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Psychosocial Dimensions of COPD for the Patient and Family

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1. Introduction

This chapter will review our current understanding from the qualitative research literature on the experience of COPD for the patient and family. It will provide exemplars from the author's past research to ground these concepts within patient and family experience. Whilst research into symptom measurement, functional and biochemical measurements of lung function and pharmacological outcomes give important insights into the physiological dimensions of COPD, methodologies that explore the psychosocial dimensions are not always well understood. Research output is increasingly valued according to clearly definable 'Levels of Evidence' (National Health and Medical Research Council, 2009). This approach makes visible the rigour of processes that underpin clinical evidence and considers practices confirmed at one extreme by double-blinded, randomised, controlled trials, through to the accepted wisdom of experts in the field. Demonstrable rigour in research is particularly important when evaluating the safety and efficacy of new drugs and interventions. In this case, large sample-sizes, strict control of variables and meticulous monitoring of the research protocol to maintain objectivity means that clinicians can weigh up, with confidence, the therapeutic choices available to them. This quantitative approach to research relies on statistical methods to determine 'truth'.

Clinicians have sought ways to apply quantitative research methods to measure psychosocial dimensions of illness and treatments. Symptom and impact scales such as the Hospital Anxiety and Depression Scale (Zigmond et al., 1983) and the International Continence Society Sex Questionnaire (Blaker et al., 2001), are examples of instruments that can identify the presence and frequency of issues of importance to patients across the COPD population. Instruments like the SF-36 (Mahler & Mackowiak, 1995) and the Sickness Impact Profile (McDowell & Newell, 1987) allow us to determine the influence of disease and interventions on a person's quality of life. Measures of adaption to illness such as the Jalowiec Coping Scale (Jalowiec et al., 1984) quantify the behavioural and cognitive coping strategies people use to deal with social, physical and emotional stressors.

These quantitative measures of psychosocial aspects of COPD are useful in their ease of applicability to large research samples. They provide an aspect of evaluation that goes beyond the purely physiological concerns of health professionals to consider the patient-

perceived impacts of health problems and treatments. What they do not always achieve is firstly, the sensitivity necessary to reveal subtle but important changes in patient experience, and secondly, an explanation of the meanings behind results. Qualitative research methods have a different purpose to positivist, quantitative studies. Rather than seeking objective 'truth', they seek to gain an understanding of the meanings of illness and treatments for people. As such, there is an acceptance of the subjectivity of experience, and an acknowledgement of the context of an experience, rather than trying to control for context.

2. Understanding qualitative approaches in COPD research

Phenomenology is an example of a widely applied method in the qualitative COPD literature. Edmund Husserl, the founder of *descriptive* phenomenology sought a rigorous scientific method, grounded in the experience of people living within their world. Husserl's transcendental phenomenology attempted to strip away what we know and take for granted about a phenomenon to reveal and describe its fundamental essence (Husserl, 1936:1970). He called this the phenomenological reduction and suggested this process required us to suspend or *bracket* our prior knowledge of the subject being studied (Husserl, 1931:1960).

Husserl's student, existential philosopher Martin Heidegger, further developed Husserl's ideas around discovering the essence of an experience to create an *interpretative* phenomenology. He did not agree that we could separate ourselves objectively from phenomena in our world. He saw people, not as passive recipients of information about, and perceptions of, objects in the world, but rather believed that we exist *in-the-world* and are drawn towards and grasp things of significance for us that need to be taken care of (Heidegger, 1927:1996).

In Heideggerian phenomenology, the essence of the experience, for example 'breathlessness in a shrinking-life world' (Gullick & Stainton 2008), acts as a lens through which to view the participants' story. The story is interpreted through language (i.e. transcripts of in-depth interviews) against the background of their personal concerns (perhaps expression of masculinity, earning a wage, social connection), that are aspects of the person's history, culture and family and comprise their *being-in-the-world*. The result is a rich narrative that interprets experiences to describe the meaning behind them for the participants.

Another common approach to qualitative inquiry is Grounded Theory. First described by Glaser & Strauss (1967) and further developed by Strauss & Corbin (1998), this method may use both in-depth interviews and field observations. The resulting data is coded progressively from the first interview by a method of *constant comparison* according to a highly structured framework. During coding, the researcher memos their ideas and these may grow into theories about the phenomena. As these theories emerge they are tested by theoretical sampling; this is a type of purposive sampling that increases the diversity of the sample, seeking participants and pursuing questioning that tests the developing theory until that particular idea is 'saturated' with enough data to evidence it. Traditionally, literature is collected only as it becomes relevant to the data, rather than as a precursor to the study. Past literature is given the same status as data and is treated as data to support the new theory. Many studies use a modified approach to this method.

Good qualitative research is underpinned by a philosophical framework to strengthen the scholarly rigour of the interpretation. Examples include *symbolic interactionism* (Blumer,

1969), which is frequently used alongside Grounded Theory to find social explanations for behaviours. Symbolic interactionism sees people as 'pragmatic actors' who constantly adjust their own behaviour in response to others, and we can do this because we have the cultural and social understandings to interpret the meaning of those actions (McClelland, 2000). Maurice Merleau-Ponty's philosophy of the body (Merleau-Ponty, 1945:1962) is an example often applied to phenomenological studies that explore the embodied experience of illness. Merleau-Ponty describes people as perceiving the world through their body which acts spontaneously, in a *taken-for-granted* manner until something goes wrong.

Other modes of qualitative inquiry informing this review include, but are not limited to, content analysis (Krippendorff, 2004) and narrative analysis (Reissman, 1994). As with all research, findings from qualitative studies should be carefully considered according to the pre-determined criteria for rigour within the chosen methodology (Ezzy, 2002).

3. Loss of *taken-for-granted* breathing

Breathlessness is at the forefront of the experience of COPD, and breathing becomes a conscious focus of the person's life. COPD has been described as "a story with no beginning" (Pinnock et al., 2011); the changes in breathing are so slow and insidious that for a long time the decline is normalised; put down to getting older or being less fit. Eventually, the breathlessness begins to impact on the person's ability to conduct their day-to-day activities and is accompanied by other respiratory symptoms and poor exercise tolerance. Petra (63 yrs) had severe COPD before she sought advice from her doctor: "... to go from my bed to the lavatory and back, I'm huffing and puffing. I thought 'This can't be right' ... I get out of breath all the time".¹

Distressing breathlessness can be precipitated by certain body positions, by activities such as walking and climbing stairs and by extremes of emotion. Environmental triggers such as excessive heat or cold, smoke or perfumes exacerbate breathlessness and people may need to anticipate and avoid these triggers. This avoidance of the triggers of breathlessness can isolate people from locations and activities that once that once afforded them pleasure (Gullick & Stainton, 2008). Chris (67 yrs) explained: "There's lots of things I'd like to do but I just can't... Get out in the garage, make things. Well, I went out the other day to try and sand down our cutting board ...there's all the dust, and ... forget it!"

Breathless people experience good days and bad days and this means that despite planning ahead, a bad day may rule out hoped for activities. Certain times of the day can be more problematic, with breathing often worse in the mornings, coinciding with the need to clear sputum and the need to attend to washing and dressing, and at night interfering with sleep. Certain times of the year can also worsen breathlessness due to extremes of temperature (Barnett, 2004). Williams (2011) reported that the person's perception of air movement made a difference to breathing, with fresh 'outdoor air' being easier to breathe.

Acute breathlessness is associated with panic, fear of suffocation, and fear of dying during an attack. People feel helpless and out of control of their bodies at these times (Williams et al., 2011, Avsar & Kasilkci, 2011, Elkington et al., 2005). Strategies can be taught that help

¹ Any unreferenced participant quotes in this chapter are sourced from unpublished interview data from research reported in Gullick (2008). All names are pseudonyms.

bring respiratory distress under control. Breathing techniques such as consciously slowing breathing, diaphragmatic breathing or purse-lipped breathing are reported widely by patients as effective ways to help manage frightening breathlessness (Fraser et al., 2006, Avsar & Kasilkci, 2011, Cicutto et al., 2004).

4. Losing control of the body's *taken-for-granted* functions

When our body works well its functions and understandings are *taken-for-granted*. For well people, the habitual functions of breathing, walking and moving the body in meaningful ways are unconsciously undertaken as the body moves purposefully towards its tasks. The existential philosopher Merleau-Ponty notes the sudden awareness of our bodies as task-orientated when function is disrupted:

"I am conscious of the world through the medium of my body. It is precisely when my customary world arouses in me habitual intentions that I can no longer, if I have lost a limb, be effectively drawn into it, and the utilisable objects, precisely insofar as they present themselves as utilisable, appeal to a hand which I no longer have... Our body comprises as it were two distinct layers, that of the habit-body, and that of the body at this moment..." (Merleau-Ponty, 1945:1962)

Sputum production, uncontrolled coughing and wheezing and urinary urgency (Avsar & Kasilkci, 2011, Gullick & Stainton, 2008) are examples of changed body behaviours that signify a loss of control, displaying the body in socially unacceptable ways. Terry (77 yrs) confided, "I cough, and I cough, and I cough and... all of a sudden it's on the table. It just comes out, no control" (Gullick & Stainton, 2008). Because these behaviours draw attention to the person's unpredictable body, they detract from enjoyable participation in family and community activities. This has been described as the 'stigma' of COPD where the illness is visible, and is associated with disability and lack of control (Johnson et al., 2007). The visibility of the illness challenges the person's personal integrity and sense of effectiveness (Leidy & Haase, 1999, Gullick & Stainton, 2008). Marcia explained of her husband Pete (66 yrs): "He goes to the club for the raffle ...and meets a chap he went to school with, just for an hour and a half... But he's on to that oxygen the minute he gets home. See, he's stubborn that way. He wouldn't dare let anybody see him using a bottle, or a wheelchair" (Gullick, 2008).

Other common manifestations of the failing body in COPD are weakness and fatigue, pain, insomnia, loss of appetite and difficulty with mobility (Elkington et al., 2005, Jones et al., 2004, Gullick & Stainton, 2008, Seamark et al., 2004). Fatigue is strongly linked to levels of breathlessness and depression and has major consequences for functional performance (Kapella et al., 2006). Fatigue is responsive to improved rest and sleep; however, sleep deprivation is part of the experience of living with COPD and the resulting constancy of fatigue makes it difficult to maintain daytime motivation. Focussing on patient perceptions of sleep, the qualitative report of Shackell et al (2007) revealed almost all participants waking more than three times per night to pass urine, and disturbances from pain and breathlessness were frequent. Some people were isolated from their daytime support structures and so felt vulnerable during the night, fearing nocturnal breathlessness and panic and wondering if they would "see the next morning". Those with poorer sleep had poorer lung function and quality of life scores and were more likely to be anxious and depressed. Daytime sleep or sleep whilst in hospital was seen as safer. It is notable that some patient strategies for insomnia actually function as barriers to good sleep including the comfort-seeking activities of drinking tea, late night TV and daytime napping. Whilst people

continue with low expectations for a good night's sleep and remain physically inactive, they remain prone to sleep problems (Shackell et al., 2007).

Anorexia & weight loss are found amongst many COPD sufferers and are associated with worsening breathlessness (Seamark et al., 2004, Jones et al., 2004). The study of Odencrants et al (2005) focussed on the experience of meals and their findings noted a number of barriers to sustainable eating. The problems began in obtaining food, with difficulty parking, breathlessness during shopping and difficulty transporting heavy groceries being contributors. Some people experienced physical challenges when preparing food, particularly if they were rushed, whilst others found it difficult to tolerate cooking odours. Some chose to smoke instead of eat.

The attraction of food is sometimes reduced due to a loss of taste sensation. Fungal infections or a dry mouth resulting from the use of puffers can make chewing painful. Coughing before or during meals can tire the person and reduce the focus on the meal, making food a real challenge during exacerbations (Odencrants et al., 2005). Keith (73 yrs) defended his poor eating to his wife Marcia, "*Do you want me to eat or do you want me to breathe? I can't do both together!*" (Gullick, 2008). People experience bloating, feel full before finishing meals and are often embarrassed by the food left on their plate. They report having their intake watched during mealtimes by family members and experienced feelings of failure, anger or sadness when they are not able to eat (Odencrants et al., 2005).

Eating smaller amounts more often and planning a number of meals in advance on a 'good day' is a common strategy to improve food availability and intake. Of concern was that Odencrants' et al's participants thought positively about their low body weight and this may be problematic given the association between low body mass index and higher mortality in COPD (Yang et al., 2010).

Pain is commonly reported in qualitative studies on COPD (Halpin et al., 2008, Elkington et al., 2005, Shackell et al., 2007) although authors do not tend to elaborate on the nature or location of pain. It is reasonable to assume this pain may in some part relate to reduced mobility, and perhaps, to age. Boueri et al (2001) noted that whilst their participants reported pain, levels were similar to healthy individuals in the community. Pain is particularly noted for people with COPD in the last year of life (Elkington et al., 2005).

5. Loss of the body's spontaneity

People with healthy bodies combine their movements and activities in a fluid manner. They spontaneously act in response to sensory stimuli, or to a perceived need to attend to a particular task, and this rarely requires a conscious appraisal of the body's capacity.

"The body is polarised by its tasks, of its existence towards them, of its collecting together of itself in pursuit of its aims". (Merleau-Ponty, 1945:1962)

People with COPD lose this spontaneous application of the body to its tasks; in fact, a lack of forward planning can leave the person gasping for breath. Chris explained, "*... things you've done all your life, you don't think, and you go to do them again. Picking things up that I shouldn't pick up and carry*". Simple activities such as walking and talking become difficult to combine (Gullick & Stainton, 2009).

Breathlessness requires the person with COPD to consider the task, the steps they need to go through to undertake it and their particular physical effectiveness on that day. They may need to research how far they have to walk, whether there may be stairs and whether a toilet is close. People need to allow more time in order to avoid having to rush or keep up. The use of oxygen bottles takes considerable planning in relation to the cylinder's duration and portability. Even just walking from one room to the next may require rest stops. Patricia (63 yrs) lamented, *"Coming out to the lounge room where the nebuliser is, opening the blinds and curtains, then sitting down to get on my nebuliser. I have to stop about five times just doing that"*.

Attending to day-to-day activities means pacing the body and spacing out activities that tax the body's breathing. Pacing of movement and activities with frequent breaks and aligning activities into sequential rather than combined tasks allows the person to recover their breathing along the way. Because of the daily variability in symptoms, people may need to take on a flexible approach to assessing, on the day, outings they have planned in advance (Barnett, 2004). Those who adjust most effectively to their bodily restrictions *listen* to their body, plan, pace, prioritise and balance their activity with capacity on that day, and try hard to achieve a certain level of contribution within realistic parameters (Lindqvist & Hallberg, 2010, Leidy & Haase, 1999, Gullick & Stainton, 2008, Fraser et al., 2006).

6. Changes in personal effectiveness

Leidy & Haase (1999) noted physical effectiveness as a core component of personal integrity that is challenged in COPD. Effectiveness is expressed as 'being able'; the body's predictability in doing what we expect or desire it to do. In sharp contrast, the failing body in COPD is nothing like what is presumed for, or wished of the body (Nicolson & Anderson, 2003). Physical effectiveness is just as much an interpersonal process that includes doing for others, as well as for one's self. This notion of contribution is an important one to most well-socialised adults. When the ability to contribute is lost to ineffectiveness and dependence, then people feel shame, self-blame and perceive the blame of others (Lindqvist & Hallberg, 2010, Barnett, 2004).

COPD symptoms often begin during a person's productive, working life. For many, there is an assumed level of physical adeptness and a physical and aesthetic appearance that has constituted their body as it is known to themselves in its predictability, and known to others in its apparent wholeness and application to visible tasks. Even though women are long established in the workforce, men still tend to perceive themselves as 'the breadwinner' and this forms an important part of their self-concept that becomes threatened in chronic illness. For men, heavier household tasks such as mowing lawns and managing gardens are frequently tied to their own and their family's perception of them in their gendered roles. Mary recalled of her husband Keith, *"...because he's always been the really strong one... He did marvellous things around the house... He doesn't do anything now... He can't, he gets too breathless. ... and he's very conscious of this and it upsets him."* (Gullick, 2008).

For men, these heavier tasks are eventually taken over by another family member, or by paid help. For women with COPD, there tends to be a sense of ownership and obligation towards housework, and they will tolerate significant symptoms to retain these duties. As the disease progresses there are often visible changes such as development of the classic 'barrel chest', significant weight loss and for some, facial and postural changes from

prolonged steroid use. Norman described changes to his wife Catherine (58 yrs), a once, striking woman who ran an exclusive boutique, *"She had this sort of wheezy voice, and she was beginning to get hunched shoulders."*

The net result of this changed capacity and appearance is that people lose a variety of modes of self-expression (Leidy & Haase, 1999). Andy, (57 yrs) explains: *"I had to give up sport, I'm a real sport nut. I had to give up walking... Of course sex was out of the question"*. Each task is considered as to whether the reward, for themselves or others, will outweigh any distressing symptoms. If the real or anticipated discomfort is thought to be greater than the perceived benefit, that task will be avoided. Rewards include either personal pleasure and fulfilment, or a task that is to the benefit or welfare of others (Leidy, 2008, Shackell et al., 2007).

7. Losing independence with body care

Severe COPD sees people coming to terms with their diminishing ability to care for themselves. Early losses in independence may include difficulty with shopping or driving. As the disease progresses, people find that basic tasks such as showering and dressing may become insurmountable, making them feel almost child-like in their dependence on others (Gullick, 2008, Oliver, 2001, Barnett, 2004). Chris was sensitive to his wife's workload around body care. *"I'm nearly an invalid, aren't I? She has to help me up the stairs... shower me... help me get dressed. Basically the stupid things I should be able to do myself"* (Gullick, 2008).

This loss of independence with self care is an enormous threat to people's sense of hope (Milne et al., 2009). Showering causes particular problems because of the effect of steam on breathlessness. Pete explained, *"I panic a little bit when I get in the bath or shower, and then I've got to get out and get dried up. I'm pushing for my breath, ... and I dry one leg down to my ankle and ...stand there and hang on to something until I get my breath and then I put the other leg up"*. Lifting arms to wash the hair, or bending to dry the feet are movements that cause considerable restriction to breathing, and so may be avoided. For people who live alone, this loss of self care may herald their movement into residential care. For people with family carers, it may alter the existing family relationship dynamics (Barnett, 2004, Gullick, 2008).

8. Changes in personality and mood

There is an important temporal framework to the experience of COPD with the visions of past, present and future selves being held in constant comparison to each other. Nicolson & Anderson (2003) describe how these gradual changes from independence to dependence lead to loss of self-esteem, loss of self-image and loss of power. The disease creates an otherness where the more visible 'medical self' is separate from the real self. Several studies reveal the nature of patient storytelling with past selves portrayed as athletic and vigorous, and present selves being barely able to walk (Bailey & Tilley, 2002, Gullick, 2008). Their future is seen in terms of loss: loss of anticipated retirement, loss of hoped for relationships with children and grandchildren (Nicolson & Anderson, 2003), and loss of 'possible selves' which are no longer conceivable (Gullick & Stainton, 2009).

This loss of independence and loss of family and community roles frequently lead to frustration, irritability and depression (Elkington et al., 2005, Seamark et al., 2004, Wilson et al., 2007). Those with advanced disease may see their life as meaningless. They communicate hopelessness, worthlessness and resignation and this can make death seem

like an attractive option (Ek & Ternestet, 2008, Oliver, 2001, Lindqvist & Hallberg, 2010). Terry (72) recounted: *“As true as I’m sitting here, ... I go to bed and I say, ‘Tonight would be a nice night to die. Take me.’ ... Really and truly, what good am I? I can’t take my wife down to the shop, I can’t walk from here to my barber who’s just round the corner...”* (Gullick, 2008).

Despite the extremes of emotions, people try to contain their feelings as emotional turmoil can bring on exacerbations of breathlessness that are difficult to recover from. This has long been recognised and described as living within an ‘emotional straight jacket’ with both positive emotions such as laughter, and negative emotions such as anger, leading to distressing dyspnoea (Rabinowitz & Florian, 1992, Dudley et al., 1980, Diethorn, 1985). Partners of COPD patients tend to avoid discussing problems, or subjects that could lead to conflict with their ill spouses, for the same reason (Ring & Danielson, 1997, Sexton & Munro, 1985, Gullick, 2008).

Hypoxia may result in cognitive and personality changes that can further isolate people from family and others in the community. These may manifest as hallucinations, confusion, memory loss or unreasonable and unsociable behaviour (Gullick, 2008, Boyle, 2009b). Betty (73 yrs) explains of her husband, Terry: *“It’s been hard... He gets very stressed and cranky over nothing... If anything goes wrong, I’ve done it... I know he’s having trouble; he can’t get about too much... It makes him more upset”*. For carers, the mood and personality changes of their loved one are often the hardest thing about living with COPD (Oliver, 2001, Wicks, 1997).

We know that rates of depression in COPD are reported at around 40% (Yohannes, 2005, Wilson, 2006) and up to 57% for those on home oxygen (Lacasse et al., 2001). Depression is further tied up in self blame and the perceived blame of others as people acknowledge the burden of their care and their ineffectiveness (Barnett, 2004). Anxiety is suffered by around a third of COPD sufferers, is a predictor of hospital admissions, and impacts significantly on the person’s quality of life (Yohannes, 2000, Jones, 1991) Despite our awareness of anxiety and depression, there remains a lack of access to psychology services that could ameliorate these symptoms (Wilson et al., 2007).

9. The confining nature of COPD for the patient and family

People with COPD and their close family members live within a shrinking life-world (Gullick & Stainton, 2008). The physical boundaries of their life are diminished as the sick person begins to avoid taxing outings and spends the majority of their time within their own four walls. Mary explained of her husband, Keith: *“He could just walk on to the verandah and play with the dog a little bit, just in the confines of what you might loosely call the house. And then he just gradually stopped doing that”* (Gullick & Stainton, 2008).

People become socially isolated as they avoid environments and situations that may trigger breathlessness. Their consciousness of the socially unacceptable nature of their coughing and spitting makes them reluctant to enter new social situations. People reliant on home oxygen concentrators may be literally tied to an electrical power source and this increases isolation for the patient and the complexity of care for the family (Boyle, 2009b). People lose shared experiences with family and friends leading to loneliness, sadness and abandonment as they not only avoid social activities but feel they are avoided by others (Ek & Ternestet, 2008, Wilson et al., 2007, Leidy & Haase, 1999). Williams et al (2011) describe this experience as like living within a ‘stagnant pool’. The physical stagnation

through loss of mobility is likened to an imprisonment; there is a stagnation and staleness of self that highlights the disparity between what the mind wants to do and what the body is able to do.

The confining nature of COPD extends to the family carer. As the physical effectiveness of the ill person declines, the workload of close family members increases. In the case of older couples, the primary carer may be facing their own health and ageing issues and the role of caring can seem overwhelming. The fear that something may happen to their loved one in their absence means that they become bound, physically to the home and psychologically to the role of caring due to a perceived need for increased vigilance. Their need to closely monitor their loved one leads to the use of phones and intercoms, listening to breathing during the night, watching for early signs of exacerbation and using the current level of breathlessness as a gauge of capacity for tasks (Boyle, 2009b, Gullick, 2008).

The experience of caring differs between spouses and other family members. The reciprocal nature of most marital relationships places caring in a framework of the historical give-and-take between partners and is sealed with the understanding of "for better or worse". Amongst younger caregivers, caring may be challenged by the competing roles of working and parenting and a different level of perceived reciprocity (Gullick, 2008, Nicolson & Anderson, 2003). Children and siblings are more likely to find the caring burdensome, and to note the lack of caring input from other family members (Gullick, 2008). Those carers with a higher level of education may find it more difficult to accept the loss of independence (Nordtug et al., 2010). Family enmeshment also makes adjustment to illness more difficult. When people weave their identities and activities around each other so completely it is difficult for any one member to function independently (Kanervisto et al., 2007).

Carers often feel weighed down by their multiple roles and feel similar losses of shared social experiences (Seamark et al., 2004). The caring role may coincide with a time of both declining health and fitness and increasing heaviness of the work of nursing. Women caregivers in particular are prone to somatic symptoms and anxiety, and although taken for granted, the frequent interruptions to sleep can be wearing (Bergs, 2002, Nordtug et al., 2010, Boyle, 2009b). Whilst some carers manage to integrate caring with employment to provide some personal time and space, others are forced into an unwelcomed, early retirement (Boyle, 2009b, Gullick, 2008). It is known that for people who are unable to leave the home for some sort of personal pursuit, there is a higher perceived burden of care (Boyle, 2009b). These losses of social participation for carers may contribute to a loss of self-identity with some women becoming unable to separate a sense of themselves from their husbands. Their future hopes for meaningful pursuits and achievements, a relaxed lifestyle and personal freedom become lost in the daily grind of their present reality (Boyle, 2009b).

The majority of social interaction for carers is with the ill person; however, males with COPD tend to isolate themselves from conversation, have a reduced interest in things, and as a consequence, have little to talk about (Bergs, 2002). This loss of intimacy through conversation is paralleled with a loss of physical intimacy, including sexual interaction (Gullick, 2008, Sexton & Munro, 1985). Where intercourse is attempted it may be frightening with distressing breathlessness distracting both partners from the

romanticism or eroticism of the moment. Whilst for many couples sex becomes less important, other forms of intimate physical contact is also avoided so that simple loving gestures such as cuddling or kissing may be lost to the caregiving spouse. Carer Claire, (55yrs) explained, “*you get used to not having those sort of things. You get used to being...not touched*” (Gullick, 2008).

Much of the caring literature on COPD focuses on female spouses. However, where both men and women are participants there appears to be a difference in caring styles and responses to caring. Women carers, in particular, take on a micro-management approach, arranging medical appointments and scrutinising diet, medication and exercise compliance and this differs from the more passive and delegatory style of male carers. Women try to play down the ineffectiveness of the sick person by secretly completing heavier jobs or slowing their pace whilst walking. They look for opportunities to promote a sense of effectiveness by leaving available the achievable jobs around the house, and only assisting with body care where it is absolutely necessary. Liz described her approach with her brother, Andy: “*I made every effort so that he didn't see a lot of the things that I did, so that he didn't know that he was incapable of doing it*” (Gullick, 2008). Women try to protect others in the family from seeing how bad things are. There is a sense of wifely duty reported, with women determined to ‘walk the road’ with their husband until the end. They can't imagine life without their partners after giving such intense care for so long. Women caregivers ignore their own health needs and become sad and worn out (Bergs, 2002).

There are a number of unmet needs amongst family carers in COPD, including the desire for better support with physical care and symptom control, and more useful information about the course of the illness (Currow et al., 2008, Bergs, 2002). Women carers are often too proud to ask for help from other family members (Bergs, 2002), whereas male carers more happily enlist outside help. Because of the intensity of carer engagement in COPD home-management, health professionals must seek the insights of carers during the patient assessment process, and educate and involve them when introducing new therapies. Carers may be the champions of patient motivation, but they are also known to actively eliminate treatment strategies they see as unnecessary or harmful (Boyle, 2009a).

10. COPD and smoking: The meanings of a ‘self-inflicted’ disease

In developing countries COPD is most often related to exposure to cooking fires. In a small group of people, an inherited alpha-1 antitrypsin deficiency can lead to early onset COPD. For the vast majority of people in the western world, however, COPD develops as a direct result of cigarette smoking (GOLD, 2010). Up to half of all smokers will die from a tobacco related disease (World Health Organisation, 2011). Whilst some manage to give up smoking easily when confronted with a diagnosis, many people continue to smoke. If the issue of smoking is to be dealt with collaboratively, clinicians need some insight into the meanings of smoking for the addicted person.

People with COPD are stigmatised by the self-inflicted nature of their disorder (Johnson et al., 2007). They experience enormous guilt and shame that may cause them to deny smoking as the cause of breathlessness, to hide their symptoms and to delay their engagement with medical services (Gullick & Stainton, 2006, Arne et al., 2007, Robinson, 2005, Earnest, 2002). Smokers have described reduced access to services because they either fear the judgement of

health professionals or because of the actual attitudes of health professionals (Johnson et al., 2007, Burrows & Carlislea, 2010, O'Neill, 2002). For example, current smoking is a contraindication for many elective surgical procedures, including lung volume reduction procedures for emphysema. People are known to have been excluded on this basis without receiving the smoking cessation support that could facilitate their access to such interventions (Gullick & Stainton, 2006). Smokers are less likely to have visited a doctor in the past year (Fisher & Hill, 1990), and smoking is associated with non-adherence to pulmonary rehabilitation (Young et al., 1999).

The context of self-infliction may create an underlying anger and resentment amongst family members, particularly where family have not struggled with an addiction of their own. This anger may make the caring burden harder to accept, but may also be intermingled with guilt over these emotions (Boyle, 2009b, Gullick & Stainton, 2006). Gary (38 yrs) explains of his father: *"They can hardly drag themselves across the room, but they'll still smoke. It makes it tough for families, you're doing everything you can, but you feel, 'What's the use of doing it if he's still smoking?' He tries to blame different things... infection in his lungs... exercise... which is so idiotic. If you had a tape, and ... let him hear himself he'd probably go "Oh... Silly!"*

Those who accept the causative role of smoking in their illness experience regret and anger for their past inability to stop (O'Shea et al., 2007). However, only a small proportion of people with COPD attribute cigarettes as the primary cause of their lung disease (Hansen et al., 2007). In a large, early survey of older smokers with or without COPD, 47% didn't think quitting would improve their health and 45% did not believe smoking was harming them (Fisher & Hill, 1990). The fact that there may be COPD amongst other family members is usually explained away as a family predisposition rather than a shared family smoking addiction. Numerous studies demonstrate the widespread denial of smoking as the main cause of breathlessness. Rather, patients attribute occupational exposure, ageing, lack of fitness and 'bad luck' as major contributors (Wilson et al., 2007, Hansen et al., 2007, Burrows & Carlislea, 2010, Gullick & Stainton, 2006). The study of Boyle (2009b) demonstrated that spouses are also inclined to find explanations for the illness that externalise the responsibility from their partners to others. Knowing other smokers who do not have COPD reinforces their beliefs.

The self-talk around the impact of smoking sometimes extends from denial of harm to positive physical, social and psychological benefits (Schofield et al., 2007, Osman & Hyland, 2005). Some research participants report that smoking makes them feel better and eases their breathing and others recall shared social experiences around smoking with affection. The issue of the pure enjoyment of smoking to the addicted individual cannot be ignored. Cigarettes have been described as a 'best friend', providing comfort and companionship (Lindqvist & Hallberg, 2010). Research participant Terry recalls and craves the sensation of smoking: *"I enjoyed smoking, and even now... I'd love a cigarette. My son ... goes outside and has a smoke. I say 'Sit in here and I can smell it.' I want the smell of his smoke."* (Gullick & Stainton, 2006).

Smoking is widely utilised tool for stress reduction. It is common for people who have succeeded in smoking cessation to later relapse due to extreme stress or bereavement (Schofield et al., 2007, Burrows & Carlislea, 2010, Gullick & Stainton, 2006). The findings that cessation does not automatically deliver better well-being adds to the problem. All ex-

smokers in the study of Burrows & Carlislea (2010) described feeling worse after quitting due to symptom exacerbation or weight gain. This was the case for Petra after her successful cessation attempt: *“I was under the impression if I stopped smoking I would get better, or I’d stay the same. And I thought, ‘I’ll give them up immediately’ which I did, straight away ... and I didn’t get any better, I felt as though I was getting worse”*. Even clinicians are unable to give reassurance of disease reversal, with slowing of COPD progression the best outcome of cessation. The lack of conviction of smoking as the main cause of illness is profound in its influence on smoking cessation failure (Hansen et al., 2007).

Smokers experience smoking as a “need of their taken-for-granted-body”. In long-term smokers, the need to smoke is an embodied and automatic function that is reinforced by triggers of daily routine such as completion of a meal, having a cup of coffee or talking on the telephone (Gullick & Stainton, 2006). For smokers, this places smoking within a framework of ritual behaviour rather than addiction (Lindqvist & Hallberg, 2010). Whilst ever the immediate embodied rewards of smoking are stronger than the longer-term and more abstract possibility of future health gains, cessation success amongst long-term smokers is unlikely (Osman & Hyland, 2005). In the context of denial, merely providing education around harmful effects of smoking is equally unlikely to make a difference. As disability progresses, for the person to continue to smoke whilst accepting smoking as the cause of their illness means they are confronted with ideas of their own inherent foolishness, selfishness or weakness, leading to self-harm and burden to loved ones, and they find this idea of themselves unacceptable. That health professionals understand these meanings of denial around smoking is central to supporting cessation attempts.

A US Clinical Practice Guideline for tobacco dependence (Fiore et al., 2000) proposes the acknowledgement of smoking addiction itself as a chronic disease. By presenting smoking in a disease framework, clinicians can move beyond the issue of patient accountability for cessation failure and create the permission to accept medical, psychological and social support. It may also reduce the anger and resentment of family members arising from the addiction.

A number of disease milestones can act as prompts to stop smoking including being confronted with a diagnosis, the threat of oxygen dependence and serious exacerbations leading to hospital admission. Patient stories frequently link periods of heavy smoking with sudden and life-threatening health events and this may strengthen the person’s resolve to stop. Taking the opportunity to communicate the ‘right words at the right time’ during a period of perceived vulnerability can be a precipitant for the person’s eventual decision for cessation (Gullick & Stainton, 2006). West & Sohal (2006) describe this as ‘motivational tension’, a point at which even small triggers may lead to an unplanned quit attempt, and supportive treatments may be most effective. In their survey of almost 2000 past and current smokers, nearly half the reported attempts at quitting were unplanned and these unplanned attempts succeeded for longer.

The approach clinicians take to smoking advice is important. It is known that smokers will resent ‘being told what to do’, and need to feel that they have reached the decision for their own reasons (Burrows & Carlislea, 2010). If clinicians seek a partnership with the patient in managing the chronic illness of smoking addiction then this may sit more comfortably in the guilt/shame milieu of smoking experience. Whilst a didactic approach to discussions is not

recommended, it must be noted that there is a strong dose-response association between the intensity of smoking cessation counselling and its effectiveness. Programs that provide person-to-person contact such as face-to-face individual or group counselling or telephone counselling have demonstrated their consistent effectiveness, and effectiveness increases with treatment intensity (Anderson et al., 2002).

11. Living with crises

COPD is often experienced as relatively quiet times interrupted by episodes of serious illness. Episodic crises create the essence of uncertainty that defines the experience of COPD (Boyle, 2009a, Oliver, 2001, Gruffyd-Jones et al., 2007). These episodes are often described by patients and carers as near-death experiences that leave people with a constant sense of their own possible death. This has been described as 'living in the proximity of death' (Lindqvist and Hallberg 2010) and from a Heideggerian perspective, 'being-towards-death' (Gullick, 2008).

Crises may be the result of panic attacks, acute chest infections, allergic reactions or acute emergencies related to comorbidities. The crisis events begin with dyspnoea that does not respond to the usual self-management strategies. Initially, people may feel the need to be on their own during acute breathlessness, sensing that others can't help bring dyspnoea under control and that there is a need to focus internally on breathing and maintaining calm (Fraser 2006). Although the onset of exacerbation is recognised with panic and dread (Leidy, 2008), people are often reluctant to seek help, hoping things will improve and hospital admission will be avoided. Professional assistance is sought only after people are convinced they can't self-manage the event (Gruffyd-Jones et al., 2007, Leidy & Haase, 1999, Bailey, 2001). Gary described his father Jack's frightening experience: "... he got a bit worried and rang the ambulance and by the time they got there all his vital signs... were starting to break down... they ended up working on him to save his life in the garage." (Gullick, 2008).

As respiratory distress increases and panic rises, people may change in appearance, may be unable to speak and may experience choking and loss of bladder or bowel control (Bailey, 2001, Gullick, 2008). These understandably terrifying events usually lead to emergency hospital admission. These crises are watershed events that mark a 'before' and 'after' in the person and family's life from which other events are then measured (Bailey, 2001). These crises underline life with COPD as uncertain and unpredictable and people fear each attack could be their last (Boyle, 2009a, Oliver, 2001). The experience reinforces the conviction of carers that they must closely monitor the person for early signs of deterioration, and this vigilance thereafter binds them emotionally and practically to the task of caring (Gullick, 2008). People will often develop emergency protocols that may define triggers for help-seeking and roles for family members that require 'understanding and trustworthiness' amongst those individuals (Bailey, 2001, Leidy & Haase, 1999).

12. Emotional coping strategies in COPD

COPD is an imposing illness in its effects on normal body functioning, daily management of the body and the home environment and on the lives of family members who give support. People find strategies around 'conscious management of self' to counter the impact of the unpredictability of the disease. Many of these strategies can be found across the literature of other chronic illnesses. These strategies include conscious control of emotions, comparing

oneself to others worse off and learning to 'go with the flow' and make the best of unpredictable symptoms (Gullick & Stainton, 2008, Seamark et al., 2004, Cicutto et al., 2004). For some people, religious faith and spirituality provide an important emotional support that can reduce feelings of powerlessness (Leidy & Haase, 1999, Bergs, 2002, Milne et al., 2009, Seamark et al., 2004, Boyle, 2009b). Coming to a point of acceptance of the disease is named by many, but elegantly articulated by Lindqvist & Hallberg (2010) who describe the process of embodying and making a relationship with the disease. This requires a conscious replacement of the previously known life structure with a new, adapted one. This allows a determination of a reframed identity and normality that includes COPD. Patricia explains *"I've just got to learn to live with it. I call it 'me and my friend'."* Part of this acceptance lies in finding different foundations upon which to build hope; from cure to coping; from old dreams to new, realistic goals; and by discovering hope in the 'rewards of the moment' (Milne et al., 2009). People find simple and meaningful pleasure in realising skills, in having a good day, in being able to achieve a walk in the park or a shopping trip or in remembering past experiences with affection (Milne et al., 2009, Ek & Ternestet, 2008, Seamark et al., 2004).

Perhaps the most significant recognition for both the carers and people with COPD is of their family as 'the best thing in life' (Gullick & Stainton, 2008). Family is not only a practical support structure, but a reason for surviving and enduring, and through children and grandchildren, embodies an important source of meaningful connectivity and joy (Leidy & Haase, 1999, Cicutto et al., 2004, Bergs, 2002, Barnett, 2004).

13. The impact of pulmonary rehabilitation for the patient and family

Pulmonary rehabilitation is a valuable treatment option in chronic lung disease and is directed towards reversing the downward spiral of disability. People with COPD tend to use their body within the limits of worsening breathlessness so that they gradually decrease their body's activity. Patricia confided: *"They say you should go out for a walk, but I just can't be bothered because I just get too tired. You know, to me it's not worth it"*.

Pulmonary rehabilitation programmes aim to reduce symptoms and disability and to reduce the person's reliance on acute health care systems by improving their understanding of the disease and encouraging active involvement and self-management. Current clinical practice guidelines (Ries et al., 2007) advise a multidisciplinary team approach, individualised patient assessment and the setting of realistic, patient-centred goals. A well-rounded rehabilitation program pays attention to the psychological, emotional and social dimensions of the patient experience, whilst trying to optimise the person's physical function by monitoring best-practice medical therapy.

Programmes usually offer a mixture of upper and lower body strength and aerobic exercise and expose the person to 'safe' breathlessness. Education sessions are an important component and typically discuss use of puffers and spacers, management of exacerbations and panic attacks, access to services and benefits, psychosocial support and understanding of Advanced Care Directives and No Resuscitation orders (Milne et al., 2009, Wilson et al., 2007). The duration and intensity of pulmonary rehabilitation programmes seem to impact on outcomes. People with mild to moderate COPD may see benefits from short to medium term participation, whilst people with severe COPD do best with programmes of at least six

months (Salman et al., 2003). The physical effectiveness gains also appear to be tied to the frequency of sessions per week (Gullick, 2008).

Having a specific COPD class means participants are empathetic towards others with symptoms of breathlessness and sputum production, and so are less self-conscious about their bodies' unpredictable behaviours (Gullick, 2008, Arnold et al., 2006). Under supervision, people become more comfortable exerting their body and are less likely to become panicked by exertional dyspnoea (Williams et al., 2010). Chris learned to manage his panic through the classes: *"The most helpful was avoiding panic attacks... It changed my outlook... I probably looked at it from the aspect 'Well, Bugger it! I can do these things' and I'd have a go at whatever it might be."* The increased sense of disease control due to greater confidence with managing medications and breathing techniques leads to a reduced likelihood of presentation to hospital (Camp et al., 2000).

Perceived physical gains include improved muscle strength, balance and mobility, reduced breathlessness and fatigue, and an improvement in joint mobility and pain management for those with musculoskeletal comorbidities. The result is that daily tasks are more achievable and require less pacing to complete (O'Shea et al., 2007, Gullick, 2008). Pulmonary rehabilitation has led to improvements in health related quality of life even where no significant improvement in lung function is demonstrated (Haave et al., 2007, Camp et al., 2000). This is in part, due to the reduction in social isolation and improved opportunities for expression of 'self' (Gullick, 2008, Toms & Harrison, 2002); patients describe feelings of enhanced well-being and hope (Milne et al., 2009, O'Shea et al., 2007), have higher self-esteem and mood (Arnold et al., 2006) and, following rehabilitation, are more likely to talk about their abilities rather than their limitations (Williams et al., 2010). Pulmonary rehabilitation can lead to a change in physical appearance and in turn, body image, and creates a sense of pride, satisfaction and achievement (O'Shea et al., 2007).

The intrinsic motivation of the person with COPD is important in determining the most successful approach to exercise training. Home-based programs may not be so successful for people who live alone or who do not have high internal levels of motivation. The notion of locus of control (Rotter, 1966) is a useful construct to predict those who may be most successful. People with a higher internal locus of control are more likely to seek information about their circumstances. They perceive a greater power to influence events through their own activities and behaviours and are more likely to believe that their labours will be successful. Those with a lower internal locus of control tend to see events as influenced by their environment, powerful others or fate. People with COPD who describe a higher intrinsic drive demonstrate more active engagement with rehabilitation and seem more successful with continuing on a home-based maintenance routine. Petra had severe COPD, but was carrying on a home-based exercise program more than a year after her initial rehabilitation: *"I have a walker... I only have to look at that and I'm at it. Never, ever will I fail! But I have two days off ... Wednesdays comes my cleaning lady... Sunday... I entertain... So all the other days, that's exercise. That's like going to a job"* (Gullick, 2008). Those whose motivation is linked to exercising with others are less likely to benefit from a home-based rehabilitation (Milne et al., 2009). Jim (60 yrs) found maintaining a home-based program challenging: *"It's pretty right what they say - 'In a group you'll do it', whereas a lot of times you'll put it off at home."*

Pulmonary Rehabilitation itself can foster subsequent patient empowerment and a higher internal locus of control by demonstrating to the participant, the positive effects of self monitoring and management of their clinical status (Cafarella & Frith, 2001). Whilst breathlessness is still a feature of the person's experience after rehabilitation, it is the change in the way breathlessness is perceived that is most important, resulting from increased confidence and a loss of fear of physical exertion. With an increased sense of control over breathing, people often find panic and anxiety are reduced or eliminated and they increase their activity levels as a result (Williams et al., 2010, O'Shea et al., 2007).

14. The impact of volume reduction interventions for the patient and family

The major limitation to exercise tolerance, and therefore to functional performance in COPD, is dynamic hyperinflation (O'Donnell & Webb, 2008). Surgical procedures, such as Lung Volume Reduction Surgery (LVRS) and Endobronchial Valve Insertion (EBV™) have expanded the therapeutic possibilities for people with emphysematous hyperinflation. The procedures aim to reduce the amount of space taken up by hyperinflated lung tissue to improve elastic recoil, and chest wall and diaphragm dynamics. LVRS is an invasive procedure that requires the resection of between 20-40% of the total volume of each lung. It is safest and most effective for people with an FEV₁ greater than 20% of predicted and a heterogenous rather than diffuse pattern of emphysema (NETT, 2001). LVRS is not a first-line treatment, but should be considered where optimal medical management and pulmonary rehabilitation fails to improve the person's clinical status (Ries et al., 2005). LVRS is known to result in significant improvements in quality of life, exercise performance and lung function, and the best results occur where surgery is complemented with an extended period of pulmonary rehabilitation (Criner et al., 1999).

In response to the potential morbidity and mortality following the major surgical procedure of LVRS, minimally invasive alternatives have been developed, and these are usually targeted towards upper zone, heterogenous emphysema. To date, the most commonly utilised approach is to insert one or more one-way endobronchial valves (EVB) to allow air to escape from hyperinflated zones and to prevent the return of air to those zones.

Whilst some patients are known to benefit from this procedure, only a minority (these tend to be those with the most hyperinflation at baseline) experience long term improvements in lung function (Kotecha et al., 2011). This improvement comes at a cost of more frequent hemoptysis, pneumonia distal to the valves and more frequent exacerbations of COPD in the few months after valve implantation (Sciurba et al., 2010). These results are confirmed in the only qualitative study of lung volume reduction procedures to date, demonstrating sustained wellness amongst most of the LVRS participants in contrast to a gradual decline in effectiveness for those who had endobronchial valve insertion (Gullick & Stainton, 2009).

Importantly, FEV₁ as the hallmark of COPD measurement, frequently does not predict the person-centred outcomes of surgery (Gullick & Stainton, 2009, Leyenson et al., 2000, Moy et al., 1999). Patients and families who accept surgical intervention for COPD feel the need to 'take a chance' on a procedure, even if they perceive that to be high-risk decision. Whilst COPD leads to shrinking of the boundaries of the self, for some, undergoing a surgical intervention allows an increase in physical effectiveness and a regaining of self. Gail

explained of her husband Jim after EBV insertion, *"He can dig in his garden...he's got a lovely veggie garden at the moment. There's lots of things he wouldn't have been able to do had he not had it done"*. Claire, (52 yrs) describes her husband Sam's regaining of self after LVRS: *"It was important for all of us to get back what he wanted; his mobility, his freedom, his right to choose what he wants... It was a chance for Sam to continue being Sam, and the surgery achieved that. He could go on being the same person that he was - he was able to continue being himself."*

15. COPD at end-of-life

End-of-life planning in COPD is an important concept that allows goal-setting for patients and families, and facilitates a peaceful and dignified death. Specialist referral to palliative care services, in combination with a partnership approach with patients and families, allows the person to retain control over aspects of the experience of dying in the context of an otherwise uncontrollable illness course.

One of the great difficulties of planning the timing of end-of-life discussions is the uncertain disease trajectory in chronic respiratory conditions. COPD has not only an insidious onset, but also, an unchartable end-stage. We know that compared to patients with lung cancer, COPD patients have more Emergency Department admissions, more anxiety & depression, and report a lower quality of life. Compared to cancer patients, financial support comes later in the disease process and patients feel in greater need of aids and appliances, and of information on services and benefits (Gore et al., 2000, Crawford, 2010). COPD patients are less likely to receive prognostic information, less likely to know they are dying, or know they are dying for less time and they are more likely than lung cancer patients to die in hospital. Relatives of COPD patients are less likely to be present at the time of death, although, we know most would like to be present (Edmonds et al., 2001).

Many General Practitioners (GPs) may not think about COPD as a terminal disease and so may not consider a palliative management plan (Halliwell et al., 2004). They do not tend to talk about what dying may be like or how long that may take (Curtis et al., 2004). The recently revised Initiative on Chronic Obstructive Pulmonary Disease guidelines (GOLD, 2010) gives brief mention of end-of-life discussions and advance directives, yet gives no strategies for these considerations or for palliative management of COPD.

A nurse participant in the study of Crawford (2010) described COPD patients as having *"nine lives... you see them sick and think they won't get through this and then they do."* This tendency for people to bounce back has led to practitioners considering how best to define the time for end-of-life discussions and interventions. For clinicians, the final phase of life may be suggested by an FEV₁ less than 30% of predicted, frequent exacerbations and admissions to hospital, and the presence of right heart failure. The need for mechanical ventilation and long-term oxygen therapy dependence also signal serious disease (Halpin et al., 2008). However, such markers are not always reliable predictors of the terminal phase of COPD (Seneff et al., 1995). Patients may have their own interpretation of the time when treatment is no-longer worth the burden that continued life presents. Scenarios that include prolongation of inevitable death, dependence on machinery, functional and cognitive impairment, unmanageable symptoms and a burden on loved ones have been noted as unacceptable by patients (Fried & Bradley, 2003).

Another complicating factor is that what is acceptable to patients may change over time as they adjust to severe illness and this may influence discussions and the willingness of GPs to initiate advance care planning (Halpin et al., 2008). It is typical of people to normalise their experience of even severe day-to-day symptoms and see themselves as sick only during acute exacerbations. This may be, in part, a coping strategy, but is also a result of the long illness trajectory. Whilst in cancer narratives, there is a definite beginning and developing plot to the 'cancer story', COPD is more likely to be insidious in its beginning and intertwined with the person's 'life story'. The unpredictability of exacerbations creates a chaotic component to the person's experience of illness, yet they may have a sense of relative wellness between these crises (Pinnock et al., 2011). Whilst people may feel that each acute exacerbation may be their last (Oliver, 2001) the threat of death recedes after a COPD crisis, or perhaps the threat of death is also normalised. The result is that death is less likely to be considered imminent and so wishes are rarely discussed with professional carers, friends or family (Pinnock et al., 2011). Where end-of-life discussions do occur, they may be poorly documented and so patient wishes may not be visible to family or other members of a multi-disciplinary team (Crawford, 2010).

Having end-of-life discussions with COPD patients and families constitutes significant emotional work for clinicians and requires 'conscious emotional management'. This comes with experience as professionals learn to feel their way with an individual, and apply emotional intelligence and empathetic skills in their discussions (Crawford, 2010). Some ways to approach these difficult conversations include beginning discussions early in the disease course, using the uncertain disease trajectory to ease discussions and building a caring and respectful relationship with patients. It is useful to have a team approach with recognition of the collective responsibility of GPs, respiratory nurses and physicians to proactively identify and use opportunities to talk about prognosis (Halliwell et al., 2004).

The aim of good end-of-life discussions is to inform without removing hope, and to bring to the forefront the wishes of the patient and family. Research participant, Mary, described how she appreciated the honesty and sensitivity of the discussions after her husband had an ICU admission: *"The doctor did tell us the dangers of intubation ...then when he was moved to ward said, 'You've come through this okay...Perhaps in the future it might happen again...You need to think what you want done, you and your family.' Just nicely ... And I thought this is great"*.

Discussing prognosis broadly in terms of a diagnostic population rather than directing it at the individual leaves room for hopeful possibilities. Physicians can foster hope by giving a 'commitment to non-abandonment', by addressing people's fears, such as fear of pain at end-of-life, and by having a management plan that addresses their changing situation (Curtis et al., 2008). Helping people to identify realistic goals and discussing their concerns about day-to-day living can also be useful (Clayton et al., 2005). The ideal is for a formal Advance Care Plan to be documented early. Again, the uncertain disease course of COPD makes this more complex, and means physicians are less comfortable with initiating such plans (Halpin et al., 2008). Fins et al (2005) point out that the process can be simplified by creating possibilities for revision of the plan, and by trying to understand and be true to the patient's core values whilst remaining flexible around practical details such as where they would prefer to die.

One marker of the end-of life stage may be the point where maximal therapy no longer provides relief of symptoms. Symptoms in the last year of life are characterised by constant breathlessness, weakness and fatigue. Pain, insomnia, depression, anxiety and panic attacks also shape the patient experience at this stage (Elkington et al., 2005). This requires a change in priorities of care, with symptom management needing the greatest focus. For example, in late-stage disease opioids may be central to dealing with dyspnoea, dyspnoea-related anxiety and pain. Clinician concerns around respiratory depression may lead to the underutilisation of opioids (Halpin et al., 2008). This may require a change in our understanding of what is 'good' or 'safe' for patients at different stages of their illness experience.

The COPD journey is a long and consuming one both for the person with the disease, and for the family carer. Whilst this may set up challenges for clinicians in understanding and supporting psychosocial concerns, it also creates possibilities for true management partnerships with our patients and their families. If we embrace these possibilities we may achieve real meaning in the care we provide, and we are more likely to locate the humanity within our practice.

16. References

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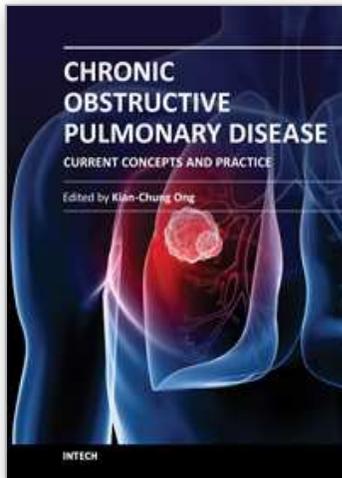
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A decade or so ago, many clinicians were described as having an unnecessarily 'nihilistic' view of COPD. This has certainly changed over the years... This open access book on COPD provides a platform for scientists and clinicians from around the world to present their knowledge of the disease and up-to-date scientific findings, and avails the reader to a multitude of topics: from recent discoveries in the basic sciences to state-of-the-art interventions on COPD. Management of patients with COPD challenges the whole gamut of Respiratory Medicine - necessarily pushing frontiers in pulmonary function (and exercise) testing, radiologic imaging, pharmaceuticals, chest physiotherapy, intensive care with respiratory therapy, bronchology and thoracic surgery. In addition, multi-disciplinary inputs from other specialty fields such as cardiology, neuro-psychiatry, geriatric medicine and palliative care are often necessary for the comprehensive management of COPD. The recent progress and a multi-disciplinary approach in dealing with COPD certainly bode well for the future. Nonetheless, the final goal and ultimate outcome is in improving the health status and survival of patients with COPD.

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