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Author Contributions

Criteria	Author Initials
Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data;	MG, TL, MJ, AH, SL, JP
Involved in drafting the manuscript or revising it critically for important intellectual content;	MG, TL, MJ, AH, SL, JP
Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content;	MG, TL, MJ, AH, SL, JP
Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.	MG, TL, MJ, AH, SL, JP

ABSTRACT

Aim:

To explore the role of coping moderators in self-management of breathlessness crises by people with advanced respiratory disease.

Design:

A secondary analysis of semi-structured interview data.

Methods:

Interviews with patients who had advanced respiratory disease, chronic breathlessness and at least one experience where they considered presenting to Emergency but self-managed instead (a 'near miss'). Participants were recruited from New South Wales, Queensland,

Victoria, South Australia or Tasmania. Eligible caregivers were those who contributed to Emergency-related decision-making. Interviews were coded inductively and then deductively against the coping moderators social support and dispositional coping style, defined by the Transactional Model of Stress and Coping.

Results:

Interviews were conducted between October 2015 - April 2016 with 20 patients and 3 caregivers. Social networks offered emotional and practical support but also had potential for conflict with patients' 'hardy' coping style. Patient hardiness (characterized by a sense of 'commitment' and 'challenge') promoted a proactive approach to self-management but made some patients less willing to accept support. Information-seeking tendencies varied between patients and was sometimes shared with caregivers. An optimistic coping style appeared to be less equivocally beneficial.

Conclusion:

This study shows that social support and coping style may influence how people self-manage through their breathlessness crises and identified ways coping moderators can facilitate or hinder effective self-management.

Impact:

This study confers insights into how social-support and coping style can be supported and optimised to facilitate breathlessness self-management. Acknowledging coping moderator interactions is beneficial for developing resources and strategies that recognise patient mastery.

Key words: breathlessness, dyspnea, self-management, coping, nursing, social support, respiratory, emergency, qualitative

INTRODUCTION

Chronic breathlessness is defined as breathlessness that persists despite optimal treatment of the underlying pathophysiology and results in disability (Johnson et al., 2017). It is associated with many advanced chronic conditions and respiratory disease such as chronic obstructive pulmonary disease (COPD) where breathlessness is almost universal (Moens et al., 2014).

Breathlessness is conceptualized as a multidimensional experience with three distinct domains relating to sensory-perceptual experience, affective response and impact (Banzett et al., 2015; Lansing, Gracely, & Banzett, 2009). Many people with chronic breathlessness also experience acute episodes or ‘crises’ that are especially distressing and often precipitate Emergency Department (ED) visits (Parshall et al., 2012). Better self-management and healthcare support can encourage patient behaviours and actions that can prevent or decrease the severity of exacerbations and subsequently also preventing potentially avoidable ED visits (Hutchinson, Pickering, Williams, Bland, & Johnson, 2017).

Self-management of chronic illness includes not only administration of treatments but also control over one’s emotional response to the illness and ability to maintain usual activities of daily living as best as possible (Lorig & Holman, 2003).

Background

The Transactional Model of Stress and Coping (‘Transactional Model’) (Lazarus & Cohen, 1977) suggests that people’s capacity to cope with a stressor such as chronic illness is affected by their subjective appraisal of the stressor and self-efficacy in controlling it using the means at their disposal. When applied to patient experiences of breathlessness crises, the Transactional Model has suggested that the most important factors in avoiding ED presentation are perceived control over the crisis and self-efficacy in managing the affective dimension of experience (Lockett et al., 2017).

The Transactional Model proposes that coping is influenced by ‘moderators’ dispositional coping style and social support. Dispositional coping styles posited as being influential include positive thinking/optimism, information-seeking and hardiness (Glanz & Schwartz, 2008). There is paucity in research on coping style in respiratory disorders that present with chronic breathlessness and available research tends to focus on COPD. One qualitative study on a sample of patients with various respiratory conditions, including bronchiecstasis, pulmonary and cystic fibrosis, found patients whom attributed negative beliefs to their breathlessness to be more prone to panic in the event of exacerbations (Hallas, Howard, Theadom, & Wray, 2012). Previous studies in COPD have found that optimism correlates with self-efficacy and adherence to breathlessness management regimens (Alberto & Joyner, 2008; Benzo, Abascal-Bolado, & Dulohery, 2015). While no studies to date have explored information-seeking in people with chronic breathlessness, low health literacy has been associated with decreased adherence and increased hospital admissions in people with COPD (Disler, Gallagher, & Davidson, 2012; Kale et al., 2015). Only one study has examined the contribution of hardiness to self-managing chronic breathlessness, defined as “a commitment to self, an attitude of vigorousness toward the environment, a sense of meaningfulness and an internal locus of control” (Kobasa, 1979, p. 1). Previous literature shows that hardier COPD patients tend to use more problem solving and had better functioning (Narsavage & Weaver, 1994) and that “hardier” patients to report more adaptive behaviours and lower distress levels in a review of various chronic conditions (Brooks, 2003).

Social support is also important for self-management by people with COPD (Disler et al., 2012; Russell et al., 2018) and chronic illnesses more generally (Gallant, 2003). Support from families and friends has been found to assist both practically (in terms of assistance with treatment administration and coordination of care) and emotionally (through increased life enjoyment and motivation) (Disler et al., 2012). A randomized controlled trial (RCT) has

shown family involvement to increase the effectiveness of an exercise intervention on improving coping and reducing psychological distress in people with COPD (Marques et al., 2015). Social support from peers with chronic breathlessness (e.g. through support groups) has also been found to help people with COPD enjoy a sense of community and lightheartedness about their condition and conversely, social isolation has been found to undermine confidence and functioning (Disler et al., 2012).

Dyadic coping is a concept that has received some attention with regard to chronic breathlessness, wherein coping is viewed as an inter- and intrapersonal process involving two people in a close relationship (e.g. spouses) (Lee & Roberts, 2018). It has been suggested that there are four kinds of dyadic coping: positive (where support is provided by one partner to assist the other in his/her coping efforts), delegated (where one partner asks the other to help with specific tasks), common (where both partners participate equally in coping efforts) and negative (where partner contributions are superficial, ambivalent, or hostile support provision) (Lee & Roberts, 2018). COPD is among other health conditions where patient perceptions of negative dyadic coping have been associated with poorer perceived ability to cope and quality of life (Meier et al., 2012; Meier, Bodenmann, Mörgeli, & Jenewein, 2011; Vaske et al., 2015), however there is paucity of research in dyadic coping in other respiratory conditions.

Whilst the above research provides some insight into how dispositional coping styles and social support may contribute to daily self-management of chronic breathlessness, no research has focused on breathlessness crises or used a theoretical model to explore relationships between different components of coping so as to highlight opportunities for intervention. A better understanding of factors that might help to avert avoidable ED presentations from breathlessness crises is important from both patient and health systems perspectives.

THE STUDY

Aim

The current article reports an analysis that applied the Transactional Model of Stress and Coping which aimed to explore the relationships between moderators, self-management and coping in people with respiratory disease during a breathlessness crisis. The aim of the original study was to explore the ED-related decision-making from the perspective of people with experience of successfully self-managing through a breathlessness crisis. Detailed methods for this study have been reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong, Sainsbury, & Craig, 2007) in an open access journal (Luckett et al., 2017). The current paper focusses on a secondary analysis of coping moderators.

Design

A qualitative approach was chosen to allow in-depth exploration of subjective experience of and attitudes towards, chronic breathlessness crises and self-management (Merriam, 2002).

Sample/Participants

Participants included adults with chronic breathlessness ('patients') and their informal caregivers who spoke sufficient English to provide written consent. Eligible patient participants had: 1) experienced breathlessness on most days in the last month from a diagnosed respiratory condition and 2) had one or more "near miss(es)" where they considered presenting to an ED for a breathlessness crisis but decided to self-manage instead and have successfully avoided going to ED as a result. This second criterion was intended to optimise opportunities for learning from patients' experiences. Patients were excluded if they believed their breathlessness crisis might be a symptom of a cardiac event or asthma attack, because of the unequivocal need to seek medical assistance in these instances. Eligible

caregiver participants were those involved in deciding whether or not the patient should present to ED, as reported by the patient.

Participants were recruited through electronic invitations on the website and national email lists of the Australian Lung Foundation and its associated support groups, as well as oral invitations at pulmonary rehabilitation group sessions at a single metropolitan hospital.

Data collection

The data used in this secondary analysis had been originally collected during a series of semi-structured interviews, telephone or face-to-face at a place of the participants' choosing.

Patient and caregiver dyad interviews were conducted either concurrently or individually, as determined by the patient. Interviews were audio-recorded and then transcribed for analysis.

Data were managed using NVivo version 11 for Windows (QSR International, 2015).

Interviews were conducted by a male health academic with a background in speech and language pathology and experience with qualitative research (Author 2) together with a female Bachelor of Medical Science undergraduate student (Author 1) in approximately half the cases.

Interview questions were open-ended and centred on participants' experience of breathlessness crises, ED-related decision-making and self-management strategies. Interview questions are listed in Box 1. The interview guideline in Box 1 was also used in any interviews with caregivers.

Ethical considerations

The study was conducted between October 2015 and April 2016 and ethics approval was gained through the Human Research Ethics Committee (HREC) at St. Vincent's Hospital

Sydney (HREC reference number HREC/15/SVH/277) and ratified by the HREC at the University of Technology Sydney.

Data analysis

An integrative approach (Bradley, Curry, & Devers, 2007) was undertaken for analysis. Initial line-by-line codes and categories were shaped inductively and iteratively before applying the Transactional Model of Stress and Coping and the concept of dyadic coping to transition to interpretative themes.

Rigour

Initial coding was conducted independently by the two interviewers (Author 1 and 2), who met after each interview to reach consensus. When transitioning to themes, contributions each code might make to elements of the Transactional Model were initially mapped by Author 1, who then met with Author 2 to discuss. Emerging ideas about how moderators contributed to the model elements were tested in subsequent interviews and data collection was ceased when no further themes emerged from interviews. A summary of findings was emailed to participants with an invitation to comment on their veracity. Of the small proportion who responded, all verified the interpretation.

FINDINGS

Participants

Twenty patients and three family members were interviewed. Two dyad interviews were conducted concurrently, while one patient chose to be interviewed separately from their family member. All three family members were male spouses. The mean duration of interviews was 38 (standard deviation [SD] \pm 13) minutes, range 23-70 minutes). Eighteen patients were recruited through support groups and two were recruited through pulmonary rehabilitation. All except one of the interviews, were conducted over the telephone. The

sample included people living in regional and metropolitan areas, variously from New South Wales, Queensland, Victoria, South Australia, or Tasmania. Patients had a mean age of 68.7 (SD \pm 5 years). Other patient characteristics are summarized in Table 1.

Themes

Dispositional coping style and social support appeared to contribute to each component of the Transactional Model of Stress and Coping. Quotes illustrating these themes are seen in Table 2.

Dispositional coping style

References to hardiness and information seeking were commonly made in the interviews as follows.

Hardiness through challenge, commitment and control

Hardiness was most often referenced by participants in terms of being self-reliant or independent and was relevant for “Meaning based coping”.

The challenge component of hardiness was manifest in this study through participants’ positive reappraisal of previous breathlessness crises as a learning experience. Some patients viewed breathlessness mastery as an exercise in project-management that required active reflection and analysis of previous experience to enable planning and preparation for future crises (Table 2, Quote 1). Several patients clearly took pride in the ‘expert’ status they had acquired over time in managing their breathlessness (Table 2, Quote 2).

The commitment component of hardiness was evidenced in patients’ preference for self-managing their breathlessness crises without professional support, many of whom set a high threshold for seeking medical assistance (Table 2, Quote 3). Commitment was manifest not only in self-managing breathlessness but, transliterally, in managing the self. Maintaining a sense of control was an important theme for most patients, with a perceived loss of control

among the key precipitants of presentation to ED and as such, hardiness was also relevant to the Secondary Appraisal of a crisis. In terms of managing breathlessness, loss of control occurred when previously tried-and-tested self-management strategies were no longer effective (Table 2, Quote 4).

At the same time, control was also used sometimes to refer to patients' personal fortitude in coping with a crisis, with loss of control perceived to involve 'giving in' to panic and losing their ability to make a reasoned decision (Table 2, Quote 5). Loss of control of both kinds was more likely to occur when patients perceived themselves to be in a situation or place they regarded as unsafe, either because it exposed them to triggers likely to worsen the breathlessness or because they could not receive help in the event they really needed it (Table 2, Quote 6).

Information seeking – knowledge as power

Information seeking was strongly related the need for control and was relevant to Secondary Appraisal, but also seemed to encourage Problem-management based coping. During a crisis, patients used objective measures (oximetry and heart rate) to appraise the severity of their breathlessness. Objective measures also assisted patients with distinguishing their breathlessness from their anxiety (Table 1, Quote 7). Some patients also reported monitoring the onset of a breathlessness crisis through the limitations in their functioning (Table 2, Quote 8).

Patients also gathered information to help them plan and prepare for the next crisis. Many placed special credence in information from health providers, in whose qualifications they placed trust (Table 2, Quote 9). A few patients reported finding the internet to be helpful in finding out information about managing future breathlessness crises, whilst others questioned the reliability of the available information (Table 2, Quote 10-11).

Whilst most patients actively sought as much information as they could find, there were a small number of exceptions who feared that ‘too much’ information might cause distress or, conversely, false hope (Table 2, Quote 12).

Optimism as a pathway to deriving meaning

Optimism was also related to the challenge component of hardiness in that patients who described finding achievements in living with breathlessness and pride in their learning to manage it also tended to identify themselves as being “glass half-full”. This seemed to contribute to their ability to revise their goals as a form of Meaning based coping (Table 2, Quote 13).

An optimistic approach also seemed related to patients’ capacity for Positive reappraisal, facilitating the acceptance of changes brought by their limited functioning and to revise their goals around these (Table 2, Quote 14).

Social support helps with appraisal and coping efforts

Social support assisted with both the Primary and Secondary appraisal of breathlessness crises, as well as contributed to Coping efforts in relation to both breathlessness and emotional regulation.

Family members helped with the Primary appraisal of crises, by recognising its onset and severity, but to varying degrees. Some patients relied on their caregivers to recognise the onset of a breathlessness crisis even before they did (Table 2, Quote 15). In another case, appraisal was shared between the patient and her husband, with the latter able to provide a more objective view of events, especially when his wife’s decision-making became impaired by hypoxaemia (Table 2, Quote 16).

Family members’ contribution to patients’ emotional regulation during a crisis was reported to work in both positive and negative ways. Some patients reported their spouses to be a

calming presence or help by reinforcing relaxation techniques (Table 2, Quote 17). Some patients however reported that family and friends could become panicked during a breathless crisis. As such, patients reported having to endure the added burden of regulating the emotions of those around them as well as their own (Table 2, Quote 18).

For many patients social support played an important role in the “Problem-focused” aspect of breathlessness management, such as through medication administration. While assistance was usually supplementary to the patient’s coping efforts, a small number of patients seemed to rely on family assistance almost entirely, such as in one dyad where the patient was too unwell to self-manage alone (Table 2, Quote 19). Patients also derived social support from local social networks, such as friends and neighbours, namely with practical day-to-day assistance (Table 2, Quote 20).

The interplay between dispositional coping style and social support

Patient responses also showed that dispositional coping styles interact within the different aspects of Transactional Coping and may be dependent on their available social support and vice versa.

Hardiness and social support have an ambivalent relationship

For many patients, knowing that social support was available when needed conferred reassurance and increased feelings of control, even if these supports were not used, indirectly contributing to feelings of Susceptibility during Primary appraisal. Interestingly, knowing that social support was available did not undermine participants’ feelings of independence. For these patients, use of social networks was occasional and non-reciprocal; as such, it did not qualify as delegation with a dyadic coping relationship but, instead, seemed to be just another non-pharmacological strategy. Taking this perspective meant that social support empowered, rather than detracted from, patient feelings of self-efficacy. This was especially

true for patients who lived alone, where the social networks in question were neighbours and friends (Table 2, Quote 21). The relationship between hardiness and social support was more complex for patients who lived with a close family member. One caregiver reported relying on the interpretation of her breathlessness crises, particularly due her nursing background (Table 2, Quote 22).

Few, if any, patients displayed 'common' dyadic coping, where the patient shared the role of 'coper' with a partner on an equal footing. Perhaps the closest was a dyad where the patient viewed the spouse's role as, equivocally, somewhere between common coping and delegation. In this dyad, the patient acknowledged her husband's contribution whilst also asserting her independence. In this case, it seemed that sharing expertise posed a threat to the patient's sense of challenge, commitment and control. Ongoing negotiation of the spouse's role appeared to result in stress on the dyad's relationship (Table 2, Quote 23).

This patient was one of only three patients who indicated that a family or friend helped them make ED-related decisions. With the exception of one man, who was receiving palliative care and deferred decisions to his partner because he felt too unwell, these patients maintained that the final choice lay with them because their first-person perspective offered privileged access to appraisal of breathlessness severity and quality (Table 2, Quote 24).

Social networks as sources or filters for information

Information-seeking patients gained information through their social networks, especially where people brought medical expertise or privileged access to information not available to the patient. In one instance, family or friends had experience and expertise as health professionals to assist with sourcing and interpreting information (Table 2, Quote 25).

Networks with other people with breathlessness provided a unique kind of experience-based information that was not available from formal sources, including management strategies to

use during a crisis that people had devised themselves. Notably, patients valued being givers, as well as receivers, of information within these networks (Table 2, Quote 26). Patients commonly reported the use of social media and internet forums not only to learn more information, but also as a means of meeting others with similar conditions, as an alternate source of social support (Table 2, Quote 27).

Dyadic coping was evident in spouses' role in collecting information as well as in regulating information flow to the patient. In the case of the one patient who avoided seeking information about her breathlessness because she found it too distressing, her husband obtained the information on her behalf, so it could still be used to inform management, whilst also regulating her emotional reactions to information (Table 2, Quote 28). Family members and friends also assisted with interpreting information during consultations, where understanding could be impeded by medical jargon and stress (Table 2, Quote 29).

Social support can facilitate optimism and meaning making

For many patients, a sense of interconnectedness with other people offered a major source of positivity and meaning in the context of declining health and contributed to their capacity for Meaning based coping (Table 2, Quote 30).

As well as providing privileged information, networking with other people with breathlessness had potential to contribute special meaning to the breathlessness experience. Patients described the relief they experienced meeting others in support groups or in pulmonary rehabilitation who had similar conditions, shifting their perception of social norms to make them feel less of an outsider (Table 2, Quote 31). Patients found this peer group provided an opportunity to share their experiences with people who had a greater level of understanding than their family and who they were less worried about emotionally burdening (Table 2, Quote 32).

Exposure to people in poorer states of health than themselves had a mixed effect on patients. Some were despondent because they interpreted this experience as a premonition of their future selves (Table 2, Quote 33). Interestingly, this same patient found attending support groups to be a source of optimism in knowing that there were others ‘worse off’ than she was. In a sense this allowed patients to move the goalposts and to positively reappraise their condition as not as severe as initially perceived (Table 2, Quote 34). A summary of how dispositional coping and social support appeared to contribute to coping is presented in Figure 1.

DISCUSSION

As predicted by the Transactional Model of Coping, this study found the coping moderators of dispositional coping style and social support to exert important influences on patients’ capacity to cope with breathlessness crises. Transposing the Transactional Model with the concept of dyadic coping revealed relationships between the moderators to be variable and complex and sheds further light on the equivocal impact of social support identified by previous studies (Meier et al., 2012; Meier et al., 2011; Russell et al., 2018; Vaske et al., 2015). In particular, our findings suggest that the interactions between social support and the dispositional style of hardiness may affect its resulting potential to either positively or negatively contribute to patient coping, either supporting or undermining self-efficacy and sense of control, elsewhere referred to as breathlessness mastery (Guyatt, Berman, Townsend, Pugsley, & Chambers, 1987). As in previous research in COPD (Narsavage & Weaver, 1994), we found the commitment and challenge components of hardiness to be a positive influence in terms of promoting a proactive approach to self-management and ‘can do’ approach to coping. However, there is a risk that more extreme levels of hardiness might

constitute a ‘double-edged sword’ if they disenable a person with breathlessness to seek social and professional support when needed. Our research suggests that attempts to enable hardy patients to reap benefits from social support might be most successful if they frame social support as a resource for, rather than a rival to, mastery. Making support a reciprocal ‘two-way street’ where patients feel they are assisting others as well as receiving help might reduce the likelihood that their sense of mastery is undermined. This can be achieved in practice by using group therapy (e.g. pulmonary rehabilitation) as an opportunity for peer-to-peer learning.

In our study, social support as a resource seemed especially important to patients who lived alone. Previous studies have shown patients with COPD who lived alone to experience worse outcomes than their counterparts who lived with others (Crockett, Cranston, Moss, & Alpers, 2002; Gudmundsson et al., 2006). Previous studies have also briefly reported friends and neighbours to assist with instrumental daily living in patients with COPD who live alone but did not explore how they can assist in managing or preparing for breathlessness crises (Ek, Sahlberg- Blom andershed, & Ternestedt, 2011; Steindal et al., 2017; Wilson et al., 2008).

One other qualitative study in community-dwelling older adults echoes similar themes to our study’s findings: older adults were reported less likely to enter the acute care system if they were engaged in informal networks such as their peers and neighbours (Cheek, Ballantyne, & Roder-Allen, 2005). Similar to our study, participants in this research perceived their social networks to be akin to a “safety net” that they used only as needed, as well as resource where they learned from one another’s experiences (Cheek et al., 2005). Where hardy patients have not developed a resource of this kind of their own volition, it may be beneficial to help them identify people who can assist in specified ways, with agreement on the conditions under which they will feel able to accept such help. As well as assessing availability of social support and willingness to seek help, discussion offers an opportunity to assess a patient’s

expertise in distinguishing warning signs and related problem-solving and decision-making (Karasouli et al., 2016; Russell et al., 2018). Home visits offer the ideal opportunity to discuss these issues within the patient's socio-ecological and physical environments and activities of daily living.

At the other end of the spectrum, our sample included two patients who seemed to have relinquished mastery to their spouse, relying on them for every aspect of self-management – even to the extent of recognizing the onset of a breathlessness crisis. Our study joins those in other health conditions in finding that these partners also act as “proxy informants” who obtain and screen information on the patient's behalf (Leydon et al., 2000; O'Brien, 2004).

Previous literature suggests contributions of this kind offer “protective buffering” that positively contributes to dyadic coping (Lee & Roberts, 2018). In cancer studies, there has been a suggestion that partner self-efficacy may act as a surrogate where patients lack this themselves (Campbell et al., 2004; Keefe et al., 2003). There is the risk that this contribution can ‘tip over’ into negative territory by hindering the patient's potential for mastery, as is suggested by inverse correlations found between family self-efficacy and patient self-management in COPD (Wang, Sung, Yang, Chiang, & Perng, 2012). While relinquishing self-management appeared to result in positive dyadic coping in the two cases included in our study, such an imbalance in responsibility seems likely to leave patients vulnerable if their partner lacks an understanding of breathlessness and its self-management, becomes unavailable, or misuses their share of control either intentionally or otherwise.

Studies in self-management in diabetes have found that certain family behaviours such as strict structure, rules and criticism (Rosland, Heisler, & Piette, 2012), or “overbearing” behaviours can result in negative patient outcomes (Rosland, Heisler, Choi, Silveira, & Piette, 2010). It is important to note that, in this study, we observed very few – if any - instances of common or ‘true’ dyadic coping, which may suggest that sharing mastery is difficult to

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achieve. Our study joins a recent systematic review in finding breathlessness crises to offer patients with COPD opportunities to learn about their condition and its management (Russell et al., 2018). However, while the reviewers associated this benefit with knowledge gained from different health professionals, our findings suggest it may be patients' capacity to reflectively appraise their experience as offering a learning opportunity that contributes most to coping. Moreover, our findings suggest that an optimistic coping style may interact with the commitment component of hardiness to enable patients to positively reappraise their response to their condition to reframe their experience and revise goals in the context of declining health. This finding is consistent with previous quantitative research that has found correlations between optimism and self-efficacy in people with COPD (Popa-Velea & Purcarea, 2014) and adherence to self-management in people with diabetes (Popa-Velea, Diaconescu, & Apostol, 2018). More generally, our findings also support previous research that suggests optimism supports coping and wellbeing for people across chronic conditions (Nowlan, Wuthrich, & Rapee, 2015). Nurses and other health professionals can draw on the principles of cognitive behaviour therapy (CBT) to encourage positive reframing and counter negative reappraisal. Where disease is advanced, acceptance and commitment therapy (ACT) is appropriate because it recognizes that negative emotions are a natural response to declining health and poor prognosis whilst also teaching strategies for defusion (Brassington et al., 2016).

Our finding that seeking information about and monitoring their condition gave patients a sense of control replicates findings from another study, albeit with patients with cancer (Blödt et al., 2018). Patients' use of online forums and social media served as a dual resource for information and social support. A previous study in COPD concluded that use of electronic media of this kind may be indicative of patients trying to address gaps information provided by health professionals, as well as to address the social isolation imposed by the debilitating

nature of breathlessness (Stellefson et al., 2017). However, our research questions this conclusion by suggesting that people with chronic breathlessness perceive their peers to have privileged, experience-based insights that are qualitatively different from the medical information that health professionals can offer. As noted above, clinicians are encouraged to seek opportunities for enabling peer-to-peer knowledge transfer in group therapy.

Previous studies of people with COPD have found social support to be a source of safety and security (Kanervisto, Kaistila, & Paavilainen, 2007) and to be a calming presence during a crisis (Disler et al., 2014). While this was echoed in our study, similar to other research we found that family members are distressed by breathlessness crises, sometimes more so than the person with breathlessness themselves (Gysels, Bausewein, & Higginson, 2007), with the result that they are less able to positively contribute to patient coping. Recent experimental research suggests that family members' distress may arise not only from their concern for the patient but also because they vicariously experience breathlessness from observation (Herzog et al., 2018). The risk, as well as benefit, that family and friends pose to patients' self-management underlines the need to ensure they receive appropriate education and training in addition to the patient (Farquhar et al., 2017). This should focus not only on ways to help manage breathlessness in the patient but also reflective skills to help them identify when they may be undermining rather than supporting self-management.

It is important to note, however, that these participants were able to distinguish between controllable and uncontrollable crises, which may denote a certain level of self-efficacy required for confidence in their repertoire of self-management skills (Russell et al., 2018) or experience managing previous exacerbations and living with their condition (Karasouli et al., 2016).

Limitations

The findings of this study are unlikely to be generalizable to the whole population of people with breathlessness. Focusing on people who reported avoiding ED admissions for their breathlessness was consistent with the study's primary aim to investigate experiences of successful self-management, but experiences are likely to be quite different in people who are less able to self-manage. The sample presented mainly with COPD however, limiting generalization to people with chronic breathlessness from other conditions. As discussed above, a focus on people who had mastered their breathlessness is likely responsible for so few caregivers meeting criteria. The high degree of hardiness demonstrated by most patients is likely also related to the fact that an unrepresentative proportion lived alone. It is less clear whether patients with both characteristics became hardy as a result of living alone or, conversely lived alone because their hardiness made cohabitation difficult. Information such as employment or other demographic data that may influence coping style was not routinely collected in this study and could be of interest to explore in further research.

The authors involved in data collection and initial coding were not clinicians and may have lacked the experience to recognise patterns or may miss lines of questioning that clinicians may be better equipped to recognise. Members of the authorship team included clinicians who had experience in respiratory care and/or self-management of chronic conditions were involved in the later stages of analysis to address this.

Finally, while the Transactional Model of Coping is perhaps the most widely used framework of coping, application of alternative theories would have yielded a somewhat different perspective. A recent systematic review and metasynthesis of chronic breathlessness experience used Tobin et al's (1989) framework for coping (Tobin, Holroyd, Reynolds, & Wigal, 1989), with a resulting emphasis on engaged versus disengaged coping styles (Hutchinson, Barclay-Kling, Galvin, & Johnson, 2018). The authors concluded that

“Breathing Space” (the ability to live well with chronic breathlessness) was maximized in patients who actively engaged with self-management and sought help proactively rather than reactively waited for a crisis to force them. The construct of engagement therefore seems similar to, but subtly different from, hardiness and optimism as applied in the current analysis.

CONCLUSION

Coping moderators appear to influence the ways people with breathlessness cope with a crisis in most aspects of the coping process, as well as the decision whether or not to present to ED. Future research is needed to identify ways by which these moderators can be effectively mobilized or supplemented.

The putative relationships between dispositional coping styles and social support suggested by our analysis requires further testing in future research. Of particular interest are any sub-groups of patients for whom hardiness presents a barrier to help-seeking (Maddi, 2006), whereas research focused on understanding patients decision-making about when to seek help has not been so far explored (Ivynian, DiGiacomo, & Newton, 2015). Whether and how coping styles such as optimism and hardiness can be developed in patients who previously lacked these are empirical questions with important potential for self-management training. Supplementing gaps in social support typically filled by family, or raising awareness to available support and strategies to manage crisis events in patients who live alone is of particular interest, as this may offer a means of intervention that may encourage coping styles without undermining independence and self-reliance.

Conflict of Interest statement

The authors have no conflicts of interest to declare.

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Tables

Box 1. Guide for semi-structured interviews with people with respiratory conditions about their experiences of Emergency Department 'near misses' for breathlessness crises

Table 1. Characteristics of 20 patients interviewed about their experiences of Emergency Department 'near misses' for breathlessness crises

Table 2. Illustrative quotes for key themes

Figures

Figure 1. Study themes mapped to the Transactional Model of Stress and Coping.

Characteristic	N (%)
Female	9 (45)
Living alone	8 (40)
Aged 65+ years	15 (75)
Primary diagnosis	
Chronic obstructive pulmonary disease	15 (75)
Restrictive lung disease	3 (15)
Bronchiectasis	1 (5)
Chronic thromboembolic pulmonary hypertension	1 (5)
Experience of breathlessness	
Lifelong	3 (15)
11-15 years	1 (5)
6-10 years	7 (35)
1-5 years	7 (35)
<1 year	1 (5)
Missing data	1 (5)
Frequency of Emergency Department near misses for breathlessness	
Weekly or more often	4 (20)
Monthly	1 (5)
11-15 times in total	3 (15)
5-10 times in total	2 (10)
<5 times in total	8 (40)
Missing data	2 (10)
Frequency of Emergency Department visits for breathlessness	
5 times or more	4 (20)
<5 times	14 (70)
Never	2 (10)

Theme: *Hardiness through challenge, commitment and control*

Quote 1 You've got to help yourself. Nobody out there is gonna take you by the hand and say, "I'll be there 24 hours to look after you". You have to do the work yourself (P09, age 68, woman with COPD).

2 (In response to a question about any breathlessness management advice from her doctor) No, basically, [the doctor] said "I'm learning from you" (P02, age 72, woman with COPD).

3 There's probably been a reasonable degree of conditioning to... to try and sort of work it through to the point where it becomes a situation where, "No, you really can't manage this yourself. You do need to seek help." I'm very aware, for example, of the symptoms of a stroke or a heart attack, and if I picked up any of those, then yeah, I'd be chasing an ambulance immediately. (P09, age 68, woman with COPD).

4 Breathe in through the nose one, two, three, four, breath out one, two, three, four. You do those kind of activities that just pull yourself into control, but you can't. You still feel it's wrong, there's something wrong. You can't... You can't get it under control. It's out of control. (P04, age 68, man with COPD).

5 [I have] the mental strength to say, "No, you must not let go, you must not give into this."... If you could persist with it and not let it go, then you will gradually recover and the sense of sort of panic and suffocating will disappear. (P19, age 64, man with COPD).

6 In the middle of the night, everything is deadly quiet, and you're thinking, "Is there anyone out there that can help me?" So that's where the panic sets in. You don't panic as much in the day... it's what you do at night. (P09, age 68, woman with COPD).

Theme: *Information seeking – knowledge as power*

7 It's more about getting the breathlessness under control but I use breathing techniques to reduce the anxiety... to bring down my heart rate... I do have a monitor which I can use to check my heart rate and my oxygen levels. I know that if they drop below a certain level then I would have to go to hospital probably. (P17, age 58, man with COPD).

8 I like to mow the lawn. My lawn's flat. And that's a judgement to make, about how well I am... if I have to keep stopping, I know I'm sick. (P20, age 62, woman with COPD).

9 My specialists give me information mainly because I ask... I want to know why I'm having that problem and what I can do about it to ensure that, you know, either it diminishes or doesn't recur. (P16, age 69, man with COPD).

10 I'll be on the internet even before [meeting with specialist] because I just want to understand. (P21, age 72, man with COPD).

11 I'm not a great fan of looking on the Internet for some of these things because I'm concerned that some of the information there might not be as accurate as it should be. (P11, age 76, man with chronic thromboembolic pulmonary hypertension).

Theme: *Optimism as a pathway to deriving meaning*

12 I'm very mindful I don't read too much about anything because I can read things into it and think I've got this and I've got that. I tend to just depend more on general stuff basically... I don't like going too much into depth with anything. (P17, age 58, man with COPD).

13 I didn't think I would ever reach 70 but I did... and I sometimes feel better than I did when I was younger because I've just learnt all the techniques. (P03, age 70, woman with bronchiecstasis).

14 I'm just a poor old fart now who's got to slot his life in a different pigeonhole... now I'm a little old man, if you like, but I'm not a housebound little old man like you would see in a nursing home... but I'm still a little old man... and it doesn't worry me at all. (P22, age 77, man with COPD).

15 He think I know what he's saying... And he get frustrated because he thinks I know what he's saying. Because in his mind what he's saying is clear but how I receive it is not clear. (F06, age unknown, partner of man with restrictive lung disease)

16 He doesn't even say anymore. He just comes with the oxygen pipe and gives it to me... And I finally go, "Okay, I crossed the line again, didn't I?" 'Cause he can hear it, he can see it, he can see the symptoms. (P08, age 60, woman with restrictive lung disease).

17 My wife now knows that if I get let's call it my panic attack, I'll call it that or my breathlessness. If I start feeling it's getting out of control, it actually does help if she tells me to calm down and to breathe through the nose. It reinforces what you're trying to do... (P04, age 68, man with COPD).

18 I actually asked my specialist back when I was travelling... "I need to know that I can look after myself without putting everyone else in panic." I hate that. It's actually embarrassing. (P09, age 68, woman with COPD).

19 [P06's partner] is a great help because I would say to him, "Do I need some Endone?"... I forget sometimes, and he writes it down... he would say "No, not for another two hours,"... He's very on the ball with everything. (P06, age missing, man with restrictive lung disease).

20 I have friends... I have the male friend... he only lives five minutes away, I've only gotta ring him. But I also have a lady here... She has run me to all my doctors appointments, she's taken me shopping, got me started, because a couple of times, I would get to the supermarket and she's always there. (P25, age 69, woman with COPD)

Theme: Hardiness and social support have an ambivalent relationship

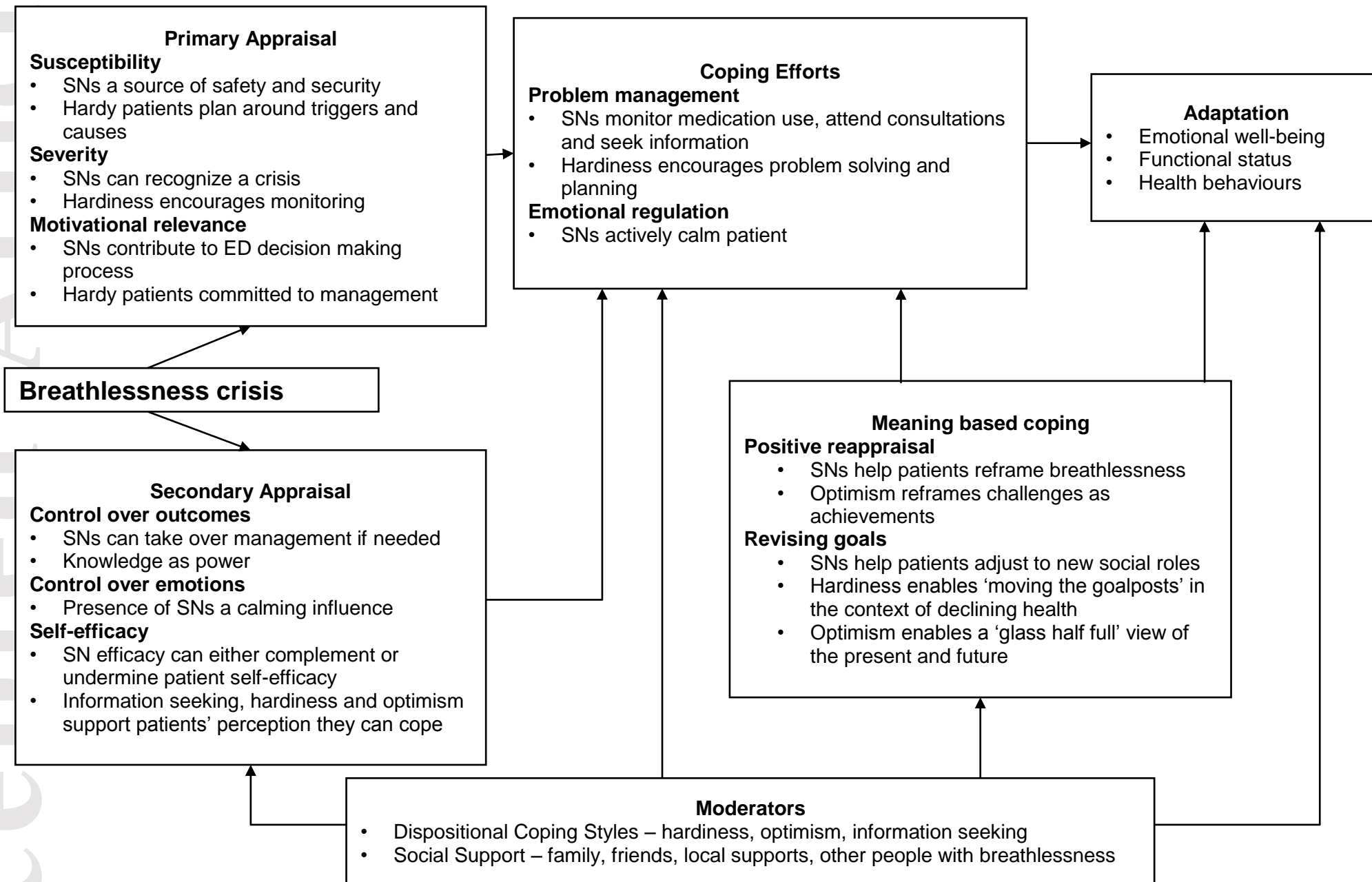
- 21 I'm in a club down here... They're always there on hand if I need help... I'm sure I can always find somebody if need be. But I'm fine on my own, and I know how good I'm doing. So, I'm happy to be on my own. (P25, age 69, woman with COPD).
-
- 22 [P10's] background is nursing... and I am very much guided by her interpretation of what's happening and we talk and get through it and we'll generally agree that, no it's gone on too long and we'll call the ambulance. (F10, age unknown, husband of woman with restrictive lung disease)
-
- 23 She's trying to be more independent, and taking some of the load off me ... She might not ask for help when she should, and that makes it very difficult for me sometimes... I'm seen as being too pushy... I'll say something to her like, 'You should have oxygen on'. And she says, "No, I don't want it... she gets low on oxygen, she can't make decisions. She doesn't always see the best for her at the end. And quite often... by the time she wants oxygen, it's too late.... (F08, age missing, husband of woman with restrictive lung disease).
-
- 24 I didn't run it past him [husband], but if I had, he would have immediately agreed I'm sure. I think he just knows over the time that I know when things are serious or not. (P03, woman with bronchiectasis).
-
- 25 Well I didn't know anything about interstitial lung disease (ILD)... and then I started doing my own research, and [my daughter]'s a student nurse and has good access to library through [university] so we were able to get current stuff on ILD, and that's helped me. (P10, woman with restrictive lung disease).
-
- 26 Well you are talking to people with similar problems to you and they often have different ways of dealing with it than you do... sometimes you can pick up something from somebody else or vice versa that's really helpful to you in the long run and helpful to them. (P16, age 69, man with COPD).
-
- 27 Oh there's definitely support [in Facebook support groups] because a lot of the time you don't want to bother your family. My wife tends to freak out sometimes. (P12, age missing, man with COPD).
-
- 28 If he thinks I'm struggling with something, he'll look on the net. Not an awful lot of research, but I don't like to know too much. I'd rather just have it in my mind that I can do things. (P20, woman with COPD).
-
- 29 It's a friend... she went around to most of my medical appointments with me... just to pick up the things I might have missed... when you are feeling stressed... you don't hear exactly what the doctor says. (P16, age 69, man with COPD).
-
- 30 If [my brother] was just completely on his own or if I was just completely on my own, mate, I could have gone long ago. Why hang about? No fun in that." (P21, man with COPD)
-

31 If [my brother] was just completely on his own or if I was just completely on my own, mate, I could have gone long ago. Why hang about? No fun in that." (P21, man with COPD)

32 It was also valuable because it was a group of people suffering from the same thing so I got comfort in knowing that there were other people there and being able to talk to people about how they operate their lives and how they do their exercise regimes (P17, man with COPD).

33 Or most people just give up... I think it would actually depress me to go down there and listen to them all, because they should be talking about what they can do to keep what they've got rather than looking to, "Oh I'll only be a couple of years in, then I'm off". [chuckle] I'm not ready for that yet. (P09, age missing, woman with COPD)

34 When I came home from that little meeting with all the people on the oxygen I felt like I was pretty cool... I thought, "Oh my God. You're doing better than you think you are. They're a lot worse off than you". So that alone is a good incentive... (P09, age missing, woman with COPD).



Glossary – ED: Emergency Department; SN: Social Networks.

1. Please start by telling me, in your own words, about the time you nearly went to Emergency because of feeling breathless but decided not to and, with the benefit of hindsight, are glad you didn't.

Prompts

- *What was it about your breathlessness that made you consider going to Emergency?*
- *Who (if anyone) made you consider going to Emergency?*
- *What else (if anything) made you consider going to Emergency?*
- *What (if anything) do you think helped you avoid going to Emergency?*
- *What (if any) information helped?*
- *What (if any) training helped?*
- *What (if any) support from a health professional helped? Were you able to contact a known healthcare professional for support? Were you advised there was no need to present by a known healthcare professional?*
- *What (if any) support from family or friends helped?*
- *Did you manage (or receive support from others) to employ strategies to calm your breathing and recover from the distressing episode?*

2. Have there been other time(s) where you did go to Emergency for breathlessness?

If 'yes'

- a) *What (if anything) was different about these time(s) compared to when you decided not to go and were glad you didn't?*
- b) *Can you give me a sequence of symptoms or sensations you feel that finally led you to go to the hospital?*
- c) *In hindsight, were you glad you went to Emergency? Why/why not?*
- d) *What (if anything) did you learn from these experiences (or indeed going to Emergency for any reason at all) about when to go to Emergency in the future?*

3. Now can you tell me about any times where you decided not go to Emergency but wished you had, or did go but thought you should have gone earlier?

Prompts

- *As for question 2, with modification as necessary.*
- *Are there any signs or other considerations that tell you that you MUST go to hospital?*

4. What (if any) self-management strategies do you use for breathlessness more generally?

Prompts

- *Self-management strategies can include things like symptom monitoring, action plans, breathing techniques, exercises and cognitive-behavioural therapy. Do you use anything like that?*
- *How useful do you find these strategies?*
- *What (if anything) could be done to make the strategies more useful?*
- *Where did you learn about the strategies you use (e.g. pulmonary rehabilitation, internet)?*
- *What (if anything) have health professionals given you in the way of training or resources for self-management of breathlessness?*
- *What (if any) self-management strategies have you developed yourself?*