Homecoming—Dignity Through Movement at the End of Life: A Qualitative Interview Study With Healthcare Professionals

Fiona Cameron, PT, MSc1, Anna Janze, RN, MSN1, and Anna Klarare, RN2,3

Abstract

Aim: To describe healthcare professionals' and volunteers' experiences of a pathway for movement on a hospice ward. Method: This was a qualitative study with an inductive approach. Data were collected in a hospice setting through 4 focus group interviews with healthcare professionals and volunteers (n = 12). The focus group participants varied in age, profession, and length of experience in palliative care. The interviews were audio recorded, transcribed and analyzed with qualitative content analysis. Results: Dignity through movement at the end of life was the main theme, complemented by 4 sub-themes. Two descriptive sub-themes: “A practical tool to facilitate physical activity” and “Companionship and goals give meaning to the day,” and 2 interpretative sub-themes: “Regaining control and having a choice” and “Feeling normal and alive” based on participants’ views of patient experiences. Significance of Results: Indications are that the pathway for movement addresses a wide range of experiences related to different aspects of being human in a difficult situation. Experiences of movement and physical activity can promote wellbeing, dignity, and a sense of feeling “at home” for patients within hospice care. The pathway for movement is simple to set up, offers access to appropriate physical activity and seems to benefit patients both in the early and later phases of palliative care.

Keywords

hospice, palliative care, movement, body awareness, dignity, well-being, qualitative

Introduction

Palliative care is based on a holistic view of humankind, in which the physical, psychological, social, spiritual and existential dimensions are interwoven.1-3 The World Health Organization’s definition of palliative care affirms quality of life and dignity, in helping patients “live as actively as possible until death.”4 Dignity is a multifaceted concept involving human value, a person’s social position, ethical actions and personal identity within a larger group.5 Symptom distress, ability to preserve their core identity and roles as well as level of autonomy contribute to patients’ perceptions of dignity at the end of life, in effect promoting courage to live despite existential pain.6 Palliative care has developed significantly during the past 30 years, resulting in a longer palliative phase of illness,7 and repeated periods of inpatient care. Without the possibility to be physically active while in hospital, there is a risk that patients will lose their independence.

The human body is built for movement and goal-oriented activity activities, as well as being the medium through which we experience and communicate with the world8,9 In normal functioning, the body is perceived as invisible and unnoticed, all its different parts automatically integrated10 but in sickness the body demands attention and becomes an object for treatment. Merleau-Ponty identified dualistic positivisms separation of the person into body and mind as a problem, and believed that in order to understand the whole person, one must also understand their context. The “Lived body” theory describes all aspects of human existence, body, mind and the present situation, as woven together in a constant interplay creating meaning. The unpredictable and failing body disturbs this interplay and can cause feelings of alienation and homelessness, with a person neither feeling at home in their body nor in their social relationships.11,12 There is a strong link between

1 Ersta Sköndal Bracke University College and Ersta Hospice Clinic, Palliative Research Centre, Stockholm, Sweden
2 Department of Health Care Sciences, Ersta Sköndal Bracke University College, Palliative Research Centre, Stockholm, Sweden
3 Department of Women’s and Children’s Health, Clinical Psychology in Healthcare, Uppsala University, Sweden

Corresponding Author:
Anna Klarare, RN, Department of Health Care Sciences, Ersta Sköndal Bracke University College, Palliative Research Centre, SE-100 61, Stockholm 111 89, Sweden.
Email: anna.klarare@ehs.se; anna.klarare@kbh.uu.se
patients’ perceptions of dignity and the body’s deterioration, because all aspects of daily life are affected by the loss of the previous “taken for granted” body.6,13 Lawton14 describes the extreme situation of “fragmentation” in which the patient retreats inwards and closes off due to overwhelming feelings of helplessness and despair.

Physical activity and exercise training have shown positive effects on fatigue, daily function and mood in patients with advanced cancer.15-17 However research regarding the experience of movement with focus on body awareness is scarce, and whether movement positively affects wellbeing for weaker patients in the later phases of palliative care warrants exploration. The aim of this study was to describe healthcare professionals’ (HCP) and volunteers’ experiences, observations, and reflections over a pathway for movement on a specialized palliative care unit.

**Methods**

The was a qualitative interview study with an inductive approach.

**Setting**

One of the authors is a registered physiotherapist working in a hospice with 20 single rooms in an urban area in Sweden. During 2019, 388 patients were cared for, 70% of whom died there, with the remaining 30% discharged, often to “Hospice at Home” or other care. The average length of stay in 2019 was 17 days. Patients’ functional levels varied from being confined to bed to being mobile, occasionally even to climbing stairs.

The Body Awareness Movement Pathway (BAMP) was prepared January – May 2019 and started in June 2019 with 4 stations (armchair cycling, sitting-standing, pulling therapy band, mindfulness breathing) and a 60 m walk, see Appendix 1.

**Participants**

All HCPs or volunteers in hospice during May-June 2019 were informed about the BAMP at a staff meeting and through email. Written information and a map were posted in the unit. Each station had a picture and written instructions.

**Data Collection**

Data were collected through focus group interviews with HCPs and volunteers.18 The unit manager invited all staff to participate and informed that it was voluntary. Four focus group interviews of 45-60 minutes were conducted, with 2 to 6 participants in each (n = 12). Nine of the interviewees were clinical staff. Authors AJ and AK facilitated all interviews. A list of questions was used to initiate discussion, with probes for elaboration, see Table 1.

Written informed consent was explained and collected at the start of each interview. Demographic data are shown in Table 2. Interviews were audio recorded and transcribed verbatim.

| Table 1. Interview Guide. |
|--------------------------|
| • What observations do you have of patients or family members using the BAMP? |
| • Have you discussed the BAMP with any patients? |
| • Have you accompanied patient or family member along the BAMP? |
| • Would the BAMP be beneficial for particular patient groups? |
| • How has the BAMP affected activity on the ward? |
| • Which results of using the BAMP have you observed in patients or family members? |
| • What challenges do you see with the BAMP in a palliative care ward? |
| • Have you tried the BAMP yourself? Any suggestions for improvement? |
| • Any other comments? |

| Table 2. Participants in Focus Groups. |
|--------------------------------------|
| Age (year) | Profession | |
| 16-25 | 0 | Assistant Nurse | 5 |
| 26-40 | 4 | Registered Nurse | 1 |
| 41-65 | 7 | Allied Health Professions | 2 |
| 66+ | 1 | Physician | 1 |
| Total | 12 | Kitchen staff | 1 |
| Gender | | Secretary | 1 |
| Men | 1 | Volunteer | 1 |
| Women | 11 | Total | 12 |
| Total | 12 | Years working at Ersta Hospice | 0.5-8 |
| | | Years working in Palliative care | 2-20 |

**Data Analysis**

All data were analyzed with qualitative content analysis.19,20 Each interview was read through several times, before being divided into meaning units. These were condensed whilst preserving the meaning. All codes were manually organized in mind maps (using the software application Simple Mind), one for each interview. Similarities and differences were then compared and clustered in varying combinations to eventually form categories. In the final stage of the process, authors brainstormed together to reach consensus in connections between the categories, thus forming four sub themes and one main theme, see Table 3.

The research protocol for the study was reviewed and ethical approval granted by Ersta Sköndal Brècke University College, number 1908-A, see Appendix 2 [in Swedish].
Results

The first two sub-themes: “A practical tool to facilitate physical activity” and “Companionship and goals give meaning to the day” were descriptive, based on the participants’ observations and experiences. The other two sub-themes: “Regaining control and having a choice” and “Feeling normal and alive” were more abstract and addressed underlying nuances. The four sub-themes were gathered under the main theme: “Dignity through movement at the end of life.”

A Practical Tool to Facilitate Physical Activity

Participants described the BAMP as an asset, something structured and positive to offer patients, as well as to inform relatives and visitors about. HCPs who enjoyed being active themselves, saw a particular value in movement and were glad to see patients using the pathway.

“. . . it is a constant dilemma, you can see people . . . that you could motivate, but we have so many other very sick patients . . . there is the wish to help. It is anyway a problem for us.”

(Focus group 4)

Focus group participants made several suggestions for development of the BAMP and they also highlighted the need for a BAMP that immobile patients could do in bed. Some saw a need for more secluded places for patients, others proposed refining the aesthetics to stimulate senses, like the sound of water or bird song.

Companionship and Goals Bring Meaning to the Day

The stations became meeting places for family and visitors around the patient. This provided opportunity for relaxed companionship and a place to socialize. Patients and HCPs also experienced companionship when the BAMP became the focus for a conversation. Sometimes the patient initiated this with a request for help or to report that they were “off to cycle,” later proudly reporting BAMP use. At other times HCPs initiated conversation with patients.

“[I remember a short spontaneous exchange of words there . . . I know that getting encouragement myself like . . . ] Are you sitting here? Wow, well done, you’re doing great”. . . I know myself that it is motivating.”

(Focus group 4)

Families occasionally supported patients in following the BAMP, but it was also useful for family members themselves. The participants reflected that it is exhausting to sit with a person who is dying, and therefore family members may need to feel control in some way to remain supportive and vigilant.
“That you can have some control over your body and… process thoughts and feelings and sometimes it is also positive to come out from the patient’s room a few minutes, collect yourself… get a little energy from breathing different air for 5 minutes.”

(Focus group 1)

Participants described different goals, a basic one was to see other people. The next level was more function orientated, regaining body control for getting out of bed independently. Other patients had goals such as becoming stronger to manage climbing stairs and return home. The level of goal seemed to influence BAMP use, like using the Motomed cycle with resistance to train muscle strength, or passively to experience movement. Participants remarked that some patients even seemed to have existential goals with the BAMP.

“She had a goal ‘no, I have to become well… I am not ready to die!’ and so I think that you, sort of, in that state get power like, when you have a goal, then you get… more energy from being able to train and the body coping with it.”

(Focus group 2)

Participants concluded that some patients felt better at having exerted themselves and accomplished something, even if the period of activity was very brief. Others were thankful that the BAMP was something to do when the days in hospice were long.

Regaining Control and Having a Choice

The participants supposed that having control over the body in movement could be a way for patients to work through thoughts about loss and death. Patients became more aware of how different parts of the body were still able to function, and this led to a feeling of control and independence that seemed to calm confusion and restlessness.

“Because some patients say: ‘Oh wonderful that I feel where my legs are… that I can pedal, I can lift them. I’m not just lying in bed like… a package, but I can move’.”

(Focus group 2)

Both the effort involved in doing the movements actively, as well as the monotonous circulation of the pedals on the Motomed cycle, were distracting and stimulated the brain to think about something else. This coping strategy promoted relaxation and alleviated anxiety or sadness.

“But I think that you always have a group of patients who maybe struggle a little more with loss and… the thought of dying. And these patients… are… also those… that have the greatest need of getting control over something, when you no longer can control all the losses you have had.”

(Focus group 1)

Some patients refilled energy from the BAMP, while others appreciated pain relief by mobilizing stiff joints and muscles. The positive effects of getting up, reducing the risk of nausea, lung infections and pressure sores, were also mentioned. Some patients preferred to be alone in a secluded place and the BAMP meant self-governed, private time, which could not be undervalued according to the participants.

“I avoid disturbing the patients I see using the pathway for movement. Because I think that it is theirs, their pathway and not mine, in fact.”

(Focus group 1)

The possibility of being able to structure their day, giving priority to certain activities in a planned way gave the patients a chance to exercise autonomy.

“Sometimes I hear ‘No, I can’t do that now because in half an hour I’m going to do the BAMP and I need to gather strength for that’.”

(Focus group 1)

In a setting with many choices out of their control, being able to decide for themselves, when, or if to do the BAMP, seemed empowering for patients.

Feeling Normal and Alive

Patients often felt good after doing the BAMP and were eager to tell others of their accomplishments. They frequently related feedback from the Motomed cycle about the distance traveled or the level of resistance as a testimony to their efforts.

“But also maybe a feeling that you can do something… you lie in bed for 23 hours of the day… and then you pull yourself out of bed and cycle… 5 minutes and maybe that’s that, yes, but I did it and that maybe is more than just a good feeling… I understand that there is more of a deeper meaning.”

(Focus group 4)

Other patients, according to the participants, experienced that having control over their bodies was evidence that they were still alive, “normal like before.” Even just being offered the chance to try the BAMP equated to being met as a person with possibilities, judged as capable, which encouraged self-esteem. The BAMP could also be a tool to acceptance.

“You could also think that the BAMP helps people to work through their feelings so that when their abilities diminish and they can no longer follow the Pathway, then they have accepted their situation.”

(Focus group 1)

Participants described that some patients could be enticed out of their rooms by the BAMP. In doing so, they opened up to the life outside and gained a feeling of freedom. Patients
inspired one another, since movements were performed in the corridors. The BAMP was also described by several participants as a pleasant pause from the constant focus on illness and dying, a sign for hope and life, in a place where you come to die.

“I believe that it has increased the quality of life in some way you could say. Made that last time . . . of life much more, . . . valuable.”

(Focus group 2)

Particularly for patients who had lived an active life, the BAMP reminded them of a real gym and a sense of feeling healthy. Participants described patients who became more physically tired but mentally alert, gaining a sense of inner peace from exerting themselves.

“There is a delightful feeling I think of being able to relax because of tiredness . . . that you have exerted yourself or you’re just tired because you’re sick. That’s a difference that I have seen a few times.”

(Focus group 1)

Discussion

The results indicated that the BAMP stimulated a variety of experiences related to being human with severe life limiting illness. Impressions were that using the BAMP contributed to promoting well-being and dignity through a holistic experience of the body as well as supporting social relationships and roles.

Studies have shown positive experiences related to physical activity in patients with advanced cancer, such as reduced fatigue, increased hope, coping and psychological well-being, as well as improved mood and quality of life. However, in these studies physical strength and fitness, rather than the experience of movement, have been the focus. Results from this study indicate positive outcomes from directing awareness to the body during movement. Participants described that even a relatively short period of movement seemed to be enjoyable for patients, a comfortable feeling of being alive and able to do something with the body, despite having little energy. These are important factors for quality of life.

Merleau-Pontys’ theory of the “lived body” is particularly relevant in understanding the complex phenomenon, in which the usually friction free relationship between all the aspects of being human, can become strained due to sickness and suffering. Movement has potential to create meaningful interactions within the lived body and its current situation, for example even awareness of small movements during breathing has shown benefit for relaxation and anxiety relief. Furthermore, increased contact with, and awareness of the body as it presents with life threatening illness, may create a foundation from which patients are willing to accept change, create new meaning and find the feeling of being “at home” in the body again.

Within caring sciences, researchers have suggested that a focus of care should be promoting meaning, control and helping patients find their way back to being “at home” in their body. Participants in this study described how patients’ ability to decide if, and when, they would follow the BAMP was significant. For seriously ill patients, the possibility of making individual decisions has been described as strengthening self-determination, creating normality and thus conferring dignity. Guilde et al similarly reported that patients who had been physically active before illness, experienced that the possibility to continue moving, supported their identity, and created a feeling of control. The sense of being independent and having control have been suggested as two of the most important aspects during the end of life.

Even though the instructions at the BAMP stations encouraged awareness of the movement in the body, many patients seemed focused on physical exercise, reporting their achievements with pride. This can be understood as a human trait, giving attention to the body as an object for care when it ceases to function as normal and thereby becomes visible. The object and its parts become the focus for strength and fitness training, and this overshadows the body as a subject, the experience of life. This leaning toward physical training may however give positive consequences (albeit temporary) including increased strength, balance and consequently independence in moving, which in turn builds self-image and autonomy, important aspects of dignity.

The study was implemented at first author’s place of work, and she was involved in developing and setting up the BAMP, as well as giving information about the project and its goals on the unit. Consequently, there was a risk of bias, although measures were taken to reduce this risk. Using a BAMP in palliative and hospice care is feasible, however further feasibility and pilot testing with elements of randomization are recommended to validate the model. The main limitation of the study is the lack of direct input from patients. Future studies may remedy this by investigating patients’ perspectives.

Clinical Implications

Present research supports the use of training and other rehabilitation methods to reduce fatigue, dyspnea, and pain as well as improving mood for patients within palliative care. Designing a BAMP for bed bound patients would increase the possibility for those in the last stages of palliative care to be physically active.

Conclusion

This study addressed the understanding of the experience of movement in a structured pathway for patients in a hospice context. The physical, psychological, social, and existential aspects of being the “lived body,” a person in a difficult situation, emerged in the results. Performing bodily movements in the end of life may support patients’ identity and autonomy, thereby promoting their wellbeing and dignity. The pathway...
for movement can also be a useful instrument for facilitating physical activity as well as stimulating community for patients in hospice.

**Acknowledgments**

Great thanks to healthcare professionals and volunteers at Ersta Hospice for their involvement and support during this project.

**Declaration of Conflicting Interests**

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

**Funding**

The authors received no financial support for the research, authorship, and/or publication of this article.

**ORCID iD**

Anna Klarare  https://orcid.org/0000-0001-7935-3260

**Supplemental Material**

Supplemental material for this article is available online.

**References**

1. Clark D. “Total pain,” disciplinary power and the body in the work of Cicely Saunders, 1958-1967. *Soc Sci Med*. 1999;49(6): 727-736.
2. Stajduhar KI, Coward HG. *Religious Understandings of a Good Death in Hospice Palliative Care*. State University of New York Press; 2012:354.
3. Saunders C. The evolution of palliative care. *J R Soc Med*. 2001; 94(9):430-432.
4. World Health Organization. WHO definition of palliative care. World Health Organization, (2020). Accessed May 10, 2021. https://www.who.int/news-room/fact-sheets/detail/palliative-care
5. Nordenfelt L. The varieties of dignity. *Health Care Anal*. 2004; 12(2):69-81; discussion 83-89.
6. Chochinov HM, Hassard T, McClement S, et al. The landscape of distress in the terminally ill. *J Pain Symptom Manage*. 2009; 38(5):641-649.
7. Liepe K, Shinto A. From palliative therapy to prolongation of survival: (223)RaCl2 in the treatment of bone metastases. *Ther Adv Med Oncol*. 2016;8(4):294-304.
8. Kowalski SL. Physical therapy and exercise for hospice patients. *Home Healthc Now*. 2016;34(10):563-568.
9. Dahlberg H. Beyond the absent body—a phenomenological contribution to the understanding of body awareness in health and illness. *Nurs Philos*. 2019;20(2):e12235.
10. Merleau-Ponty M. *Phenomenology of Perception*. Routledge & Kegan Paul; 2013.
11. Copp G. A review of current theories of death and dying. *J Adv Nurs*. 1998;28(2):382-390.
12. Rasmussen BH, Tishelman C, Lindqvist O. Experiences of living with a deteriorating body in late palliative phases of cancer. *Curr Opin Support Palliat Care*. 2010;4(3):153-157.
13. Rasmussen BH, Jansson L, Norberg A. Striving for becoming at-home in the midst of dying. *Am J Hosp Palliat Care*. 2000; 17(1):31-43.
14. Lawton J. Contemporary hospice care: the sequestration of the unbounded body and dirty dying. *Sociol Health Illn*. 1998;20(2): 121-143.
15. Paltil H, Solvoll E, Loge JH, Kaasa S, Oldervoll L. The healthy me appears: palliative cancer patients’ experiences of participation in a physical group exercise program. *Palliat Support Care*. 2009;7(4):459-467.
16. Salakari MRJ, Surakka T, Nurminen R, Pylkkänen L. Effects of rehabilitation among patients with advances cancer: a systematic review. *Acta Oncol*. 2015;54(5):618-628.
17. van den Dungen IA, Verhagen CA, van der Graaf WT, van den Berg JP, Vissers KC, Engels Y. Feasibility and impact of a physical exercise program in patients with advanced cancer: a pilot study. *J Palliat Med*. 2014;17(10):1091-1098.
18. Barbour R. *Doing Focus Groups*. 2nd ed. Sage; 2018.
19. Lindgren BM, Lundman B, Granheim UH. Abstraction and interpretation during the qualitative content analysis process. *Int J Nurs Stud*. 2020;108:103632.
20. Granheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. 2004;24(2):105-112.
21. Gulde I, Oldervoll LM, Martin C. Palliative cancer patients’ experience of physical activity. *J Palliat Care*. 2011;27(4):296-302.
22. Sauter S, Franzén E, Lübcke A. *Fysioterapi i palliativ vård—Rörelseglädje tills livet tar slut*. Studentlitteratur; 2018.
23. van Uden-Kraan CF, Chinapaw MJM, Drossaert CHC, Verdonck-de Leeuw IM, Buffart LM. Cancer patients’ experiences with and perceived outcomes of yoga: results from focus groups. *Support Care Cancer*. 2013;21(7):1861-1870.
24. Henoch I, Osterlind J. Development of the 6S Dialogue Tool to facilitate person-centred palliative care. *J Adv Nurs*. 2019;75(1):3138-3146.
25. Johnston B, Smith LN. Nurses’ and patients’ perceptions of expert palliative nursing care. *J Adv Nurs*. 2006;54(6):700-709.
26. Johnston BM, Milligan S, Foster C, Kearney N. Self-care and end of life care—patients’ and carers’ experience a qualitative study utilising serial triangulated interviews. *Support Care Cancer*. 2012;20(8):1619-1627.
27. Ternestedt B, Andershed B, Eriksson M, Johansson I. A good death: development of a nursing model of care. *J Hosp Palliat Nurs*. 2002;4(3):153-160.