity and unity.<sup>6</sup> *‘I think doing it in a group is good, because it is encouraging, as you are spurring one another along.’* Comparing themselves with others was a source of inspiration and an incentive for participants. The group exercises also helped to alleviate the sense of a loss of physical ability. *‘Being a sporty person, that’s the sort of thing that I miss.’* The act of accomplishing tasks in a group enhanced participants’ self-worth, which increased their ability to do more, which in turn reduced their levels of fatigue. *‘It gives us the opportunity of trying something new, of trying something*

*different, and perhaps after a while you realise you can do other things.*' The diversional therapy changed participants' psychological response to their symptoms. *'It makes you forget everything else; I mean I forget ... I forget to be breathless.'* Interaction with staff during group work was seen by patients as a key element of rehabilitation.

### Regaining hope through caring

Although the rehabilitation programme consisted mainly of group work, participants described receiving individual attention, feeling important and cared for, which nurtured a positive outlook and hope. *'The care here has been excellent, [I've been] well pampered; it does make you feel very special.'* Participants felt that staff, through attentive listening and responding to them as valued individuals, were giving them the opportunity to express emotions during conversations without time constraints, thus producing an atmosphere of comfort and security. Participants also reported that the therapeutic interventions not only had a positive effect on their bodily health – with an increase in strength and reduction in pain, fatigue and dyspnoea – but also had emotional and spiritual benefits. Participants found aromatherapy particularly beneficial, describing it as relaxing both physically and psychologically. *'Complete relaxation, absolute heaven just to be, just for somebody to do something for you [...], it was lovely, making you relax [...], making you relax in your mind.'*

### Regaining hope through control

Participants reported that, before rehabilitation, physical pain frequently disturbed their normal sleeping patterns and was often associated with cramp, muscle spasm and lymphoedema. Reduction in pain through interventions such as the use of compression stockings for lymphoedema management had a beneficial effect on participants' mobility and well-being. *'The stockings do help, the legs don't ache so much and it makes it easier to walk.'* Fatigue, requiring will, effort and courage to keep going, was also a frequently mentioned symptom. *'I wouldn't have thought about getting up and going for a walk, it just wouldn't have appealed to me. I just wouldn't have had the energy.'* Dyspnoea was often perceived as being even worse than pain or fatigue. One participant called their lungs

## Box 2. What fosters hope during palliative rehabilitation?

Participants found that the following key factors helped them regain hope during palliative rehabilitation:

- Active interaction
- Diversion
- Unity and wholeness
- Feeling valued as an individual
- A comforting environment
- A sense of well-being
- A positive change in attitude
- Challenges
- Achievable goals
- Incentives
- Normality

'the main engine of your body', which meant that any reduction in lung function was felt to be a step nearer to death, causing psychological and emotional distress, an increase in dyspnoea and loss of control.

After rehabilitation, participants reported an improvement in mobility, muscle strength and stamina. From a psychological point of view, they reported feeling more positive, relaxed, accepting, with the ability to 'do normal things' and be in control, which contributed to their sense of hope. *'I think it's because I'm seeing other people and I'm not feeling sorry for myself. [...] Now I'm even doing the washing up at home, and I never would have dreamt of doing that*

### Gaining a sense of control may be the turning point in the rehabilitation process

*a few months ago.'* Participants described being in control of their symptoms and felt they had improved physically and psychologically. *'There was a great change in my health from when I first came to the palliative day care centre. [...] I was very, very low, I was extremely low. I was still very weak and weary and tired, and that tiredness has disappeared completely.'*

Participants' perceptions were that palliative rehabilitation had improved their quality of life by giving them some sense of purpose, a reason to live rather than just existing.

### Discussion

Participants had different backgrounds and experiences, but they also had things in common: their diagnosis, similar symptoms of pain, dyspnoea and fatigue, and the fact that their overall well-being had deteriorated since diagnosis. These factors are common to most people living with cancer referred to palliative day care centres. Therefore, although the number of participants was small, findings from this study may be applicable to a wide variety of people with a cancer diagnosis and palliative care settings offering rehabilitation.

Prior to rehabilitation, participants felt isolated and often became anxious and withdrawn, which led to loss of control, low mood or depression. This state of isolation is described by Fromm<sup>7</sup> as one of the major behavioural responses to the loss of hope. As found by other studies, emotional and spiritual pain were seen to be as stressful as physical pain.<sup>8</sup> Psychological symptoms appeared to affect, and be affected by, perceptions of fatigue, physical symptoms and disability, especially in those with dyspnoea, as has also been found by Pearman<sup>9</sup> and by Lee.<sup>10</sup> Changing from a negative to a positive attitude was perceived to be key to the change in bodily health, supporting Mellon's findings<sup>11</sup> and stressing the psychological as well as physical effect of rehabilitation.

Participants mentioned the importance of the environment created by staff, which was in contrast to the clinical setting, where an individual seems to exist solely through their pathology, symptoms, disability and limitations.<sup>12</sup> Findings indicate that not all the symptoms experienced by people with cancer can be directly attributed to the disease itself. The environment of the day care centre provided peer recognition and respect, the opportunity to belong to a group and engage in human relationships, a sense of security and protection, and the opportunity for creation and recreation.<sup>13</sup>

Buckley and Herth<sup>14</sup> have proposed seven hope-fostering strategies, including interpersonal connectedness. This 'connectedness' may have promoted trust, enabling the healthcare professionals to explore participants' unique and individual stories. This gave participants freedom to adjust and accept what was happening to their bodies. Once this process had taken place, participants felt able to achieve more in their lives.

Palliative rehabilitation diminished feelings of hopelessness<sup>15</sup> by providing a sense of control. Gaining a sense of control may be the turning point in the rehabilitation process, bringing people from isolation and depression to competence and self-esteem – a process that is achieved by their own actions.

Thus it can be said that palliative rehabilitation provides the support needed to reduce both the physical and psychological isolation commonly experienced by people living with cancer.

## Conclusions

Palliative rehabilitation enables people not only to learn how to control their long-term symptoms, but also to create new meaning. In our study, an open and supportive environment fostered a sense of hope and gave participants the mental well-being and physical energy to look outwards and regain a sense of connectedness with themselves and their lives, enabling them to live rather than just existing.

Box 2 highlights key factors that helped participants regain hope during palliative rehabilitation. Further research is needed to explore these findings, by conducting questionnaire-based surveys in other hospice settings offering palliative rehabilitation, and by using validated questionnaires assessing quality of life administered before and after palliative rehabilitation.

### Declaration of interest

The research described in this article was sponsored by the Association of Chartered Physiotherapists in Oncology and Palliative Care, Medi UK Ltd and the Board of Trustees of the specialist palliative care centre at Lewis-Manning Hospice, Poole, Dorset. The authors declare that they have no financial relationship with these organisations and that there is no conflict of interest.

### References

1. Davies NJ. Cancer survivorship: living with or beyond cancer. *Cancer Nurs Pract* 2009; **8**: 29–34.
2. Hindle S. Cancer survivorship and the role of support workers. *British Journal of Healthcare Assistants* 2010; **4**: 482–485.
3. McClement SE, Chochinov HM. Hope in advanced cancer patients. *Eur J Cancer* 2008; **44**: 1169–1174.
4. Belchamber CA, Gousy MH. Rehabilitative care in a specialist palliative day care centre: a study of patients' perspectives. *Int J Ther Rehab* 2004; **11**: 425–434.
5. Smith JA. Beyond the divide between cognition and discourse: using interpretive phenomenological analysis in health psychology. *Psychology Health* 1996; **11**: 261–271.
6. Belchamber CA. Participants' perception of groupwork in the management of cancer symptoms in older people. *Groupwork* 2009; **19**: 79–100.
7. Fromm E. *Revolution of Hope: Toward a Humanized Technology*. New York: Harper and Row, 1970.
8. Chen ML. Pain and hope in patients with cancer: a role for cognition. *Cancer Nurs* 2003; **26**: 61–67.
9. Pearman T. Psychosocial factors in lung cancer: quality of life, economic impact, and survivorship implications. *J Psychosoc Oncol* 2008; **26**: 69–80.
10. Lee EH. Fatigue and hope: relationships to psychosocial adjustment in Korean women with breast cancer. *Appl Nurs Res* 2001; **14**: 87–93.
11. Mellon S. Comparisons between cancer survivors and family members on meaning of the illness and family quality of life. *Oncol Nurs Forum* 2002; **29**: 1117–1125.
12. Galvin D. The Clinical Attitude in Rehabilitation and Alternatives ... A Reaction. In: Woods DE, Wolf A, Brubaker D. *The Clinical Model in Rehabilitation and Alternatives*. New York: National Rehabilitation Counseling Association and World Rehabilitation Fund, 1983: 39–43.
13. Bauer D. *Foundations of Physical Rehabilitation: A Management Approach*. Edinburgh: Churchill Livingstone, 1989.
14. Buckley J, Herth K. Fostering hope in terminally ill patients. *Nurs Standard* 2004; **19**: 33–41.
15. Scialla S, Cole R, Scialla T, Bednarz L, Scheerer J. Rehabilitation for elderly patients with cancer asthenia: making a transition to palliative care. *Palliat Med* 2000; **14**: 121–127.

Caroline Belchamber, *Physiotherapy Lecturer, School of Health and Social Care, Bournemouth University, Bournemouth*; Mamood Gousy, *Principal Lecturer, School of Health and Social Care, University of Greenwich, London*; Caroline Ellis-Hill, *Senior Lecturer, Centre for Qualitative Research, School of Health and Social Care, Bournemouth University, Bournemouth, UK*