MEANINGS OF BEING OLD AND LIVING WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE

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ABSTRACT

The aim of this study was to achieve a deeper understanding of the meaning of the lived experiences of elderly persons suffering from Chronic Obstructive Pulmonary Disease (COPD) and in need of everyday care. Interviews with six persons were interpreted using phenomenological-hermeneutic method. The first structural analysis showed severe problems in daily life due to old age with a decaying body. In the second structural analysis dialectic experiences were found: resignation - contentedness, loneliness - connectedness and feeling homeless - feeling at home. The interpreted whole revealed a difficult life situation formed both by ageing and illness and was characterised by conflicting experiences. The life, suffering and comfort of elderly persons who are ill with COPD must be understood as a whole, since ageing is just as important as the experience of illness. The findings support the assumption that these patients would benefit from palliative care in late stages of their disease.
SAMMANFATTNING

INTRODUCTION

Palliative care can contribute to quality of life for patients from the point where the disease is established as incurable until the end of life. When the disease progresses over a long time, palliative care along with rehabilitation can add to the patient’s wellbeing. The focuses of palliative and hospice care has so far been mostly on cancer patients. There is, however, an increasing awareness that patients with other life threatening conditions, not least the elderly, would benefit from palliative care\(^1\), and it is a question of ethics and justice to develop palliative care adapted to their needs.\(^2\), \(^3\), \(^4\)

Chronic Obstructive Pulmonary Disease (COPD) is the fifth most common chronic disease in the world. It is characterised by irreversible obstruction of the airways, producing coughing and emphysema. The disease is developing slowly but inevitably. In severe stages dyspnoea and chronic hypoxemia are common symptoms. Many patients then receive domiciliary oxygen treatment.\(^5\)

A review of literature revealed that patients with COPD suffered from various physical symptoms. Foremost were breathlessness and other symptoms from the airways.\(^6\), \(^7\) Patients also experienced fatigue\(^8\), \(^9\) and disturbed sleeping patterns.\(^10\) The most severely ill showed other signs of bad health such as pain, weakness, xerostomia, lack of appetite and constipation.\(^6\) Their psychic health was also deteriorated by depression and
anxiety, and they were considered to have a heavier symptom burden than palliative cancer patients. These symptoms had a negative impact on their quality of life. The patients were often dependent on help from family, friends or home help services. They sometimes suffered from a negative self-image and they could have problems adapting to the limitations caused by the disease. Patients with advanced COPD had to face psychosocial problems and social isolation. Many individuals received support from family and friends, but some of them gained little understanding from people in their environment.

Most of those suffering from COPD are elderly. Additional diseases are common and they might have to face significant losses. Facing loss of capacities and disintegration due to ageing can also be very demanding.

All these hardships can evoke suffering for the patient, i.e. a response to a threat to one’s self, being or existence. A behavioural response to such threats has been conceptualized by Morse as partly enduring and partly emotional suffering. Enduring is seen as a response to a threat to one’s integrity or self and is characterised by blocking painful emotions focusing on the present. It makes day-to-day functioning possible, but it does not bring relief. To attain relief and move on to reaching a reformulated self, it is necessary to enter emotional suffering. This means that the significance of what has happened is recognized, and the sufferer is often very distressed, releasing the earlier
hidden emotions. Recovery can involve a reformulation of self and an acceptance of an altered life-style and future.

Suffering and alleviation in patients with cancer have previously been studied.\textsuperscript{18} For the present study patients with chronic obstructive pulmonary disease were selected, since they have a long term illness with a prominent decrease in quality of life. It is acknowledged that these patients often require a great amount of palliative care in the late stages of the disease and at the end of life.\textsuperscript{2, 5, 6}
AIM

The aim of this study was to achieve a deeper understanding of the meaning of the lived experiences of elderly persons suffering from COPD and in need everyday care.

METHODS

The approach of this study was explorative and the sphere of interest was the life world in terms of lived experiences of persons with COPD. Thus open interviews, in which the participants were encouraged to talk freely about their everyday lives and experiences, were considered an appropriate method. The narrations about their lived experiences formed the material for analysis and their words were supported by documentation of posture, gestures and movements.

In agreement with Frank, the concept “patient” was purposely avoided when referring to the participants. As he states, persons with a chronic disease are not necessarily patients all the time.
Participants

A home care service in a community in western Sweden was chosen for the study.

Participants were recruited among patients who met the following criteria:

- diagnosed with chronic pulmonary disease
- over 65 years of age
- recipients of nursing home care or residents in nursing home/service flat
- Swedish-speaking
- ability to partake in conversations concerning their daily lives and experiences.

District nurses gave patients short information of the study and asked for consent for the interviewer to contact them by telephone for further information, and seven persons agreed. During these calls they received extensive information about the study. One woman declined participation due to tiredness and informed consent was obtained from six persons, two women and four men. They were thus included in the study. The participants were 78 – 88 years old and all of them were diagnosed with COPD. All but one received domiciliary oxygen treatment. Two of them lived in their own homes and the others in nursing homes/service flats. Since they were for instance farmer, housewife and university graduate, their social background varied. The interviewer met them privately in their homes and the interviews lasted between 25 and 70 minutes. The ethical
committee at the medical faculty of Göteborg University, Göteborg, Sweden approved the study (dnr Ö643-01).

The interviews started with an inviting question: “Would you like to tell me about your experiences of living with a chronic pulmonary disease?” The role of the interviewer was then to follow the interviewee through these experiences and to ask consecutive questions when necessary. All but one interview were audiotape-recorded. One man did not permit the use of a tape-recorder, so that interview was documented by field-notes. These notes were transcribed immediately after the interview. Field-notes were also taken after each interview to account for the interviewer’s experience of feelings and non-verbal expressions shown during the interview. They also offered a possibility for the interviewer to reflect on her experiences during the interviews.

**The interpretation process**

The interviews were analysed in accordance with a phenomenological-hermeneutic method inspired by Ricoeur’s interpretation theory. The aim of this method is to reach the meaning of the narrated phenomenon. The analysis consists of three interrelated phases: naïve reading, structural analysis and comprehensive understanding. The interpretation was supported by comparisons with the field-notes. The audio-recorded interviews were transcribed verbatim by the interviewer who then read the transcriptions while listening to the tapes and documenting non-verbal
elements. The narratives were then read and listened to several times to gain a survey of the content and ideas for the structural analysis. Each interview was considered separately and a short statement describing the content was written down. Then all the interviews were reflected on as a whole and questions for further analysis were formulated. For the structural analysis the narratives were read repeatedly in search of meanings to be found in the documented experiences of living with COPD. The meanings found were grouped and compared in order to find themes and patterns. Hard and trying experiences as well as comforting and alleviating experiences were revealed and gradually, through further comparisons, a dialectic pattern became evident.
INTERPRETATIONS AND FINDINGS

Naïve reading

The naïve reading revealed many aspects of life with COPD. The experience of illness was one of several conditions which made life difficult. Other hardships seemed to be more related to life in old age in general. The participants described their lives with COPD in old age as being hard – but they felt they had to struggle on. This formed a significant background to feelings of loneliness, meaninglessness and homelessness, but they also mentioned close relationships and meaningful activities as rewarding and alleviating.

First structural analysis - Living with COPD: it’s a hard life

Living with COPD in old age meant struggling with difficult circumstances. Life was considered as “hard work”. The participants described breathlessness, which caused difficulties in the daily activities. They found it hard to perform household chores or leisure activities. Just to get up in the morning, get dressed and move from one room to another required all their strength. These tasks were also very time-consuming, because they had to stop every now and then to get their breath. One woman, for instance,
became very breathless just by walking a few metres from her bed to a chair. She had to rest several minutes before she could start talking.

The participants also experienced a high degree of tiredness. This, of course, added to their difficulties and made it hard for them to maintain independence. They were – to varying degrees – dependent on practical help from their families and/or the home help service and the staff in the nursing homes. They were also more or less housebound, due to their illness.

"...things I used to do...manage to go to town...that’s not been possible lately..."  

They also described their dependence on medication and domiciliary oxygen treatment. This treatment was sometimes considered as making life complicated. The required technical equipment could be an obstacle, preventing such things as visiting family over night or leaving their home for more than a short outing. Some of the participants also expressed grief for having caused the illness themselves by their habit of smoking. They pondered on what the outcome would have been if they had not started smoking or if they had stopped smoking earlier.

"If I had quit smoking then maybe I would have been much better now."
They also gave vivid descriptions of their other diseases, which afflicted their daily life. Some of the participants observed that life in advanced age might be rather dull, even if one did not suffer from a disabling disease. As COPD develops gradually over time these people, all of them over 75 years old, had lived with the disease and its consequences for a long time. The deterioration had been gradual, and they seemed to have adapted to the conditions, at least partially.

"There is no turning back. You can’t puzzle your head with what it would have been like otherwise. You have to take life as it comes."

It was evident from the narratives that life with COPD in old age was very different from the active and fulfilling lives the participants used to lead previously. Some of them did not find life very meaningful any longer. They also missed their former way of life, things like travelling, visiting friends, inviting the family for dinner or taking interest in different hobbies.

**Second structural analysis - dialectic patterns**

Three dialectic patterns were discovered in the narrations: resignation – contentedness, loneliness – connectedness and feeling homeless – feeling at home. The dialectic aspects were more or less at hand in all the narrations. However, some accounts were more uniform describing mainly hard and trying experiences or mainly comfort and alleviation.
Resignation – contentedness

Some of the participants expressed experiences of being resigned and sad. They did not expect much from life anymore, as they knew that they could not change the circumstances or alter the course of their disease.

“So I live as long as I live. Life isn’t very rewarding, certainly not.”

Other participants, however, were content with their lives in spite of all the difficulties encountered. They were hopeful and kept on struggling to make life as good as possible. This sense of contentedness shifted between a passive contentedness and a more active attempt to do the best of the situation. Several of the participants seemed to move between these poles – sometimes very quickly

“You have to learn that quickly; to be satisfied with what you have. Unless you can change it. But if you can’t...I have to be satisfied with what I have.”

In this statement the words indicated satisfaction with life, but the voice held a note of resignation. This struggle between resignation and contentedness seemed to influence the other areas of life described below.
Loneliness – connectedness

Life with COPD in old age meant being alone and feeling lonely. Those living in their
own homes seldom met anyone but the family and the home care aides/home care nurses.
The loneliness was considered to be partly due to their inability to engage in social
activities such as visiting friends and family.

“I have no opportunity to meet with old friends. That’s a disadvantage.”

A feeling of being neglected by the family, who might live close at hand but did not have
time or interest to visit regularly, was also expressed. Among those living in nursing
homes loneliness were pronounced. They met the staff regularly, but they said that the
residents did not associate very much. One man for example reported that some of the
other residents suffered from Alzheimer’s disease, and he considered them difficult to
associate with.

Another aspect of loneliness was that life seemed to lack a meaningful content. They
were not able to maintain activities and interests earlier enjoyed. A great deal of time was
passed in inactivity or reading the paper, watching television or talking in the phone as a
pastime.
"...time goes by, but it’s not very inspiring."

Participants who had led a very active life with a lot of manual labour had special
difficulties of this kind. They described themselves as hardworking competent people,
who did not like being useless. A male participant stated:

"I don’t do much now...as I can’t do anything, I can just as well lie were I am...There
hasn’t been any work done lately."

It was clear that he evaluated his present situation in comparison to his working life; he
was not happy with the outcome.

The sense of connectedness held experiences of security and happiness. The
connectedness with the family gave the participants a sense of belonging. The practical
support they received was highly valued and was recognised as a prerequisite for
remaining in their homes. Several of the participants talked about children, grandchildren
and great-grandchildren with pride and showed photographs during the interviews.

“Yes, everything is OK with the children...you can’t ask for more...they have good
positions and have done very well.”
Another source of connectedness was the ability to maintain hobbies and interests in spite of the illness. An engaging hobby was described as adding to one’s wellbeing, as well as diverting the mind from sad and miserable thoughts.

“I have a wonderful grand piano ... when I feel like being in that mood; I sit down and play for a while. And if I’m not in that mood, I might ease my mind by playing.”

This was, of course, easier for those who enjoyed hobbies which did not require so much physical strength such as playing an instrument or reading.

An important part of connectedness was the feeling of being connected and content with one’s former life. The present difficulties were alleviated by memories of a good and useful life.

“...I have been very active. I know how much I’ve done before.”

Interviewer: “Do you feel joy when thinking of past times?

Participant: “Yes, I do, because I’ve had a good life.”

There were no absolute polarities between loneliness and connectedness. Some of the participants described both kinds of experience vividly.
Feeling homeless – feeling at home

Several of the participants had moved to nursing homes or service flats, due to the difficulties in managing their daily lives on their own. Even if they could accept this intellectually, they still felt sorry for it. Some expressed a deep sense of sorrow. Having been forced to leave everything that was well known and familiar was expressed as a profound sense of rootlessness.

“I don’t think I have my home here...this is not a real home.”

A special aspect of homelessness concerned the participants’ opinion of the oxygen treatment. Some of them felt rather uncomfortable with this technology and used terms such as being “bound to it” or “captured by it”. A sense of being stigmatised by it was also expressed. It was thus considered embarrassing to meet unknown people when you had to carry a hissing oxygen cylinder and a long set of tubes.

“When the oxygen keeps hissing and everyone asks: what is that? So you avoid going anywhere with it.”

The risk of losing control over your life was also part of the experience of homelessness. This was reported by those receiving home care services. The experience of having to wait for assistance, never knowing exactly when it would come, was very stressful for
persons who were more or less helpless on their own. The following was said by a woman who recalled such experiences while receiving home care before she moved into a nursing home:

"...I did have help from the home care service...but it was hard many times. They were supposed to come in the morning...they came at nine o’clock or at half past nine – that was very late."

Being able to remain in their own homes was considered important. One’s own home gave a sense of security. One participant discharged himself early from hospital because he felt much better when at home. Living in a home created by yourself and your family over the years also seemed to add to the above-mentioned sense of connectedness. Being surrounded by cherished and familiar things was important for one’s sense of identity and self-esteem. The feeling of being at home was, however, described as fragile. The participants were well aware that deterioration in their condition could force them to leave their homes.

Some participants clearly expressed their appreciation of the oxygen treatment. They had integrated the technology in their homes and in their lifestyles. In one home the long oxygen tubes had been neatly arranged to avoid stumbling and allow the man to move easily from room to room. Thus the oxygen was considered a prerequisite for life, and these participants seemed to feel at home with it and be comfortable with the required machinery.
“This [the oxygen] is the help – my life-line.”

Participants could also feel at home when living in a nursing home or a service flat. This experience was closely connected to receiving appropriate help from caring staff.

“You just say one word and they understand, and then they will act accordingly”

“I can get as much help as I want...They will do everything I want...just tell us, they say.”

The experiences varied greatly between the participants. Those who lived in nursing homes/service flats expressed more feelings of being lonely than did those who lived in their own homes. In almost all the interviews, however, both experiences were present. The only aspect evoking entirely opposite views was the oxygen treatment. Some declared that they were uncomfortable with the equipment whereas others were quite comfortable and happy with the treatment.
The lived experiences of being old and living with COPD comprised both illness and being old and frail, thus substantial difficulties. The experiences in daily life were dialectic. Resignation to the difficult circumstances was found along with contentedness and efforts to make life better. This mixture also characterised the other aspects of life; the sense of connectedness with family, former and present life was at hand simultaneously with feelings of loneliness. Likewise, experiences of feeling at home were mixed with those of feeling homeless. Each of the experiences held the opposite as a possibility, i.e. loneliness held a longing for connectedness, and connectedness held the dread of loneliness. The sense of feeling at home similarly involved the risk of becoming homeless, whereas feeling homeless held the longing for a home of one’s own. The experiences were sometimes quickly transformed to their opposites.

Dialectic experiences have previously been found by Qvarnström in her study of dying patients. The evident dialectic can serve as a reminder not to interpret old people’s experiences simplistically. They are not first and foremost lung patients who happen to be old, but rather old persons who also have a pulmonary condition. Their experiences must be regarded from the old people’s wide horizon of life. In agreement with Nilsson’s study concerning very old peoples experiences of ageing, one must take into account that elderly people seem to evaluate their present situation according to their
contentedness with past and present life, activities, relations, philosophy of life and future perspective as well as according to their health. To understand the old people’s experiences their lives must be considered as a whole.

In this investigation being old and because of that living with a decaying body\textsuperscript{26} was just as prominent as suffering from a chronic illness. This could be interpreted according to the concept of corporeality (cf. Merleau-Ponty\textsuperscript{19}). We are bodily in the world, but when we are healthy this is taken for granted. When we are getting old or stricken by illness, on the other hand, the assimilation of self and body is disturbed, and our body might be regarded as an object. This seemed to be true for the participants in this study, as they struggled with many bodily problems, still trying to maintain independence. Their ill and ageing bodies certainly set limits for their lives.

Morse et al\textsuperscript{29,30} studied this phenomenon in different groups of patients. They discovered that patients had varying experiences regarding their bodies. One of the concepts was “the resigned body”\textsuperscript{30}, an aspect which seems to be applicable to the findings in this study. This concept tells us that permanent changes have occurred. The body might have become unrecognizable and dysfunction is permanent. This can threaten the person’s identity. “The pain of the resigned body is loss”\textsuperscript{30} The person who is ill has to surrender the former self and life-style and begin the laborious task of reconfiguring life within the confines of the ability of his or her body.
The findings in this study might be interpreted in accordance with this concept and Morse’s\textsuperscript{17} theory of suffering. The polarity between the experiences could be summarized in two statements:

1. If the person who is ill does not recognize the resigned body, he or she is confined to endurance. This makes reformulation of self hard, if not impossible.

2. If the person who is ill recognizes the resigned body he or she will have the prerequisites for transcendence to emotional suffering. Reformulation of self and reconciliation with life is then possible.

The experiences described in this investigation revealed movements between these polarities; sometimes enduring and sometimes emotionally suffering. This is consistent with Morse’s\textsuperscript{17} findings. In some narrations, however, confinement to endurance appeared. The experience of severe bodily problems seemed to make it impossible to muster the necessary strength to move on into emotional suffering. In these narrations expressions of resignation, loneliness and feelings of homelessness were more prominent. One hypothesis is that the bodily problems required all energy, thus making it necessary to withhold the emotions evoked by existential and spiritual concerns. Other experiences were more consistent with emotional suffering. Even the experience of having \textit{“suffered trough”}\textsuperscript{29} and beginning to reformulate one’s self and accept the life conditions forced upon one by the disease were found. In these narrations contentedness, connectedness and feeling at home were dominating experiences. The conception of the oxygen treatment in these narrations was indeed interesting. It seemed that the
participants had integrated this rather complicated machinery so well, that it had become an extension of their bodies, (cf. Merleau-Ponty\textsuperscript{19}).

In the literature anxiety is acknowledged as a common symptom in patients with COPD.\textsuperscript{6,11} The findings in this study, however, did not reveal prominent experiences of anxiety. This might be due to methodological reasons. Anxiety seems to be connected with very severe dyspnoea and tiredness.\textsuperscript{11} Those who are so ill might not be strong enough to partake in interviews and may thus have been excluded by the district nurses.

In the light of our current knowledge; how are severely ill, elderly persons with COPD best cared for? Several researchers\textsuperscript{2, 6, 12} consider that they would benefit from the holistic approach of palliative care. In view of the findings in this study, we argue that in such palliative care the control of physiological symptoms must not be a goal but a means to comfort the patient and alleviate his/her suffering. Hardships thus lightened, the patient may be able to deal with other aspects of life. For the staff in palliative care, it is important to respond to the cues of enduring or emotional suffering. With appropriate comforting strategies the person who is enduring can be strengthened and suffering can be alleviated.\textsuperscript{31} We must also be aware that transcendence to emotional suffering is not always in itself desirable; in certain situations it might be better for the suffering individual to continue enduring.\textsuperscript{17}
Elderly people with chronic diseases, such as COPD, are cared for in many different settings. Wherever they are, they are likely to be in need of palliative care. It is hardly realistic to extend specialist palliative care to all these people. The challenge for the future must be to train the staffs who care for the elderly, thus expanding palliative knowledge throughout the community and nursing care. Cooperation with palliative consultant teams could be very helpful in achieving this.
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