

Living with breathlessness: a systematic literature review and qualitative synthesis

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Take home message

Breathing Space: A conceptual framework for patients' coping, help-seeking and clinicians' response to breathlessness

Short title: Breathing Space: a qualitative synthesis

Widespread effects of breathlessness

The concept of “total dyspnea” (126) was used as a theoretical framework with which to analyse the data with respect to the widespread effects of breathlessness. It is important to realise that each of these realms affects the other, for example not being able to do physical activities can lead to changes in roles and social isolation can result in depression. Thus the concept of “total dyspnea” enables patients to be seen as complex, whole people in need of a holistic understanding of the many ways breathlessness affects their lives, on which effective management can be based.

Physical effects

Chronic breathlessness exacts a heavy physical toll, leading to curtailment of activities of daily living, disability, increased dependence on others and poor quality of life. Patients commented, across studies, that activities of daily living such as self-care and shopping are severely disrupted:

“The worst thing I think is the stairs, going up and down the stairs. Ordinary household chores I find difficult. Very restrictive, because of your breathing. And now of late... even simple things like having a shower and getting dressed.” (Patient) (41)

“I can walk around 200 yards and then I have to sit down and rest even on a flat road.

You could walk round the shops, but you couldn’t carry anything.” (Patient) (88)

This reduced ability to carry out activities of daily living results in dependency on others which can be difficult to come to terms with:

“Being dependent on somebody used to make me upset in the beginning. Sometimes, although I was forcing myself to the limits not to ask for help, I was trying to manage my own work. But now, both me and people around me got accustomed to this disease.” (Patient) (29)

Not only does breathlessness impose physical limitations on patients, but their carer’s physical health can be affected by their role of carer. Individuals describe how their own health suffers:

“No time to worry about my physical health.” “My health is not too good, I am physically worn out, anyhow I try not to think about it so much ... One has to work put food on the table and take care of the home as well.” (Carer) (35)

Psychological effects

Breathlessness is closely interrelated with anxiety and panic, often leaving patients and carers feeling very vulnerable:

“Then I'd be fine but I am all the time worried—worried when this breathing will attack me again” (Patient) (97)

Not only do patients feel anxiety due to breathlessness but so do those that care for them:

“It ain't just me; it's my family as well. I've got two boys and my wife and they have to go through it as well, people tend to forget them . . . they just think about the person whose got the illness, not the people they've got around them and it does affect them big time, they get emotional, they're frightened.” (Carer) (70)

Breathlessness can also lead to depression as a result of the physical limitations experienced and the subsequent losses felt. Inability to be as active as they had previously been leads many patients to feel depression:

“Depression is the biggest problem. It is the worst, because if you were an active person all your life and now you're inactive, it's hard to accept.” (Patient) (117)

The strain of looking after someone who is depressed can exact a toll on those who care for them and lead them to feel depression too:

“He wouldn't have it that there was anything wrong with him. But that's just a thing, but between us we're we're alright, it just a strain, a constant strain of trying to keep him (...) not happy, but trying to keep him thinking positively and just trying to get through each day and some days it's not too bad and other days it's a real struggle ... he's becoming more and more depressed.” (Carer) (33)

“I had become so depressed just after Christmas that I used to sit down at night, just crying ... I went to my GP and he gave me some pills and I think they have helped me a bit ... I have at least stopped crying. Still I am awfully tired mentally, and sad, terribly sad, mentally I am worn out.” (Carer) (35)

Understanding the psychological difficulties that are faced by breathless patients and their carers is the key to help them manage breathlessness; unfortunately not everyone feels they get the understanding they deserve:

“The emotional thing is extremely, extremely important. You don’t get the understanding ... you can just like get caught up in a downward spiral and you end up in this little place all by yourself ...”
(Patient) (43)

Social effects

As previously described chronic breathlessness affects both patients and their carers significantly physically and psychologically, this in turn brings about various social consequences for them; including social isolation, changes to relationships and altered social roles.

Living with breathlessness on a daily basis results in developing ways of dealing with its impact and commonly patients describe how this culminates in changes in their lifestyle, often including some self-imposed limitations:

“I used to love dancing, I can’t you know, and going anywhere where there’s music now, no, because I want to get up and I can’t and it upsets us.” (Patient) (27)

As a consequence many become isolated and live with a constant sense of loss over all the activities they feel they are no longer able to do:

“My husband would say: ‘Shall we go down and see John and Juliana?’ and the thought of walking out that gate into the car, I would be absolutely gasping, I made excuses not to go out and this is what happens, the more you’re housebound, the more depressed you get.” (Patient) (66)

“We often feel lonely and on the edge of things.” (Patient) (63)

This isolation results in psychological distress and changes in relationships with others for both the patient and their carer:

“Gradually we have had less and less to talk about ... gives the impression that he has no interest anymore, neither in myself nor in his surroundings. I think this is some kind of envy of me, in my heart I can feel it ... After he started to go in and out of hospitals we stopped being good friends like we used to be ... The disease has isolated him from the family and myself, and now we have restricted issues to talk about ... it makes me sad when I think about it.” (Carer) (35)

Also intimate relationships can be affected by breathlessness, however these issues may go untackled:

“I am really in need of some form of intimate contact with him, but I do not want to press him ... and this is something one cannot talk so easily about ... I am afraid he could sense it as an accusation.”
(Carer) (35)

Both patient and carer may feel that their roles change when living with breathlessness. The physical effects of breathlessness mean that lifting and movement are constrained and activities like cooking, cleaning, decorating, making love or carrying shopping may become very difficult. When breathless people feel unable to do the activities that they associate with their gender role they feel less of a man or a woman, which can be very distressing:

“It’s the silly things . . . not being able to carry the shopping . . . I was brought up in the Victorian school . . . the man always carries the bags....” (Patient) (36)

“For people like Chris that you can’t actually see any physically wrong with them. I don’t know, it makes life that little bit more difficult when you go out coz people look at you, like if I’m carrying the shopping bags and he’s walking, doesn’t bother me in the least, but people look and then it makes him feel awkward.” (Carer) (65)

“He feels angry about the way breathing limits his life, he has been active all his life and now he can’t do anything about it. He further describes problems with maintaining an active sex life and is deeply concerned about it. His cancer and his breathing are affecting all parts of him not just his lungs; his breathing has been bad enough but this (impotence), he feels not a complete man anymore....” (Carer) (89)

Carers also undergo changes in their roles, often moving away from having an intimate relationship (e.g. spouse) to having to take on many new roles and may lead to giving up work:

“It’s a hard time I tell you and it gets you down. When you think what the nurses do in hospital, giving him his tablets and everything. I’m doing a thousand jobs as well. I’m just going crazy because you don’t get to the end of it... We’re nurses, we’re doctors, we’re housewives, we’re cooks, we’re gardeners.” (Carer) (98)

This change in roles may lead to having to give up work and can adversely affect the relationship leading the carer to re-evaluate aspects of their life:

“Over the last 8–9 years, I feel inside that my role’s completely changed. Somewhere in all of this, I’ve lost who I am. I’m more like his nurse or ‘I need you’ kind of thing. That’s it – I need you, and I don’t know how to explain it. I just feel like somewhere me, myself, I’m lost. I don’t know who I am any more. I don’t know if anybody can understand that.” (Carer) (101)

Existential effects

There are many existential concerns associated with chronic breathlessness including inability to carry out religious observance, difficulty determining how best to use their remaining life, the daily struggle sometimes resulting in a lack of will to live and also the fear associated with the imagined manner of death.

Living with the burden of chronic breathlessness can mean that people are unable to continue on with their chosen religious observance at the very time they feel most in need of that support:

“I went down to Mass then in the car and my wife said to me ‘You shouldn’t go down because you’re not able to walk all that far’ and I really couldn’t walk from the car park—I attempted and failed— it is only maybe about 200 yards—and I’d only gone a few yards and I said ‘Look I can’t—you’re right I can’t go any further—I’ll have to stop’—so I had to come back and get into the car and go home.”
(Patient) (97)

Patients’ difficulties in determining how best to use their remaining lifetime arise from a number of issues, involving both diagnosis and prognosis with respect to their underlying condition. Patients find that there was a lack of information with respect to their diagnosis and that often it meant little to them:

“We were just told that it was COPD. I had never heard of it and in fact, I couldn’t remember the sequence of letters for a long time.” (Patient) (67)

Often the relief at not having cancer means that patients do not realise the severity of their condition, as this is not clearly described to them:

“I’ve been to the doctors and they’ve told me I’ve got COPD. ‘What is it?’ The doctor hasn’t even explained what those four letters mean and the worst thing about it is it starts off with C, and first thing you think: ‘Oh, have I got cancer?’ But this is the thing that is wrong, it’s [COPD] not a well-known disease, yet it’s one of the greatest killers.” (Patient) (67)

Little attention is paid to describing likely prognosis with patients being left in a limbo, feeling they had an uncertain future and living day by day without planning:

“Erm, you know, I can’t really say [how I see the future] we’ll just take each day as it comes.” (Patient) (67)

The lack of meaning of the diagnosis and inattention to prognosis means that they are unable to determine how they wish to spend the time left to them:

“At the time we weren’t really told that was a degenerative condition that it would gradually get worse. At the beginning we weren’t told that it was a general decline. We were just told this is what you’ve got, get on with it. Yes, in the beginning I would have liked a little bit more information. At least it prepares you for the general decline in his health.” (Patient) (67)

Many people feel doubts over whether their life is worth living and express the desire to end their lives in order “to end the struggle to breathe” (Patient) (34):

“When the shortness of breath was at its extreme, I thought I was going to die and saw a coffin beside me and then I was in a tunnel... I did have thoughts about suicide and I envied the dead.” (Patient) (89)

Also fear of the manner of their death can be a concern, with many patients unaware of both how their underlying condition may bring about their death and also how it could be medically managed by appropriate palliative care. With this lack of knowledge many patients (and also carers) believe that they may die with the feeling of suffocation that is regularly experienced with increased breathlessness and fear this greatly:

“I’ve always said I’m not afraid of dying ‘cause I know where I’m going. But when I get short of breath I get scared – I don’t know why – I shouldn’t. I think smothering to death is a hard way to go.” (Patient) (120)

“My worst fear is of slowly suffocating, dying gasping for breath when I’m alone here in my flat on me own, that’s my worst fear.” (Patient) (113)

“I have this constant fear that he will stop breathing, so I need to sleep near him so I can be on the alert if something happens.” (Carer) (33)

When these issues are not discussed and planned for then the manner of death may indeed be very distressful for all concerned as described by the husband of a patient who died from lung cancer:

“...drown in her secretions sitting upright looking into my eyes crying for help. It was a nightmare and now I can’t get those pictures out of my head, I know I did my best but I failed her-it was exactly what we didn’t want, my life is in complete tatters.” (Carer) (89)

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