



King's Research Portal

DOI:

[10.1016/j.jpainsymman.2016.04.010](https://doi.org/10.1016/j.jpainsymman.2016.04.010)

Document Version

Peer reviewed version

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Gysels, M., Reilly, C. C., Jolley, C., Pannell, C., Spoorendonk, F., Moxham, J., Bausewein, C., & Higginson, I. J. (2016). Dignity through integrated symptom management: lessons from the Breathlessness Support Service. *Journal of pain and symptom management*, 52(4), 515-524. <https://doi.org/10.1016/j.jpainsymman.2016.04.010>

Citing this paper

Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

General rights

Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Research Portal

Take down policy

If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

Dignity through integrated symptom management: lessons from the Breathlessness Support Service

M. Gysels, PhD, MA, BA, C.C. Reilly, PhD, MSc, BSc, C.J. Jolley, PhD, MRCP, MA (Hons), C. Pannell, Femke Spoorendonk, MD, MSc, BSc, J. Moxham, MD, FRCP, C. Bausewein, PhD, MD, MSc, I.J. Higginson, BMedSci, BMBS, FFPHM, PhD, FRCP

PII: S0885-3924(16)30297-4

DOI: [10.1016/j.jpainsymman.2016.04.010](https://doi.org/10.1016/j.jpainsymman.2016.04.010)

Reference: JPS 9188

To appear in: *Journal of Pain and Symptom Management*

Received Date: 27 February 2015

Revised Date: 2 March 2016

Accepted Date: 29 April 2016

Please cite this article as: Gysels M, Reilly CC, Jolley CJ, Pannell C, Spoorendonk F, Moxham J, Bausewein C, Higginson IJ, Dignity through integrated symptom management: lessons from the Breathlessness Support Service, *Journal of Pain and Symptom Management* (2016), doi: 10.1016/j.jpainsymman.2016.04.010.

This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.



Original Article**Dignity through integrated symptom management: lessons from the
Breathlessness Support Service**

Gysels M^{1,2} PhD, MA, BA, Reilly CC¹ PhD, MSc, BSc, Jolley^{3,4} PhD, MRCP, MA (Hons), CJ Pannell C¹, Femke Spoorendonk¹ MD, MSc, BSc, Moxham J^{3,4} MD, FRCP, Bausewein C^{1,5}, PhD, MD, MSc, Higginson IJ¹ BMedSci, BMBS, FFPHM, PhD, FRCP

¹King's College London, Cicely Saunders Institute, Department of Palliative Care, Policy & Rehabilitation. Bessemer Road, London SE5 9PJ, UK

²Centre for Social Science and Global Health, University of Amsterdam, Nieuwe Achtergracht 166, 1018 WV, Amsterdam, the Netherlands

³ King's College London, Department of Asthma, Allergy and Respiratory Science, Bessemer Road, London, SE5 9RS, UK

⁴Respiratory Medicine, King's College Hospital NHS Foundation Trust, Denmark Hill, London SE5 9RS, UK

⁵Department of Palliative Medicine, University Hospital Munich, Munich, Germany

Corresponding Author: Marjolein Gysels
Merwedeplein 8 iii
Amsterdam 1078ND
Tel: +31621153392
Fax: +31202213566
mhgysels@gmail.com

Tables: 3

References: 27

Word count: 4597

Abstract

Context: Dignity is poorly conceptualized and little empirically explored in end of life care. A qualitative evaluation of a service offering integrated palliative and respiratory care for patients with advanced disease and refractory breathlessness uncovered an unexpected outcome, it enhanced patients' dignity.

Objectives: To analyse what constitutes dignity for people suffering from refractory breathlessness with advanced disease, and its implications for the concept of dignity.

Methods: Qualitative study of cross-sectional interviews with 20 patients as part of a phase III evaluation of a randomized controlled fast-track trial. The interviews were transcribed verbatim, imported into NVivo, and analysed through constant comparison. The findings were compared with Chochinov et al.'s dignity model. The model was adapted with the themes and sub-themes specific to patients suffering from breathlessness.

Results: The findings of this study underscore the applicability of the conceptual model of dignity for patients with breathlessness. There were many similarities in themes and sub-themes. Differences specifically relevant for patients suffering from severe breathlessness were: a. Physical distress and psychological mechanisms are interlinked with the disability and dependence breathlessness causes, in the illness-related concerns; b. Stigma is an important component of the social dignity inventory; c. Conditions and perspectives need to be present to practice self-care in the dignity conserving repertoire.

Conclusion: Dignity is an integrated concept and can be affected by influences from other areas such as illness-related concerns. The intervention shows that targeting the symptom holistically and equipping patients with the means for self-care, realized the outcome of dignity.

Keywords: breathlessness, palliative care, dignity, patient experience, advanced disease, dyspnea.

Running title: Dignity through integrated symptom management

Accepted for publication: April 29, 2016.

Introduction

Dignity is a central ideal in health care. It is considered as the essence of medicine[1] and nursing[2] and it is a basic value in human rights statements[3], policy documents[4] and professional codes[5]. It is generically defined as being worthy of esteem or respect, underpinning a normative frame that should shape our relations with and treatment of others[6]. The concept of dignity has been criticized as lacking clarity and direction for practice[3, 7]. It leaves space for a variety of interpretations and can be accommodated as a central argument in conflicting positions, for example, by both proponents and opponents of euthanasia.

Dignity is an established value in the palliative care philosophy and authors repeatedly state it should function as an explicit goal in end of life (EoL) care[8, 9].

There is a lot at stake around dignity at this stage. The loss of dignity for people at the EoL is associated with high levels of distressing symptoms, and psychosocial and spiritual problems, and the loss of the will to live[10]. However, dignity is poorly conceptualized in EoL care and little empirical exploration is available on this issue. One study developed a conceptual model of dignity based on experiences of terminally ill cancer patients[10]. It comprised three categories: illness-related concerns and the social dignity inventory (which both can have negative effects on dignity) and a positive dignity conserving repertoire which might buffer these.

A symptom which is highly prevalent and causes considerable suffering is breathlessness[11, 12]. It is associated with fear and anxiety and causes disability, loss of independence and social contact[13]. It is responsible for high levels of hospital admission[14], and consequently hospital death, and it is related to increased loss of will to live[15]. A specialist integrated palliative care intervention – the Breathlessness Support Service (BSS) – was developed to relieve refractory breathlessness (i.e. continuing despite optimal medical treatment) and was evaluated by a phase III study[16], according to the MRC Guidance for complex interventions[17, 18]. In the quantitative analysis the BSS significantly improved quality of life for patients by 16%, improved survival and other outcomes compared to controls[16]. The qualitative data uncovered an unexpected outcome of the intervention as promoting patients' dignity[19].

This paper is an analysis of what constitutes dignity for people suffering from breathlessness with an advanced illness. It attends to how patients perceive dignity and which factors influence it. This is important with a view to operationalising the concept in EoL care practice. It can also shed light on the applicability of the model for a population with different diagnoses and suffering from breathlessness, and expand the understanding of the concept.

Methods

Context and sample

The BSS is an outpatient clinic based in the Cicely Saunders Institute at King's College Hospital in Southeast London.

In the trial, 86 patients accessed the BSS, and of these, a sub-sample of 20 patients was recruited to participate in qualitative interviews. For their identification a sampling frame was used (see Table 1). Patients taking part in the RCT were referred through health professionals from respiratory medicine, pulmonary rehabilitation, cardiology, palliative care services, community services and GPs. They were included when they had breathlessness on exertion or at rest due to advanced disease such as cancer, chronic obstructive pulmonary disease (COPD), chronic heart failure (CHF), interstitial lung disease (ILD) or motor neuron disease (MND). Patients were required to take part in short-term physiotherapy. Patients were excluded if they had breathlessness of unknown cause or a primary diagnosis of chronic hyperventilation syndrome or if they were too ill to attend the clinic or unable to provide informed consent. The intervention consisted of two clinic visits to the BSS out-patient service,

and a home visit where they were assessed, referred and treated by 1-2 specialists per visit. The intervention is explained in more detail elsewhere[16].

Data collection

A researcher who did not have prior contact with the patients during the BSS intervention conducted interviews at the end of 12 weeks after enrolment. All interviews took place at the patients' homes. One interview happened in a nursing home which was the place where the patient was living. The interviews were semi-structured and in-depth. A topic guide was used in order to ensure that all relevant topics were systematically covered throughout the interviews. Questions addressed patients expectations, experiences, views about the intervention. Interviews were tape-recorded and transcribed verbatim.

Analysis

The transcribed interviews were imported into an NVivo database. Coding started with the pre-determined categories of the dignity model but its scheme was expanded inductively to capture additional experiences of issues that compromised or enhanced their dignity. Through a process of constantly integrating categories and their properties, or constant comparison, the findings became relevant at a more abstract level. The findings were then compared with the model[10], the new relevant themes and sub-themes were added to the model and those which were not found in the data were removed.

Results

A total of 20 interviews were conducted with 10 patients who suffered from COPD, 6 from ILD and 4 from cancer. Demographic data and clinical information was collected in the context of the RCT (see Table 2). Most of the targets of the sampling frame were achieved. However, the recruitment of patients with cancer was difficult; only four people were included in the qualitative study from the ten people targeted. One of the reasons for the low number of patients with cancer could be due to a concurring intervention with this population in a nearby hospital, who could not be included in this study as it could have biased our outcomes.

As in the dignity model[10], we can discern three major categories from the data: 1. Illness-related concerns, 2. Social dignity inventory, and 3. Dignity conserving repertoire. The analysis showed experiences, events, emotions in these categories where dignity becomes an issue in a patient's illness trajectory (see Table 3).

1. Illness-related concerns. This theme is dominated by the theme of symptom distress, which refers to the anguish caused by the symptom of breathlessness. It is further differentiated into three sub-themes: Physical distress, psychological distress and functional capacity. The data are inundated with descriptions of events caused by

breathlessness and accounts of the resulting disability. These sub-themes are not listed separately as they are so entangled.

Interviewer: *You are ok, you look a little bit breathless?*

Participant: *Yeh, this is what I'm like when I lift a weight [...], any weight at all, you know, over a certain [...] weight. I lift this (participant is lifting some magazines) it is all right, but heavier than that, [...] if I go over 30 percent of water in the kettle, I get breathless. If I keep it below 30 percent of water, I am alright. You know, it is the weight thing.* (P01043)

Someone else evaluated the impact breathlessness had on her daily life, limiting every activity, even the most basic impulses in reaction to these limitations.

...being flawed by something that, has just robbed me of everything basically, and then not even having the breath to sometimes even be able to scream, get the frustration out, or to even explain what is happening to me cause I can't speak. (P01055, woman with ILD).

The distress caused by breathlessness is due to the physical unpleasant experience as well as the impact it has on functional capacity and this affects someone's independence.

I was dying [...], this was it, this was life. I couldn't do anything I'd got to the stage where I was [...] almost housebound [...] and my husband had actually ended up taking over all the chores, even to having to help me dress and go to the toilet, have a bath and it had all come on quite quickly so, I didn't know what to expect. (P01073, woman with COPD)

Breathlessness also causes considerable mental distress triggering anxiety, panic and feelings of fear of dying.

...and you've got a fear: 'is that the last breath you're going to take?' although I've got no fear of dying don't get me wrong [...] and I don't panic but the ooh, 'is this going to go away?'. (P01041, woman with COPD)

But the suffering of breathlessness is reinforced by the lack of information about the symptom and its progression and patients live with a lot of uncertainty regarding the nature of their illness and their future.

I would like someone to explain what the hell is happening to my lungs to make it stop, to make it get better and to make it never come back. That would have been fantastic... have some clear understanding of lung disease in general, that they could answer any kind of question [...] I had. (P01055, woman with ILD)

The patient below contrasted the information he finally received about his illness with the bleak prospect given to him earlier and how that had affected his sense of life being worth living.

Participant: *...on Dr X's laptop [...] it showed me exactly what was happening and he explained everything [...] I learned more in that hour than I have done in four years*

because he sat down and he says, now this is what happens here and this is what happens there [...]. I (sigh) I mean I was supposed to be dead, um...

Interviewer: *What do you mean by...?*

Participant: *No, I went to hospital X and I said, [...] to one of the doctors: how long have I got to live? and he says, 18 months, you'll be lucky to see your 64th birthday. [...] my 18 months is up now and me 64th birthday's in 2 months time.*

Interviewer: *Oh really, you're still here?*

Participant: *Yeh just you know, but when somebody says something like that to you...*

Interviewer: *How does that make you feel?*

Participant: *Horrible, you know, you think is it bloody worth it, and [...] I do get days when I get really down (P01058, man with COPD)*

2. Social dignity inventory

The themes in this category derive from the social environment and the way others relate to people suffering from breathlessness, which have an influence on people's sense of dignity. Five sub-themes were uncovered here: stigma, recognition of the symptom, care tenor, privacy boundaries, and burden to others.

2a. *Stigma* has a profound impact on patients' relationships with friends and family, their behavior in public, help-seeking, and their outlook on life. Conditions as COPD or lung cancer are often seen as self-inflicted through smoking and patients feel responsible for their breathlessness and disability.

I could walk round this square [...], but I go so slowly and I keep stopping and I get embarrassed because I think people are looking at you but why should I be like that? I mean. I'm not doing anybody any harm, it's me. I think oh, you know, I'll take the rubbish out and I'll stop about half a dozen times and sometimes someone will come out and I haven't got the breath to talk to them and that embarrasses me, but I shouldn't really should I? I torture myself all the time, I shouldn't get embarrassed, should I? (P01030, woman with COPD)

2b. *Recognition of the symptom.* Against the background of the stigma attached to breathlessness, patients were relieved that there was finally a place where their complaints were recognized as worthy of care. They said it was an unprecedented experience to be able to present their problems to professionals who were competent in its management, and who were aware of its implications.

...and I was right down in the dumps and [...] I felt like nobody really cared but by coming there, I knew that people did care, they are trying to look [...] to help. I didn't feel like the help was out there but the help is out there (P01055, woman with COPD).

2c. *Care tenor* refers to other people's attitudes towards patients suffering from breathlessness, in society and in care services. The interviews showed that this is a central element in people's sense of dignity. In the context of the evaluation of the BSS, the first issue raised by patients was the caring way they were related to by staff. This was expressed in the respectful way they were welcomed, the genuine concern staff showed to improve patients' conditions, and the environment of the Cicely Saunders Institute which aimed since the design stage of the building to embrace this value of care in its architectural features. Patients explained what they meant by the

caring approach of the service and how that made them feel respected as a person. They contrasted this to previous experiences with health services where they felt they were treated as a number, to be informed instead of communicated with.

... by just saying hello, you know, [...]. You sat there and somebody pass, 'hello are you all right', yeh, you know [...] 'would you like a cup a tea' [...] it's just human to human situation. But that environment makes you: you are in the right place, you know. There is no guessing going on, [...]. You are gonna get the best of their mind [...], and they display that to you. Yeh, both occasions I was in peace with that place. (P01043, man with COPD)

... you're given that little bit more time. But, they listen to your side... but I mean you shouldn't be treated as a number, you know. I mean should have a little bit of dignity you know. (P01058, man with COPD)

... they explained everything [...]. Properly and all proper words, understandable words, not some, you know, you meet some of these people and they just think you're thick like...

Interviewer: *medical jargon or...*

...talk down to you. If you talk down to me I won't talk back to you [...] they didn't, no magic, just normal, natural. (P01043, man with cancer)

... but even sort of just the waiting environment really was just more comfortable, wasn't just hard light and hard seats and cause it was even where the chairs were positioned you could actually talk to people, you know... (P01055, woman with ILD)

I've never known a place that I've been to that I've, I felt at home and I think when you can turn round and say a hospital makes you feel at home that is a lot. (P01041, woman with COPD).

2d. *Privacy boundaries* refers to the extent to which one's dignity can be respected or violated through infringing on one's personal space.

... there was this kind of faceless voice at the end of the phone [...] and asking me very, extreme personal questions without saying, 'I know this is extremely difficult, is this a good time to talk to you'. It wasn't even appropriate for me to talk to her at that moment because I had somebody with me. (P01055, woman with ILD)

2e. *Burden to others* refers to the loss of meaning of life when being dependent.

... I told them quite frankly that I had no intention of having carers in my home. Well, if I got to that stage I'd want to go to Switzerland and that's the end of it. (P0168, woman with ILD)

3. Dignity conserving repertoire

This category consists of positive elements that can possibly buffer the negative influences of the illness-related concerns and the threats of the social dignity inventory. Three sub-themes can be distinguished: a. the conditions underlying the

other two dignity promoting elements in this category: b. dignity conserving perspectives, and c. dignity conserving practices.

3a. *Conditions for dignity promoting repertoire* make it possible to adopt or maintain perspectives or practices that help to bolster or preserve one's dignity. The analysis showed that knowledge about successful strategies, and qualities as confidence and motivation serve such a supportive function.

... they encourage me to have a go, and I have a go and it works (P01044, man with cancer).

... it's important to keep your confidence high when you've got something like that because it can knock you for six, if you can't catch your breath. Then you can't do the basics and that will erode your confidence so anything that kind of helps you keep your confidence high or keep that level of self esteem up is important for people [...] cause then you're more likely to take your medication or look after yourself, you're more likely to turn up to that appointment, more likely to keep [...] going really. (P01055, woman with ILD)

3b. *Dignity conserving perspectives* are ways of bolstering qualities or views that conserve respect. These can be based on inherent individual characteristics as well as on newly acquired insights. We found three subthemes: hopefulness, a balance between acceptance and fighting spirit, and pride.

Hopefulness was mentioned in the sense that patients did not feel abandoned. While they experienced a lack of understanding regarding the nature and management of breathlessness in health facilities, at the BSS people felt that they were worthy of care, because even in the face of this difficult symptom, staff looked for ways to provide relief.

Hospital X is the place well, 'we can't do anymore for you', but with you... I've been handed a bit of hope... (P01058, man with COPD)

For breathlessness more is needed than just accepting one's situation. This is due to the disability cycle where breathlessness deceives patients into carefulness and reduction of activity and leads to worse disability. The woman below was well aware of the need to maintain a precarious balance[20] between acceptance of having a chronic illness and on the other hand a fighting spirit in order to keep active and not give in to resignation.

... holding onto the expectation of getting better rather than just being told well, we can't fix you, you can't fix yourself you're going to stay this way and just accept it, cause I'm in a fighting position and I'm not going to accept it, things have to get better and they will do. (P01055, woman with ILD)

Pride can be maintained in the face of the limitations imposed by breathlessness. This patient told about his participation in the walking test at the service.

I wanted to show off and I did, and I scored good didn't I? (P01043, man with COPD)

3c. *Dignity conserving practices* are practical strategies patients apply to enhance or maintain their sense of dignity. Sub-themes are: living in the moment, practicing self-care, reciprocate care.

Living in the moment is one of the strategies patients mentioned to keep life worth living.

I [...] take each day as it comes and get on with it. (P01045, man with cancer)

Practicing self-care is a skillful requirement to maintain a precarious balance which allows a certain level of well-being. Those who succeed can derive an accomplished feeling from it, recognizing the expertise and insight it requires.

I'm more confident in myself, make me know I can do more for myself. Before I didn't. Many things I can really do for myself whereas I didn't think I was capable before. (P01044, man with cancer)

You can say '[...] doctor, I'm getting an infection', and they wait for sort of green gunge to appear by which time you can say 'I'm calm, [...] you can't say that I'm panicking', so [...] therefore telling me what I'm feeling is not what I'm feeling, and I'm not being talked out of that. If you're approaching the situation calmly then you can get your appointment passed and [...] get help more swiftly. As opposed to someone saying 'you're hysterical just calm down, [...] your breathing would be better, that's what the problem is, you haven't got an infection. Whereas you know your own body, you know when you've got an infection. (P01055, woman with ILD)

3d. *Reciprocity for care* refers to the wish for giving something back for what patients experienced as good care and this can give them the opportunity to feel useful.

... anything that I can help people, or [...] when you get students [...] as we do over the doctor's, I'll always be more than willing because they've been such a help to me (P0104, woman with COPD)

Discussion

The findings of this study underscore the mechanisms of the conceptual model of dignity in patients with a progressive illness where illness-related concerns and the social dignity inventory have negative effects on dignity, which might be buffered by a positive dignity conserving repertoire[10]. Our data suggested different themes and sub-themes from those constituting the categories of this model. This is possibly due to the different sample included in this study and the different angle from which we approach dignity. Whereas the study underpinning the original model developed by Chochinov et al. worked with terminally ill cancer patients, the data from this study are based on patients with different advanced illnesses who had participated in an intervention to alleviate their symptoms and concerns, especially refractory breathlessness.

Breathlessness is such a dominant symptom that patients reduce all their suffering to their breathing problems which may override or aggravate other illness-related concerns. Episodes of breathlessness, whether or not in combination with constant breathlessness causes serious physical distress, requiring skilled concentration work to keep it under control[21]. It triggers other symptoms such as anxiety and panic[22], and the experience can be so profound that it leads to intense fear of dying[13, 21]. This threat to one's life often persists when episodes of breathlessness have subsided and they are exacerbated by the uncertainty which exists around the progression of one's condition[23]. Breathlessness impacts directly on patients' functional capacity and therefore we did not list it as a separate theme under the category of illness-related concerns. The disability and the dependence breathlessness causes are all interlinked with the physical distress and the psychological mechanisms which are triggered in response to this symptom.

The themes of the category of the social dignity inventory are also different from the categories identified in the original model. The most important theme here was stigma which plays a considerable role in how the symptom is experienced. Breathlessness is often understood as a self-inflicted problem, due to a habit of smoking, for which patients are held responsible[24]. Patients prefer to avoid showing the signs of breathlessness – coughing, struggling for breath, restrictions in moving etc. – in public, as they feel it deprives them from their dignity. The stigma attached to breathlessness is one of the reasons why there is a lack of recognition of this symptom, and why there is so little knowledge about its consequences and how to manage it[24]. Therefore, patients were extremely grateful for the caring way they were treated at the service. They contrasted this with the undignifying circumstances they had experienced before when looking for help. The personal approach was contrasted with their experience of being treated as a number in other services, the respectful communication with the medical jargon which tends to be used in health facilities. The politeness of staff at the BSS signaled professionalism to patients and the welcoming approach and environment was seen as an affirmation to their dignity.

Being a burden to others, was experienced as an important concern[25], and in one case as a reason for wanting to end one's life. Concerns about privacy also appeared from the data, and show that these are not restricted to institutional settings. Social support and aftermath concerns did not emerge as sub-themes from the interviews. Aftermath concerns may be lacking due to the uncertainty of prognosis in non-malignant conditions which the majority of the sample consisted of.

In the dignity conserving repertoire, we found an additional theme to the perspectives and practices bolstering dignity. These are the conditions for the perspectives and practices: knowledge that self-care is the key to well-being and confidence that one is capable of practicing it, and that it works. The sub-themes hopefulness, balance between acceptance and fighting spirit, and maintenance of pride emerged as perspectives. The other perspectives in the Chochinov model – continuity of self, role preservation, generativity/legacy, autonomy of control were not found. As practices emerged: living in the moment, practicing self-care and reciprocity. Living in the moment also appeared in the model, but there were no examples of maintaining normalcy and the need for spiritual comfort in our data.

Our findings underscore the applicability of the dignity model through the many similarities in themes and sub-themes which we identified. This was despite the differences characterising the samples between the studies. Patients had different conditions, were from different geographic regions, and were living in different settings. This suggests that many of the concerns regarding dignity have broader relevance. However, we also found a number of themes and sub-themes which were of particular relevance to patients suffering from severe breathlessness. These can point to areas which need addressing in the relief of distress caused by this vexing symptom. Raising awareness about breathlessness and the elimination of stigma appeared here as important elements in the relief of suffering. The conditions and perspectives need to be present to practice self-care which is key in the well-being of patients with breathlessness.

The aim of most dignity therapeutic interventions is formulated in terms of reaching those areas that lie beyond the typical symptom distress paradigm. Dignity therapy tends to target dignity via the dignity conserving repertoire and most interventions are directed towards greater patients' autonomy by involving them in decision-making about their treatment, or help patients leave a legacy by realizing a product that documents their life[26-28]. This study shows that an intervention which starts from the symptom can have the effect of enhancing dignity. The findings show that for patients where breathlessness is such a pervasive symptom and has an influence on all other aspects of life, an intervention directed to the symptom with a holistic approach, can promote dignity. This concurs with Macklin's view that dignity is a concept which can not be compartmentalized[2]. It needs to be tackled from the most important issue that impinges on patients' self-worth and followed through at all levels where it causes distress. Conducting an intervention with a generativity document for patients with breathlessness would perhaps promote dignity in certain areas but it would miss all the symptom-related problems. Therefore, it is not so much the focus (symptom versus psychosocial/spiritual) which is important for a dignity intervention but rather the integrative approach, recognizing the inter-relatedness between its components, as well as its interactive nature, where dignity is understood as a quality which is shaped through relationships between patients and their carers and the wider community. It is precisely the combination of these features, a well-resourced service which provides the means to equip patients to practice adequate and supportive self-management that make the BSS into an empowering intervention, providing dignity-enhancing care.

The study's findings are based on interviews enquiring about patients' experiences of the care provided by the BSS, and not on direct questions about people's ideas of dignity. However, the accounts are full of reflections and examples which patients identified as enhancing or compromising their dignity. The sample only comprised 20 patients, all suffering from breathlessness but with different conditions. A larger sample could shed light on whether there are differences in the themes and sub-themes which can influence dignity between different conditions. The sample has a larger number of patients with non-malignant conditions than initially targeted. This may have made the differences found in themes and sub-themes from the original model more pronounced. We aimed to sample between 4-6 patients with a NRS breathlessness score < 3 which we achieved (patient IDs 2,3,6,9). The low number of patients with low breathlessness scores at rest is reflective of the patient group i.e. patients with refractory breathlessness and also the inclusion criteria of the study[16].

We used the NRS to stratify patients with regards to breathlessness intensity; however, as breathlessness is subjective experience combination breathlessness intensity and quality, these results discuss patient's individual experiences / impact of breathlessness on their lives, thus we are confident that the results are unlikely to be influenced by the distribution of our NRS breathlessness scores[29].

Conclusions

This paper presents an analysis of the dignity-promoting features of the BSS on the basis of the dignity model developed by Chochinov et al.[10] The findings support the applicability of the dignity model for people with refractory breathlessness, but change some of the themes and sub-themes that populate the three categories mediating the experience of dignity. This is the first study to provide empirical evidence of how breathlessness compromises patients' dignity, and which elements of care can promote their sense of self-worth. Dignity is generally conceived as an existential experience and interventions generally approach it at this level. But dignity is a concept which is much broader and can be affected by influences from other areas such as the illness-related concerns. The intervention shows that targeting the symptom holistically, by equipping patients with the means for self-care, realized the outcome of dignity.

Disclosures and acknowledgements

This study is funded by an NIHR-grant from Research for Patient Benefit (PBPG-0808-17311). This paper presents independent research funded by the National Institute for Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG- PB-PG-0808-17311). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health. Additional funding was also provided by Cicely Saunders International (CSI). The funders had no role in the design and conduct of the study, collection, management, analysis, and interpretation of the data; preparation, review or approval of the manuscript; and the decision to submit the manuscript for publication.

We thank all the patients who participated in this research. We also thank everyone who referred patients in to this study, especially the Palliative Care, Respiratory Medicine and Physiotherapy Departments at King's College Hospital, and the Community Palliative Care teams across Guy's and St' Thomas hospitals. Thanks to Julie Fuller and Joanna Davies for providing administrative support during this project.

Contributors

IJH, CB, CJJ, and JM conceived the idea of the study and secured funding. IJH, CB, CJJ, CCR, JM set up the study. CCR, CJJ and IJH provided the intervention. CB and CCR oversaw the study. CCR, CP, FS recruited participants and conducted and transcribed the interviews. MG analysed the data and wrote the paper, in collaboration

with CCR and IJH. All authors commented on and contributed to the final draft. IJH is the guarantor. All authors had full access to all of the data of the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Competing interests

None declared

Ethics approval

Ethics approval was granted by the King's College Hospital Research Ethics Committee (Ref. 10/H0808/17). The study meets the requirement of the local Research Governance Framework. All patients provided informed consent.

References

1. Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M: **Dignity in the terminally ill: a cross-sectional, cohort study.** *The Lancet* 2002, **360**(9350):2026-2030.
2. Macklin R: **Dignity is a useless concept.** *British Medical Journal* 2003, **327**:1419-1420.
3. Mann J: **Dignity and health: The UDHR's revolutionary first article.** *Health and Human Rights* 1998, **3**(2):31-38.
4. Department of Health: **A New Ambition for Old Age London.** In. London: Department of Health; 2006: [http://http://www.dh.gov.uk/en/Publications and statistics/Publications/PublicationsPolicyAnd Guidance/DH 4133941
5. International Code of Nurses: **The International Code of Ethics for Nurses.** In. Geneva; 2012: <http://www.icn.ch> (accessed 13 June 2013).
6. Gallagher A, Sarah Li, Wainwright P, Jones IR, Lee D: **Dignity in the care of older people -A review of the theoretical and empirical literature.** *BMC Nursing* 2008, **7**(11):doi: 10.1186/1472-6955-1187-1111.
7. Sandman L: **What's the use of human dignity within palliative care?** *Nursing Philosophy* 2002, **3**:177-181.
8. Geyman JP: **Dying and death of a family member.** *Journal of Family Practice* 1983, **17**:125-134.
9. Rurup ML, Buiting HM, Pasman HRW, van der Maas PJ, van der Heide A, Omwuteaka-Philipsen B: **The reporting rate of euthanasia and physician-assisted suicide: a study of the Trend.** *Medical Care* 2008, **46**(12):1198-1202.

10. Chochinov HM HT, McClement S, Kristjanson LJ, Harlos M: **Dignity in the terminally ill: a developing empirical model.** *Social Science and Medicine* 2002, **54**:433-443.
11. Currow DC, Smith J, Davidson PM, Newton PJ, Agar MR, Abernethy AP: **Do the trajectories of dyspnoea differ in prevalence and intensity by diagnosis at the end of life? A consecutive cohort study.** *Journal of Pain and Symptom Management* 2010, **39**(4):680-690.
12. Solano JP, Gomez B, Higginson IJ: **A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease (COPD), and renal disease.** *Journal of Pain and Symptom Management* 2004, **31**(1):58-69.
13. Gysels M, Bausewein C, Higginson IJ: **Experiences of breathlessness: a systematic review of the qualitative literature.** *Palliat Support Care* 2007, **5**(3):281-302.
14. Escalante CP, Martin CG, Elting LS, Cantor SB, Harle TS, Price KJ, Kish SK, Manzullo EF, Rubinstein EB: **Dyspnea in cancer patients: Etiology, resource utilisation, and survival - Implications in a managed world.** *Cancer* 1996, **78**(6):1314-1319.
15. Tatarzyn D, Chochinov HM: **Predicting the trajectory of will to live in terminally ill patients.** *Psychosomatics* 2002, **43**(5).
16. Higginson IJ, Bausewein C, Reilly C, Gao Wei, Gysels M, Dzingina M, McCrone P, Booth S, Jolley C, Moxham J: **Integrated palliative and respiratory care for patients with advanced disease and refractory breathlessness: a randomised controlled trial.** *Lancet Respiratory Medicine* 2014, **2**:979-987.
17. Campbell M, Fitzpatrick R, Haines A, Kinmonth AL, Sandercock P, Spiegelhalter D, Tyrer P: **Framework for design and evaluation of complex interventions to improve health.** *BMJ* 2000, **321**(7262):694-696.
18. Medical Research Council: **MRC framework for development and evaluation of RCTs for complex interventions to improve health** In. London: Medical Research Council; 2000.
19. Gysels M, Reilly C, Jolley C, Pannell C, Spoorendonck F, Bellas H, Madan P, Moxham J, Higginson IJ, Bausewein C: **Fulfilling the ideal of good care for patients with refractory breathlessness.** submitted manuscript.
20. Gysels MH, Higginson IJ: **Self-management for breathlessness in COPD: the role of pulmonary rehabilitation.** *Chron Respir Dis* 2009, **6**(3):133-140.
21. Simon ST, Higginson IJ, Benalia H, Gysels M, Murtagh FE, Bausewein C: **Episodes of breathlessness: Types and patterns - A qualitative study exploring experiences of patients with advanced disease.** *Palliative Medicine* 2013, **27**(6):524-532.
22. Booth S, Silvester S, Todd C: **Breathlessness in cancer and chronic obstructive pulmonary disease: using a qualitative approach to describe the experience of patients and carers.** *Palliative and Supportive Care* 2003, **1**:337-344.
23. Gysels M, Higginson IJ: **The experience of breathlessness: The social course of COPD.** *Journal of Palliative Care* 2010, **39**(3):555-563.

24. Gysels M, Higginson IJ: **Access to services for patients with chronic obstructive pulmonary disease: the invisibility of breathlessness.** *Journal of Pain and Symptom Management* 2008, **36** (5):451-460.
25. Pleschberger S: **Dignity and the challenge of dying in nursing homes: the residents' view.** *Age and ageing* 2007, **36**(2):197-202.
26. Chochinov HM, Kristjanson LJ, Breitbart W, McClement S, Hack T, Hassard T, Harlos M: **Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial.** *Lancet Oncology* 2011, **12**(8):753-762.
27. Hall S, Goddard C, Opio D, Speck P, Martin P, Higginson IJ: **A novel approach to enhancing hope in patients with advanced cancer: a randomised phase II trial of dignity therapy.** *BMJ Supportive and Palliative Care* 2011, **1**(3):315-321.
28. Houmann LJ, Ryhald-Hansen S, Chochinov HM, Kristjanson LJ, Groenvold M: **Testing the feasibility of the Dignity Therapy interview: adaptation for the Danish culture.** *BMC Palliative Care* 2010, **9**(21).
29. Jolley C, J M: **Dyspnea intensity: a patient-reported measure of respiratory drive and disease severity.** *American Journal of Respiratory and Critical care Medicine* 2016, **193**(3):236-238.

Table 1: Sampling frame for qualitative interviews

	Cancer	Non-cancer (COPD/ CHF/ILD etc.
Severity of breathlessness		
NRS < 3	4 – 6	4 – 6
NRS ≥ 3	4 – 6	4 – 6
Sex		
male	4 – 6	4 – 6
female	4 – 6	4 – 6
Age		
< 50 years	2 – 3	2 – 3
50 – 65 years	2 – 3	2 – 3
≥ 65 years	2 – 3	2 – 3
Caregiver situation		
living with caregiver	4 – 6	4 – 6
no caregiver	4 – 6	4 – 6
Intervention		
Fast-track	4 – 6	4 – 6
Waiting list	4 – 6	4 – 6
Total	10	10

Table 2: BSS patient demographic and clinical characteristics

	Age	SEX	Diagnosis	Carer present	Ethnicity	NRS Breathlessness average 24hrs	NRS Breathlessness worst at rest	NRS Breathlessness on exertion	FEV ₁ % predicted	VC % Predicted	FEV ₁ / VC	SaO ₂ (%)
1	77	Female	COPD	No	White British	10	6	10	58	90	75	91
2	84	Male	COPD	Yes	Black Caribbean	6	3	8	52	81	53	97
3	72	Male	ILD	Yes	Black Caribbean	7	0	9	37	42	63	93
4	79	Male	COPD	Yes	White British	6	6	10	42	49	68	96
5	52	Female	COPD	Np	White British	5	10	10	58	76	61	95
6	78	Female	COPD	No	White British	6	4	8	37	94	32	96
7	74	Male	COPD	No	Black Caribbean	5	7	10	26	25	75	95
8	71	Male	CA	No	Black Caribbean	8	7	10	14	20	54	94
9	64	Male	CA	No	White British	7	2	8	58	56	80	98
10	40	Female	ILD /Other*	Yes	Black Caribbean	5	7	9	53	62	76	97
11	63	Male	CA	No	White British	4	6	9	58	63	77	97
12	63	Male	COPD	No	White British	5	5	8	24	22	84	95
13	42	Female	COPD	Yes	Black British	6	6	8	34	29	99	96
14	52	Female	ILD	No	British Asian	7	5	9	43	54	69	94

15	74	Female	ILD	Yes	White British	7	5	8	63	65	77	90
16	77	Male	CA	Yes	White British	6	0	8	68	66	79	96
17	54	Female	COPD / HF	Yes	White British	8	7	10	15	61	21	92
18	75	Male	ILD	Yes	White British	5	3	8	53	47	85	96
19	64	Female	COPD	No	White British	9	6	10	29	60	42	88
20	84	Male	ILD	No	White British	3	0	5	92	100	68	96

CA, Cancer; COPD, chronic obstructive pulmonary disease; ILD, interstitial lung disease; HF, heart failure; NRS, Numerical Rating Scale; FEV1 ,forced expiratory volume in one second; VC , vital capacity; PEF, peak expiratory flow; L, litres; % pred, % predicted.

Table 3: Dignity categories: themes and sub-themes in breathlessness (Chochinov et al. Dignity in the terminally ill: a developing empirical model Social Science and Medicine, 2002, 54: 433-443)

DIGNITY CATEGORIES: Themes and sub-themes		
Illness-related concerns	Social Dignity Inventory	Dignity Conserving Repertoire
Symptom distress <ul style="list-style-type: none"> • Physical distress • Psychological distress <ul style="list-style-type: none"> ○ Anxiety ○ Panic ○ Fear of dying ○ Uncertainty • Functional capacity <ul style="list-style-type: none"> ○ dependence 	Stigma Recognition of the symptom Care tenor Burden to others Privacy boundaries	Conditions for dignity promoting repertoire <ul style="list-style-type: none"> • Knowledge • Confidence Dignity conserving perspectives <ul style="list-style-type: none"> • Hopefulness • Balance between acceptance and fighting spirit. • Maintenance of pride Dignity conserving practices <ul style="list-style-type: none"> • Practicing self-care • Living in the moment • Reciprocate care.