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Experiences of older people following an acute exacerbation of COPD: a phenomenological study

Abstract

Aims and objectives

To explore the experience of patients affected by COPD following hospitalization due to an acute exacerbation event.

Background

Chronic Obstructive Pulmonary Disease (COPD) is a progressively debilitating disease, often with very burdensome symptoms such as acute and chronic breathlessness and fatigue. Acute exacerbation often creates a life threatening event. Exacerbation can also have substantial psychological effects including anxiety and depression although this aspect is less well researched – especially amongst people with COPD recovering from an acute event and facing a return home.

Design

A descriptive phenomenological study.

Methods

In depth interviews were conducted with twelve COPD patients recently recovering from an acute exacerbation of their COPD. Data were analysed using Colaizzi's phenomenological framework.

Results

Four themes were identified from the data: a sense of loss and frustration, hopelessness, uncertainty about the future and fear of becoming a burden. Participants expressed quite negative views including a loss of hope, uncertainty about their future care and the burden they may become on their families. They appeared stressed and anxious as a result of the acute event they had experienced.

Conclusions

This study shows that an acute episode of illness can generate a sense of hopelessness and uncertainty about their future care in people with COPD. This occurs as they recover physically and think about the future, often in quite negative terms.

Relevance to clinical practice

For healthcare professionals it is important to take into account the potential feelings of loss, hopelessness and uncertainty that people can experience following an acute exacerbation of their COPD and ensure that psychological care is available as physical recovery takes place. Such care to include good discharge planning, giving patients time to express concerns and referral to counselling services if appropriate.

SUMMARY BOX

- This study increases our understanding of how people with COPD respond to acute episodes and how these episodes make them reflect on their own future life.
- Hope plays a significant role in improving the quality of life of these patients and it is important that nurses do all they can to help patients develop some sense of hope or to manage the negative emotions that COPD can create.
- Practitioners should ensure patients and families have pre-discharge care planning that addresses increased care needs.

Keywords

COPD, Phenomenology, patient, older person, hospital, interviews, chronic illness, chronic obstructive pulmonary disease, illness-meaning, nursing.

INTRODUCTION

Chronic Obstructive Pulmonary Disease (COPD) caused the deaths of over 3 million people in 2015 (WHO, 2017). It is also a disease that is on the increase - with the World Health Organization (WHO) predicting a 30% rise in incidence over the next decade unless we become better at reducing smoking and other behaviours that cause COPD (WHO, 2013).

A central feature of COPD is a reduction in the capacity of the lungs due to a permanent narrowing of the airways – sometimes accompanied by a reduction in the elasticity of the lung that prevents full expansion. This change in lung condition is usually secondary to long term exposure to pathogens such as tobacco smoke or

other chemicals that damage lung tissue – this process then leads to frequent episodes of shortness of breath and poor oxygenation of tissues and organs. In certain circumstances this can lead to an acute admission to hospital (Landers, et al., 2015; Kessler et al., 2011; Barnett, 2005). It is also the case that hospital admission rates increase as the disease worsens (Andersson, et al., 2006; Giacomini et al., 2012). However, little is known about how people living with COPD experience the immediate aftermath of an acute episode. This study is designed to make a contribution to this gap in the COPD knowledge base and discuss the implications for COPD care.

BACKGROUND

Several studies have investigated the lived experiences of people with COPD by using qualitative methods but this work mainly focuses on the experience of physical symptoms (Martindale, et al., 2013; Chang et al., 2016; Costa et al., 2016). For instance, Chang et al. (2016) explored how people with COPD experienced an acute admission during hospitalization and work by Costa et al. (2016) focused on how dyspnoea impacts on both patient and caregiver. Both studies reported a desire by patients to live their lives as normally as possible, but that they expressed concerns about their ability to do this as their COPD disease progressed (Milne, et al., 2009).

Research by Harrison et al. (2015) found that some patients with COPD associated their condition with feelings of shame linked to their inability to live independently and also that their lifestyle had contributed to their illness. In addition, the research on COPD highlights that uncertainty about when their health may deteriorate, the

inability to predict exacerbations and uncertainty about future care needs creates anxiety amongst patients (Harrison, et al., 2015; Lewis, et al., 2012; Lewis, et al., 2014).

Another issue with COPD is that there is not a clear stage where the illness moves from a chronic to a terminal illness (Habraken, et al., 2007; Epiphaniou, et al. 2014).

This can impact on the type of care COPD patients receive. For example, Beernaert et al. (2016) suggest that end of life planning should occur earlier in the disease process – but that this is often not the case. Similarly, Landers, et al., (2015) argue that people with COPD do not always have discussions with their care providers about the worsening of their illness and that certain events, like an acute exacerbation, can serve as times when health professionals should introduce end of life care discussions. However, this can be a problematic issue for health care professionals as acute exacerbations of COPD are not wholly predictive of long term prognosis – and identifying the right time to introduce a more palliative approach is a difficult clinical decision (Reinke et al., 2008; Gott et al., 2009).

COPD care is complex in that it is an unpredictable disease process, has periods of stability but also acute episodes, requires the coordination of the multi-disciplinary team and can affect patients physically and emotionally. Nurses are central to the coordination and delivery of this care. This ranges from the management of physical problems, helping with emotional and psychological care and also the planning of future care needs. It also includes – at some stage - engagement with people with COPD about their end of life care needs. At this point nurses again become central as they are key professionals in coordinating the multi-disciplinary team and also are likely to be closest to the person and their family to be a strong advocate (Gott et al., 2009).

Although there is some qualitative research into the experiences of people with COPD there is a need to further identify the emotions and experiences they encounter when a worsening of their condition occurs. This is especially important during the immediate aftermath of an exacerbation– as this is likely to reveal their state of mind at that point where nurses have the opportunity to make a positive intervention. There is also very little qualitative literature on end of life issues in COPD and more research to shed light on this is required. Consequently, this study intends to add to the COPD care knowledge base and strengthen the body of qualitative research in this area - thereby helping to improve COPD care.

METHODS

Given the aim to explore the lived experience of people with COPD this study employed a descriptive phenomenological approach (Colaizzi, 1978). Phenomenology enables researchers and participants to focus on individual lived-experiences (Walters, 1995; Sasso, et al., 2015) and is a method designed to fully capture human experiences and gain a better understanding of the phenomenon under investigation (Hustavenes, et al., 2011; Barnett, 2005). Colaizzi's method is often used in health related research as it provides clear steps for analysis and is advocated as a strong method for exploring patient experiences that produce meaningful results for clinicians. It also allows the production of an overall 'exhaustive statement' of the phenomenon that provides a powerful and succinct summary of the experience under investigation – again, helpful to health professionals wishing to gain an overall insight into the experiences of their patients (Sanders, 2003).

The study used a purposive sample of participants recently admitted with an acute exacerbation of COPD but who were then stabilized and were preparing for discharge. The location of the study was a large teaching hospital in Northern Italy. Potential participants were identified by clinical staff and given an information sheet about the project. Although the participants had been living with COPD for a number of years they were not formally diagnosed as being in the 'end of life' stage of their disease and were not receiving care designed to be palliative. Their exacerbations were being actively treated with the intention of stabilising their COPD and enabling them to leave hospital. Their records indicated that no discussion had formally taken place regarding the ultimate trajectory of their COPD. If willing to take part, their names were given to the research team. Ethical approval was obtained from the Liguria Regional Ethics Committee (CER Liguria Reg. Number: P.R. 402REG2015). All participants gave their written consent when they agreed to take part in the study and confirmed it again just before being interviewed. No personal identification details are reported to ensure anonymity and pseudonyms are used to attribute data extracts.

Data were collected through in-depth interviews between April 2016 and December 2016. Interviews were guided by a flexible interview schedule (see Table 1) and were audio-recorded and transcribed.

Transcripts were entered into NVivo 10 to facilitate data management and analysis. Data were analyzed using Colaizzi's descriptive analysis framework (Colaizzi, 1978), which consists of 6 stages:

1. Participants' narratives are read to get a sense of their overall experiences.
2. Significant statements are then highlighted.
3. Each significant statement is then allocated an interpretative meaning unit (Table 2).
4. These interpreted meaning units are then arranged into larger themes (Table 3).
5. From these themes an '*exhaustive description of the phenomenon*' is created (Colaizzi, 1978, p. 43).
6. Finally, the researcher assembles an overarching statement that sums up the participant's experience of the matter under investigation.

Rigour within the analysis was assured by an application of Lincoln and Guba's (1985) criteria for qualitative trustworthiness. Due to the participants being discharged it was not possible to conduct 'member checking' as a tool to address credibility, however, other steps were taken – particularly, by ensuring the analysis process was scrutinized by all members of the research team. Confirmability is demonstrated by the presentation of examples of the data analysis process through its various stages in tables 2 and 3 – to present something of an audit trail of the analysis process. This can show both adherence to Colaizzi's method and show how raw data contributed to themes and meaning units. The fact that the research team were all involved in the analysis process also contributes to conformability by reducing the risks of individual researcher bias. The data was also interrogated for 'negative cases' and data collection ceased when it was considered that data provided a 'thick description' of the phenomenon. With regard to transferability, the findings of this study provide specific examples of the COPD patient experience that

other researchers can use to compare, contrast or expand upon during their research in other cultures and settings.

FINDINGS

Twelve patients agreed to be interviewed and their demographic data are shown in Table 4.

Four themes were constructed from the individual meaning units: a sense of loss and frustration, hopelessness, uncertainty and fear about the future and fear of becoming a burden. The following are presented as an overall description of the experiences of these participants (under pseudonyms) following an acute exacerbation of their COPD.

Sense of loss and frustration

The impact of COPD on everyday life, especially when the disease has progressed to the later stages, is a recurring theme. Symptom control, in particular, the control of dyspnoea, plays a significant role in improving patients' quality of life. Older patients with COPD often have comorbidities that may affect the diagnosis and the use of health care services. An older person identified himself as "an infant learning to walk". In this sense, the loss of the ability to participate in leisure activities was mentioned:

Huh, well, it takes a bit of courage to face this situation... I say..., you can't expect to want too much, you get what you can. My typical day, right now, I get out of bed, have breakfast and then wait, from one chair to another, eh, how do you want my day to be? All my life I have had breathing problems!

So... so... On the other hand, what can I do?! (Mary)

The disappointment of not being able to expect too much is the reason for the anger that an older patient with COPD had with himself - considering himself dead long before he actually was:

I will be angry until I die, because I died in 2005. I was a healthy, active man, a little man but strong. Now, I can't even get out of bed and go; nothing, nothing, I have a shattering weakness. (Gareth)

They felt they were to blame for their situation and this compounded the sense of loss they were experiencing:

There is nothing else to do. It's all here, on my own, of bad luck and luck, there's nothing else to do. (Ben)

Hopelessness

Closely linked to feelings of loss participants described a growing feeling of hopelessness as they become increasingly short of breath:

There is nothing to do because (laughs and swings his hand), at my age, huh ... then ... then I do not know what to say because ... when you are old you are old. (Tom)

In fact, the phrase 'hopeless' was used – according to one participant – by staff caring for him at the hospital, reinforcing his feelings about his deteriorating health:

Here they did say that the situation was hopeless, that I had COPD and that I would have to come here regularly to be checked if it did go ahead (progress) if it gets worse or remains. So, on that beautiful summer day in 2005 they pulled the trigger on me. (Gareth)

Uncertainty and fear about the future

The exacerbation and the changes it created were things that generated feelings of uncertainty about the future – particularly about how they were going to cope:

At home, it will be terrible, yes, I had to rent an apartment here, next to my daughters; but now I don't know. In the early days, they could afford to get a caregiver for me to help me eat, etc. But only if I'll be a little stronger than I am now. (Mark)

Upon discharge following hospitalization for an acute exacerbation, participants also faced new uncertainties about their illness and the professionals who provide their care and support:

But I tell you that I'm a little worried, because I worry about going back home, but not from the financial point of view, just from the standpoint of what I will do and how I will face life in this way, you know. (Kit)

The most recurrent theme about the return to domestic life after their hospital experience was that they would become a burden to others – especially family members – leading to a loss of their dignity caused by an inability to look after themselves.

Fear of becoming a burden

Participants all described how they are often reliant on their family for care, even if they were living alone:

P: I have my relatives but I live alone, but I've got my children, is that ... well, they are always involved in my care. (Sam)

Related to this was a concern whether the extra care they would need could be provided by their family, and that they were worried about becoming a burden:

At my age it is certain that the children, grandchildren... all have their own business, children can't take care of their sick person constantly, and that's why problems occur, because then the explanations with doctors are very difficult ... and at home certainly they can't take care of me constantly. (Tom)

An overarching description

The data in this study provides an 'exhaustive description' of the phenomena of COPD exacerbation - and in keeping with the methods of Colaizzi the following

'overarching statement of the phenomenon' is offered to succinctly and accurately describe these experiences:

The immediate experiences of patients after an acute exacerbation of their COPD is a negative one. It creates a sense of loss in terms of their previous health and vigour and introduces uncertainty in to their lives. This experience also creates a sense of hopelessness about their future care and creates concerns amongst them that they may place a burden on their family in the future. They also feel that they are losing control over their lives as a result of their COPD worsening.

DISCUSSION

The themes that emerged from the analysis highlight how the participants experienced the acute episode of their COPD and thought about their immediate future – experiences and thoughts that were overwhelmingly negative. The acute episode appeared to draw their attention to what would follow – and this is marked by the strong sense of loss and hopelessness they describe. These losses were linked to the deterioration in their physical health and concerns for the future. The participants in this study add to our understanding of how people with COPD respond to acute episodes in their health – especially how they appeared to be losing hope about their health in the future.

Research on hope in COPD is fairly limited and controversial (Stenzel, et al., 2015). Research by Robinson et al. (2017) found that COPD patients did express some kind of hope about the future, although they also reported feelings of grief and loss related to their COPD. However, the participants in Robinson et al's., study were not

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all interviewed in the immediate aftermath of the severe exacerbation event, as were the participants in this study. This study shows how the initial feelings of patients are quite bleak in terms of their outlook and indicate that this is an important message for nurses as some form of emotional intervention following an acute episode may be beneficial. Indeed, other work with COPD patients has also indicated the sense of hopelessness as being a feature of the emotional response to an exacerbation of COPD (Olsman, et al., 2015).

The data in this study also resonates with that of some other qualitative work on COPD. Particularly, those studies that connect emotional concerns to the worsening of physical symptoms such as breathlessness –for example in the work by Chang, et al., (2016). However, the self-determination described by Milne, et al., (2009) was not evident within the participants of this study. Similarly, the participants in this study did not report any feelings of stigma as reported by Harrison et al. (2015). However, the experiences of loss described in this study are in line with Harrison et al.'s (2015) work on COPD patient experiences.

A number of authors identify that the trajectory of COPD can make it difficult to identify when an 'end of life' situation is reached and when palliative care should be considered (Johnston, et al., 2016; Beernaert et al., 2016). However, recognising and planning for this is an important part of COPD care according to Gott et al., (2009). The participants in this study did not explicitly mention they felt near the end of their life – or mention their death. However, they did express anxieties about their COPD becoming worse and the impact that may have on them. The exacerbation event in COPD could be a clear example of the 'milestones' in COPD described by

Landers, et al., (2015) where a conversation about end of life care could be initiated. Indeed, in other life limiting illnesses there are points where a discussion about palliative care should begin (Epiphaniou et al., 2014) and COPD nurses could possibly learn from cancer care for example, developing skills to communicate sensitively with patients about end of life issues, helping families prepare for bereavement and enhancing their skills in relation to palliative care matters such as symptom control and pain relief. It is clear that COPD patients and their families have expressed a need for discussions with health professionals (Hasson et al., 2009; Epiphaniou et al., 2014) but that this needs to be done gradually and sensitively. The participants in this study may have benefited from a dialogue of this kind as a way of addressing their anxieties – however, this would need to follow careful discussions about what people with COPD are told about their prognosis.

The emotional fear of returning home after hospitalization was clearly a difficult issue for participants. They appeared to struggle to see themselves as belonging to their home; they were disaffected, and felt they could be a burden on their family. Their house was no longer something familiar or well known - leaving hospital for an uncertain future was a significant fear. In critical illness situations, patients rely heavily on the health care team to support them and to be aware of the potential physical and emotional challenges they may face when they leave hospital (Fraser, et al., 2006; Cawley, et al., 2014). This is clearly an issue that needs more attention in COPD care.

This study also highlights the importance of good care planning and positive interventions in COPD. Wolkowski and Carr (2017) discuss the potential use of respite care for COPD patients that can both alleviate patient anxieties about not

being able to cope at home and also give relatives a break from caring. This is certainly one intervention nurses could consider following an acute exacerbation of COPD and has been found valuable in other COPD studies (Wilson et al., 2008).

A number of studies highlight the psychological impact of COPD (Lewis, et al., 2012; Lewis, et al., 2014; Harrison et al., 2015), however this study shows that health professionals managing COPD patients after an acute exacerbation should pay more attention to these particular stressors and develop interventions to address them. There are a number of ways this could be done. First, nurses are key managers of multi-disciplinary care – in COPD care this should involve referral to counselling and other emotional support professionals when COPD patients demonstrate significant anxieties. This links strongly with the work of Habraken, et al., (2007) and Goodridge, et al., (2008) who identify the importance of addressing the mental health of people with COPD.

Second, nurses should treat an acute exacerbation of COPD as an opportunity to sensitively start a dialogue with the patient and family about long term prognosis and likely care needs – including where appropriate, end of life care. This is certainly advocated by Landers, et al., (2015) who stress the importance of open discussions with people about their COPD prognosis. Third, COPD nurses should also recognize when strategies to develop physical and emotional coping mechanisms, such as CBT related stress management techniques and practical help from occupational therapy could be used to develop confidence and self-reliance. This requires the use of judgement about the patient and their stage of illness – and again, relies on nurses to instigate referral to health psychologists and

similar professionals. In addition, COPD nurses should assess the opportunities they have to refer patients to respite care, rehabilitation care and other forms of community based care when planning a patients discharge – interventions that have been advocated as important elements of COPD care in other studies (Hasson et al., 2009; Wolkowski & Carr, 2017).

LIMITATIONS

Although providing useful data in a poorly researched area, this is a relatively small study and further research with larger numbers of people with COPD would be useful. This study did not enquire into the prior knowledge that the participants held about their prognosis – direct questions about this would have been unethical – so further research that looks at how prior knowledge may impact on experiences of acute exacerbation of COPD would be useful. This study was conducted in one country so the findings may be reflective of the culture of that country. Furthermore, the participants were patients in a single hospital – albeit the largest acute care hospital in the region where most COPD care occurs - and data from other institutions may add to the findings of this study. However, this study provides a useful reference point for other research among people with COPD in other cultures and settings.

CONCLUSION

The aim of the study was to explore the experiences of older patients with advanced COPD and the impact of being admitted to hospital following an acute exacerbation of their illness. The themes that emerged from the interviews were: a sense of loss and frustration, hopelessness, uncertainty and being a burden. In the main this

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study reinforces and strengthens the existing qualitative research on COPD - particularly the fact that after exacerbation seems to be a key time when patients feel most anxious and focus on their future care needs – and feel uncertain about their future. This stage on the COPD trajectory should be recognised as significant and used as an opportunity to balance strategies to provide hope along with using these events for a sensitively timed and managed discussion about prognosis and potential end of life care requirements. This will involve nurses acting as key professionals within the multi-disciplinary COPD care team.

RELEVANCE TO CLINICAL PRACTICE

Nurses who care for older COPD patients should acknowledge the enormous impact that the disease has on everyday life, especially in the later stages of the disease. COPD nurses need to use their skills to explore interventions to improve hope – perhaps through self-care or coping strategies – with their patients. However, they also need to use their clinical experience and symptom monitoring skills to judge when an acute exacerbation may act as a trigger event for starting a dialogue with the patient and their family about end of life matters – a dialogue that may be helpful even if this event does not signal that the ‘end of life stage’ has been reached yet. However, predicting the trajectory of COPD is difficult and highlights the need for a nursing research agenda on this issue – to identify factors in COPD that may signal that someone is entering the final stages of their illness. COPD nurses also need to be aware of – and contribute to- the process whereby COPD patients are made aware of the possible trajectory of their illness early in the disease process. This preparatory work will make later discussions about palliative care easier to initiate. Finally, COPD nurses should act as the bridge between

patients and their families to help patients express their anxieties about their future care – especially their feelings of being a burden – in a safe and supportive manner. More research is required to explore how these different types of interventions can be implemented successfully.

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Table 1 – Interview guide and exemplifying questions

Ice-breaking questions

After the mutual presentation, the interviewer thanks the participant.

Some starting questions may be:

“Is it clear why we are here? Are there things that are unclear? What did you think when I invited you?”

The interviewer can continue with questions about personal characteristics (age, education level, the year of the diagnosis, domestic situation and family composition).

Central questions

“Could you please tell me how you feel right now? If you want, could you tell me how you deal with your situation?”

“What happened when you got the hospital?”

“How do you feel about your illness and how it affects you?”

“How did this sudden worsening of your health make you feel?”

“How did you feel/what did you think when health professionals told you were going to be discharged?”

Closing questions

“Is there anything else you want to tell me about? Are there any episodes that have come to your mind?”

Before ending, the interviewer thanks again the participant.

Table 2 – The definition of meaning units (extract)

Participant (pseudonyms)	Significant statements	Meaning units
Kit	But I tell you that I'm a little worried, because I worry about going back home, but not from the financial point of view, just from the standpoint of what I will do and how I will face life in this way, you know ...	He is worried about the future. He seems to despair about his life from now on.
Mary	Huh, well, it takes a bit of courage to face this situation ... I say ... you can't expect to want too much, you get what you can. My typical day, right now, I get out of bed, have breakfast and then wait, from one chair to another, eh, how do you want my day to be? All my life I have had breathing problems! So ... so ... On the other hand, what can I do?!	She recognises she will need courage to face her life after leaving hospital. She imagines his life being full of difficulties. She adopts a fatalistic view of the future – out of her control.
Sam	I: Do you live alone or...? P: No, I have my relatives but I live alone, but I've got my children, is that ... well, they are always involved in my care.	He is concerned about the help he will receive from his family in the future. He "sounds" sorry for this.
	I: And... did they talked about when you will go home? P: No. I have not even asked to tell the truth, because in the meantime it is useless to stand there and ask to do ... so until it is time, you do not go home.	He seems to feel that it is the professionals who should raise the topic of his future care – not him. He does look passive without expectations.
Tom	At my age it is certain that the children, grandchildren ... all have their own business, children can't take care of their sick person constantly, and that's why problems occur, because then the explanations with doctors are very difficult ... and at home certainly they can't take care of me constantly.	He feels like an inconvenience or burden. He is aware that his family have busy lives to explain and excuse their lack of help for him.
	There is nothing to do because (<i>laughs and swings his hand</i>), at my age, huh ... then ... then I do not know what to say because ... when you are old you are old.	He feels his outlook in life is bad. He is pessimistic. He feels out of control and that there is nothing he can do to help himself.
Mark	At home, it will be terrible, yes, I had to rent an apartment here, next to my daughters; but now I don't know. In the early days, they could afford to get a caregiver for me to help me eat, etc. But only if I'll be a little stronger than I am	He is concerned about the future – his health and also his financial situation. Concerned about not being able to fund his

Participant (pseudonyms)	Significant statements	Meaning units
	now.	future care.
Andrew	How you can declare that you go home and you will be more comfortable? How? If there will be the room that I've used to have, all right, But ... it won't be ...	He feels concerned and afraid about going home. He is uncertain about the physical place he will go to.
George	I did not phone myself (<i>the emergency number</i>), I called the doctor on duty who sent me to the hospital. But I told him: "I did not ask." I had indeed said: "I do not want to disturb an ambulance when there are people who definitely are more in need than me."	Feels a burden on health care services.
Gareth	Here they did say that the situation was hopeless, that I had COPD and that I would have to come here regularly to be checked if it did go ahead (progress) if it gets worse or remains. So, on that beautiful summer day in 2005 they pulled the trigger on me.	The way he is communicated with about his illness – 'it is hopeless'. He is upset at receiving a diagnosis that makes him feel his life has changed – for the worse.
	I will be angry until I die, because I died in 2005. I was a healthy, active man, a little man but strong. Now, I can't even get out of bed and go; nothing, nothing, I have a shattering weakness.	He is disappointed of not being able to expect too much. He has lost his healthy habits. He feels frustration and anger.
Ben	There is nothing else to do. It's all here, on my own, of bad luck and luck, there's nothing else to do.	He sees his illness as bad luck. He feels hopeless about the future.
Lucy	I live alone, but ... I have my daughter, but I'm alone. And now, I think that this problem will come out ... where ... we will see what to do, I do not know what to do ... We need to find a solution ... I should still stay at home by myself. But ... They are my children who are worried.	Concerns about future care from her family. She is aware her family is worried about the care she will need at home.

Table 3 – From meaning units to themes (extract)

Meaning units	Themes
He is worried about the future. He seems to despair about his life from now on.	Uncertainty and fear about the future
She recognises she will need courage to face her life after leaving hospital. She imagines his life being full of difficulties. She adopts a fatalistic view of the future – out of her control.	Sense of loss and frustration
He is concerned about the help he will receive from his family in the future. He “sounds” sorry for this.	Fear of becoming a burden
He seems to feel that it is the professionals who should raise the topic of his future care – not him. He does look passive without expectations.	Hopelessness
He feels like an inconvenience or burden. He is aware that his family have busy lives to explain and excuse their lack of help for him.	Fear of becoming a burden
He feels his outlook in life is bad. He is pessimistic. He feels out of control and that there is nothing he can do to help himself.	Hopelessness
He is concerned about the future – his health and also his financial situation. Concerned about not being able to fund his future care.	Uncertainty and fear about the future
He feels concerned and afraid about going home. He is uncertain about the physical place he will go to.	Uncertainty and fear about the future
Feels a burden on health care services.	Fear of becoming a burden
The way he is communicated with about his illness – ‘it is hopeless’. He is upset at receiving a diagnosis that makes him feel his life has changed – for the worse.	Hopelessness
He is disappointed of not being able to expect too much. He has lost his healthy habits. He feels frustration and anger.	Sense of loss and frustration
He sees his illness as bad luck. He feels hopeless about the future.	Sense of loss and frustration
Concerns about future care from her family. She is aware her family is worried about the care she will need at home.	Fear of becoming a burden

Table 4 - Patient characteristics

Gender	10 males 2 females
Age range	71-90 years
Education	6 primary 3 lower intermediate 2 upper intermediate 1 bachelor Degree
Time since diagnosis (years range)	2-30
Home oxygen use	9