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.

Cancer 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. 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. 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. 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:

- 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
- 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.

**Method**

An interpretative phenomenological approach 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.

**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

**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.
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.5

### 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.6 ‘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

### Table 1. Physical symptoms experienced by participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Cancer diagnosis</th>
<th>Pain</th>
<th>Dyspnoea</th>
<th>Fatigue</th>
<th>Lymphoedema</th>
<th>Cramps</th>
<th>Dry cough</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Right breast cancer (recurrence)</td>
<td>Yes</td>
<td>––</td>
<td>Yes</td>
<td>Yes</td>
<td>––</td>
<td>––</td>
</tr>
<tr>
<td>2</td>
<td>Bilateral breast cancer</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>3</td>
<td>Renal cell carcinoma</td>
<td>––</td>
<td>Yes</td>
<td>Yes</td>
<td>––</td>
<td>––</td>
<td>––</td>
</tr>
<tr>
<td>4</td>
<td>Cancer of the oesophagus</td>
<td>––</td>
<td>Yes</td>
<td>––</td>
<td>––</td>
<td>––</td>
<td>––</td>
</tr>
<tr>
<td>5</td>
<td>Cancer of the colon</td>
<td>––</td>
<td>––</td>
<td>Yes</td>
<td>––</td>
<td>––</td>
<td>Yes</td>
</tr>
<tr>
<td>6</td>
<td>Right breast cancer (recurrence)</td>
<td>Yes</td>
<td>––</td>
<td>Yes</td>
<td>––</td>
<td>––</td>
<td>––</td>
</tr>
<tr>
<td>7</td>
<td>Prostate cancer</td>
<td>––</td>
<td>Yes</td>
<td>Yes</td>
<td>––</td>
<td>––</td>
<td>––</td>
</tr>
<tr>
<td>8</td>
<td>Cancer of unknown primary</td>
<td>––</td>
<td>––</td>
<td>Yes</td>
<td>––</td>
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</tr>
</tbody>
</table>
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 ‘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 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.

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

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

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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 Fromm7 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.\(^8\) 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\(^9\) and by Lee.\(^10\) Changing from a negative to a positive attitude was perceived to be key to the change in bodily health, supporting Mellon’s findings\(^11\) 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.\(^12\) 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.\(^13\)

Buckley and Herth\(^14\) 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\(^15\) 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**

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**References**


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