Carers and breathlessness

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ABSTRACT

Purpose of the review:

Informal carers play a key role in supporting patients living with breathlessness in advanced disease, but with considerable impacts on their own well-being. The purpose was to review recent advances in our understanding of the caring role in refractory breathlessness, its impacts on carers, and interventions to support them.

Recent findings:

A systematic literature search resulted in 28 included papers that could be mapped to four broad areas of carer enquiry: the carer role (n=6), role impact (n=7), carer support (n=11), and carer views (n=4). Search terms focused on breathlessness, but few of the included papers were exclusively on breathlessness: most were disease-related, predominantly COPD. There were a range of methodologies, including four systematic reviews; UK studies were most common.

Summary:

Carers of patients with breathlessness take on a role characterised by uncertainty, largely unsupported by health care professionals (HCPs). HCP acknowledgement of these carers, their contribution, and the impact of the caring role, is lacking. The patient-carer dyad should be considered the unit of care. Carer intervention should be individualised, supporting carers as clients and co-workers. There was a dearth of studies recruiting via primary care, focusing on conditions other than COPD, and longitudinal work.

KEYWORDS

Carers, breathlessness, COPD

INTRODUCTION

Chronic breathlessness has wide-ranging, inter-related physical, psychological, social and existential consequences for both patients and family and friends supporting them [1] (informal carers). Carers play a key role in supportive, palliative and end of life care for patients with advanced respiratory conditions [2]. There is growing interest in their role in supporting patients with breathlessness (carers as co-workers [3]), and in the impacts of that role on carers themselves (carers as clients [3]) and ways to support them. A systematic search was therefore conducted to identify recent relevant literature: Box 1 summarises the search strategy.

[Box 1 about here]

RESULTS

Twenty-eight papers were included [4-31]: Table 1 summarises their characteristics. Search terms focused on breathlessness, but few included papers were exclusively on breathlessness: most were disease-related, predominantly COPD. There were a range of methodologies, including four systematic reviews; UK studies were most common. The 28 papers were mapped to four broad areas of carer enquiry (some addressed more than one area): carer role (n=6 [4-9]), role impact (n=7 [10-16]), carer support (n=11 [17-27]), and carer views (n=4 [28-31]).

[Table 1 about here, or appended]

Carer role

Bove et al's focus group study found spouses of patients with severe COPD experienced the carer role as undefined, with unpredictable responsibility [4•]. They were in a constant state of alertness due to fear of breathlessness, felt helpless and found it exhausting. Carers lived with modified social lives involving compromise, strategising, loss of contacts (including family), and managing reactions of others. They strove to maintain normality whilst trying to motivate the patient, taking on tasks and responsibilities with increasing concern about their future caring role. They experienced ambivalence about their relationship, struggling to preserve dignity whilst coping with patients' personality changes. They were willing carers but wanted support and knowledge for the role, and inclusion in decision-making with health care professionals (HCPs) [4•].

Aasbø et al used qualitative interviews to explore how carers negotiate their role with patients and HCPs during acute COPD exacerbations [5•]. Carers lacked understanding and support from HCPs and were not always acknowledged as competent despite shouldering considerable responsibility. To avoid losing HCPs' cooperation carers strove to avoid being considered interfering or preventing HCPs from using their expertise, with implications for their own ability to maintain safety for the patient (in terms of managing their condition and the exacerbation) and control. There was again uncertainty in the carer role; the need to negotiate characterised its complexity, highlighting discrepancies between practice and policy regarding collaborative care [5•].

Hutchinson et al explored emergency department presentation of breathlessness using prospective patient survey methods and clinical record review [6•]. Most patients attending due to acute-on-chronic breathlessness had non-malignant conditions. They identified key roles of family and friends: when asked who they talked to about their breathlessness it was usually their family doctor, but a quarter said family or friends. And when asked who was involved in the decision to attend the emergency department just over a third said themselves or family or friends, whereas the GP surgery or paramedic was involved in only about a fifth of decisions. Decisions on whether to present at the emergency department in acute-on-chronic breathlessness represents a significant burden for carers [6•].

Bryant et al focused on the role of carers as co-workers in COPD: providing direct care, encouraging adherence to HCP recommendations, acting as health advocates, and providing emotional and psychosocial support [7]. Their systematic review examined how the carer role has been operationalised in interventions to improve outcomes for people with COPD. None of the nine included studies had intervention components directly targeted at carers: most included carers in HCP-delivered dyadic or group education sessions about COPD. Seven studies reported effective interventions (broad range of outcomes), with mixed risk of bias [7].

Figueiredo et al conducted qualitative interviews with male carers exploring experiences of husbands (n=7) and sons (n=5) caring for family members with moderate to severe COPD [8]. Men were committed, dedicated carers; differences between husbands and sons reflected relational and generational differences relevant to intervention design. Differences related to the meaning of the commitment (for husbands an extension of the marital role, for sons a filial obligation), challenges and constraints (husbands struggled with household tasks and preserving their wives' integrity, sons struggled to conciliate their personal and professional lives with caring), fears and concerns about the future (husbands feared losing their life partner, sons feared inability to fulfil the role through illness), needs (husbands wanted practical skills, sons wanted information and self-confidence), and positive aspects (husbands gained from their wives' self-confidence and emotional strength, sons considered caring an opportunity for personal growth) [8].

Kayyali et al explored HCP perceptions of current COPD care pathways in five European countries [9]. Their findings predominantly related to service organisation and delivery but also reported the lack of a specified role for informal carers within those care pathways, and lack of professional support for that role [9].

Impact of carer role

Using survey methods, Badr et al examined individual-level predictors of patient and carer depression in COPD, and how dyad members effect each other's depression [10•]. Using PHQ9 thresholds, 20% of carers had mild and 8% moderate to severe depression. Multi-level models (dyads as unit of analysis) found higher levels of depression for both dyad members associated with less frequent patient self-management, higher carer burden, and being in poorer health. Women (patients or carers) were more likely to be depressed [10•].

Bernabeu-Mora et al also explored carer depression in COPD, but for patients hospitalised for acute exacerbations [11•]. Forty five of the 87 carers recruited reported depression at patient hospitalisation, with the strongest independent predictors of depression being spousal relationship, breathlessness, and severe airflow limitation. Depression resolved for 40% by 3-months post-discharge. Those caring >20 hours/week for patients with dependencies had decreased odds of remission; carers of patients with dependencies post-discharge had increased odds of becoming depressed [11•].

Carers of hospitalised COPD patients were also investigated by Goris et al, but regarding care burden [12]. Their descriptive study of 112 carers (using validated tools) found higher levels of care burden for female carers, those who stated their physical and psychological health was affected, and those reporting difficulties giving care and needing help. Lower levels of social support were found for those with lower income, those whose physical and psychological health was affected, and, interestingly, for spouses [12].

Freeman et al examined associations between breathlessness and distress for both patients and carers receiving palliative home care as a unit of care, using data relating to 6,655 patients from an established database of service users [13]. Carers of patients with breathlessness were more likely to exhibit distress than those of patients not reporting breathlessness [13].

Tan et al explored interrelationships between carer burden, emotional status and quality of life among carers of patients with lung cancer participating in a feasibility randomised controlled trial (RCT) of a respiratory distress symptom cluster intervention [14•]. Analysis of data from 43 patient-carer dyads on validated scales found relationships between carer burden, quality of life and carer depression and anxiety. Carer depression and anxiety was also associated with patient depression and anxiety, suggesting that lung cancer patients and carers should be viewed as a unit in supportive service models [14•].

Impacts extend beyond physical and psychological. Dzingina et al’s cross-sectional secondary analysis of data from a RCT of a palliative breathlessness support service enabled costing of informal (and formal) care [15••]. More than 75% of the 105 patients received care from family or friends. When cost of informal care was added to that of formal care, mean costs over a 3-month period rose by >250% from £3,253 (standard deviation £3,652) to £11,507 (standard deviation £9,911); informal care accounted for over 70% of costs. Over 64% of informal care cost related to the number of hours on call (45%), providing help inside the home (9%) and personal care (8%). One factor associated with increased care costs was increased breathlessness [15••].

Mansfield et al’s systematic review of the volume and focus of research output relating to burden and unmet needs of carers of patients with COPD included 27 papers and identified a significant increase in publications [16]. Most were descriptive studies (n=25); only one measurement and one intervention study were found. Fourteen studies examined relationships between patient or carer factors and carer burden; only two measured carer burden over time. They identified a need for rigorous measurement tools to more accurately characterise carer burden to enable development of evidence-based interventions [16].

Carer support and interventions

The first step in carer support is identifying them [2] yet Sampson et al’s retrospective cohort study of a UK primary care database of 13,693 bereaved cohabitees, which included carers of patients dying from cancer and lung disease (as well as dementia), concluded that recording of carers of terminally ill people was sub-optimal: only 6.9% of cohabitees were recorded as carers [17]. They also found the proportion of cohabitees with six or more consultations increased the year after bereavement (from 17.8% to 20.4% for COPD cohabitees) [17]. Systematic registration of every carer was one of several components of a Dutch COPD care programme tested by Cramm and Nieboer [18]: care delivery in accordance with the Chronic Care Model was associated with co-productive relationships (shared decision making) between professionals, COPD patients and their carers [18].

Farquhar et al reported on a mixed method RCT of a palliative care breathlessness intervention service for patients with non-malignant conditions (predominantly COPD) and their carers [19•]. Carers had anxiety and depression scores higher than population norms. Carers of patients receiving the intervention achieved greater (non-significant) reduction in their ‘distress due to patient breathlessness’ (numerical rating scale), and their anxiety, compared to controls. Qualitative analysis of carer (and patient) views identified positive service impacts both for patients and carers. Mechanisms of impact related to breathlessness acknowledgement and validation, and improved knowledge, which enhanced understanding and confidence for carers (and patients), reducing feelings of being alone with breathlessness. A potential therapeutic effect of trial-participation was identified for both patients and carers, additional to the intervention [19•].

Similar benefits of trial participation were found for carers by Ellis et al in their nested qualitative study to elicit views of patient and carer participants in a feasibility RCT of a respiratory distress symptom cluster intervention in lung cancer [20]. Carers reported greater understanding of symptoms through participation and appeared reassured by contact with the research team (which they regarded as a form of monitoring the patient’s illness) [20]. Johnson et al sought views of carers (and patients) on the feasibility of an RCT to test the effect of a handheld fan on physical activity and carer anxiety in patients with refractory breathlessness but only one carer was recruited to this aspect of the study from the 12 patient recruits [21].

Figueiredo et al reported on a secondary analysis of the effects of a family-based pulmonary rehabilitation programme on close family carers of older patients with COPD [22•]. Quantitative data suggested the intervention maximised carers’ adaptive coping, potentially preventing negative psychological outcomes through improved family coping, reframing, spiritual support seeking and mobilising to acquire help, reduced carer burden and physical demands of caring, improved reactions to caring and family support; qualitative data confirmed these benefits [22•].

Man et al sought to gain stakeholder consensus on key priorities for developing breathlessness rehabilitation services for patients with COPD and chronic heart failure: patient exercise training was considered a core component with other interventions, including the needs of carers [23].

Three papers related to the Learning about Breathlessness Study programme to develop an educational intervention for carers of patients with breathlessness in advanced disease [24-26]. Farquhar et al’s systematic narrative review on educational interventions for carers found none focused on breathlessness [24•]. A follow-on qualitative study identified six topics carers of patients with breathlessness want to learn about (and why): 1) understanding breathlessness, 2) managing anxiety, panic and breathlessness, 3) managing infections, 4) keeping active, 5) living positively and 6) knowing what to expect in the future [25•]. And Ewing et al reported clinicians’ views (online survey) of educational interventions for carers on breathlessness: predominant current practice was to educate carers by educating patients, and clinician advice on developing an intervention was patient-centric e.g. joint education with patients, giving carers practical advice and strategies for helping patients, and then measuring patient outcomes [26•]. Appetites for an intervention were strong in both clinicians [26•] and carers [25•].

Rosa et al’s integrative review focused on the concept of resilience and family caring in COPD (12 papers) [27•]. Resilience was most often understood using a deficit, rather than an asset, model of health in COPD caring (focusing on problems rather than mobilising skills, knowledge and resources). They suggested carers need positive coping strategies to enable them to continue their caring role, and that better understanding of the concept of resilience may help nurses understand which supportive nursing interventions are more effective in helping carers [27•].

Carer views

Nakken et al's cross-sectional study of 188 patient-partner couples investigated differences between male and female partners of patients with COPD regarding their own characteristics and the perception of patients' characteristics: female partners thought male patients were less care dependent and had more symptoms of depression (no such sex-related differences were found in patients) [28].

Alami et al gathered relatives' (and patient and practitioner) views of pulmonary arterial hypertension (PAH), and potential improvements for medical care strategies, through qualitative interviews [29•]. There were divergent views of PAH and its impact. Relatives found PAH hard to understand; it disrupted relations with family and friends, and required them to adopt a caring role. They felt excluded from the care process (which focused on the patient), and lacked information on how to manage problems like fainting. They felt patients minimised aspects of the disease, such as breathlessness, and its impact on daily life [29•].

Collier et al's qualitative study of carers' perspectives on caring for someone on long-term oxygen therapy (LTOT) found that caring for someone with refractory breathlessness was extremely distressing [30•]. Carers felt benefits of LTOT were often overestimated and potential harms underestimated. Carers need opportunities to collaborate with clinicians in evidence-based decision making, and information and education about pharmacological and non-pharmacological strategies to manage refractory breathlessness, including LTOT [30•].

Schmidt et al compared perceptions of non-invasive ventilation (NIV) by intensive care unit (ICU) physicians (n=311), nurses (n=752), patients (n=396) and their relatives (n=145) in a prospective, multicentre (n=32 ICUs) questionnaire study [31]. High NIV session-related anxiety was identified in 45% of relatives (and 37% of patients). They suggested that interventional studies are warranted given the close partnership required for NIV between a conscious patient and their (formal and informal) carers [31].

CONCLUSION

Recent evidence finds carers of patients with breathlessness taking on a role that is characterised by uncertainty, largely unsupported by HCPs. There is a lack of HCP acknowledgement of the contributions of, and impacts on, carers regarding breathlessness. HCPs should consider the patient-carer dyad as the unit of care. Carer intervention should be individualised, supporting carers both as clients and co-workers. There was a dearth of studies recruiting via primary care, focusing on conditions other than COPD, and longitudinal work.

KEYPOINTS

1) Carers of patients with breathlessness take on a role that is characterised by uncertainty and unpredictability.
2) Carers are rarely acknowledged and largely unsupported by health care professionals: they should be supported both as clients and co-workers.
3) There was a lack of studies recruiting via primary care, focusing on conditions other than COPD, and longitudinal work.

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Conflicts of interest

MF was an author on four of the 28 included papers.

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Papers of particular interest, published within the period of review (January 2016-May 2017), have been highlighted as:

• of special interest

•• of outstanding interest

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Box 1: Search strategy			
Dates:	January 2016 and May 2017 (16/05/2017)		
Databases:	Medline, CINAHL, Scopus, PsychInfo, PubMed		
Search terms:	Carers/caregivers/family members/relatives/informal carers	AND	Breathlessness/dyspnea/dyspnoea/ shortness of breath
Inclusion criteria:	• Findings relate to carers and breathlessness • Empirical study or systematic review only • Peer-reviewed • Written in English		

Table 1: Characteristics of included studies (by broad area of enquiry, then citation)

Broad area of enquiry regarding carers	**First author, year (country)**	**Carer recruitment**	**Carer characteristics**	**Patient diagnosis/group**	**Methodology**
Carer role	Bove et al, 2016 [4•] (Denmark)	Via patients attending secondary care pulmonary department	22 carers 11 women, 9 men Mean age: 69.4yrs (61–82yrs) 21 cohabited >20yrs	Severe COPD (GOLD stages C & D)	Qualitative: Focus groups with carers (n=3)
Carer role	Aasbø et al, 2016 [5•] (Norway)	Via nurses from ambulatory secondary care pulmonary services	10 spousal carers 6 women, 4 men Aged 61-84yrs (7 >70yrs)	Severe or very severe COPD	Qualitative: Semi-structured interviews with carers
Carer role	Hutchinson et al, 2017 [6•] (UK)	N/A	N/A	Patients attending emergency department with	Quantitative:

				acute-on-chronic breathlessness	Clinician administered patient-report survey Clinical record review
Carer role	Bryant et al, 2016 [7] (n/a systematic review)	Various (systematic review)	Various (systematic review)	COPD	Systematic review
Carer role	Figueiredo et al, 2016 [8] (Portugal)	Via clinicians of patients attending secondary care outpatients	12 carers All male 7 husbands: mean age 70.9yrs (SD=8.8) 5 sons: mean age 43.4yrs (SD=10.5)	Moderate to severe COPD	Qualitative: In-depth semi-structured interviews with carers
Carer role	Kayyali et al, 2016 [9]	N/A	N/A	COPD	Qualitative: Semi-structured interviews (face to face and email)

	(Five European countries: England, Ireland, the Netherlands, Greece, and Germany)				with health care professionals
Carer impact	Badr et al, 2016 [10•] (USA)	Via patient participants who were attending secondary care outpatient clinics	89 carers Mean age 54.8yrs (SD=16.0) 68 women (76%), 21 men In carer role for >6 months	COPD	Quantitative: Structured interviews with 89 patient-carer dyads (data collected separately)
Carer impact	Bernabeu-Mora et al, 2016 [11•] (Spain)	Via patients admitted to secondary care pulmonary service	87 carers Depressed carers: mean age 62.9yrs (SD=13.49s); 43 women (96%), 2 men	COPD (hospitalised)	Quantitative: Structured face to face interviews with carers during admission

			Non-depressed carers: mean age 61.79 yrs (SD=12.82); 35 women (83%), 7 men		Structured phone interviews with carers 3-months post-discharge
Carer impact	Goris et al, 2016 [12] (Turkey)	Via patients admitted to secondary care chest diseases service	112 carers Age groups: ≤39yrs n=32 (28.6%) 40-49yrs n=24 (21.4%) 50-59yrs n=26 (23.2%) ≥60yrs n=30 (26.8%) 84 women (75%), 28 men	COPD (hospitalised)	Quantitative: Structured face to face interviews with carers during admission
Carer impact	Freeman et al, 2016 [13] (Canada)	Sample drawn from anonymised interRAI Palliative Care Assessment data gathered on 6,655 palliative home care	6,530 carers No age/sex data Primary carer relationship to client: Child 29.1% (1,897) Spouse/Partner 58.6% (3,823)	Various: Cancer only 59.7% (3,973) Non-cancer only 9.8% (649) Both cancer + non-cancer 27.2% (1,812) Unspecified 3.3% (221)	Quantitative: Cross-sectional analysis of data collected by trained assessors (e.g. nurses, social workers, case managers) using

		clients as part of a pilot implementation	Other 12.4% (810) No carer 1.9% (125)		information from observation and discussion with the client
Carer impact	Tan et al, 2017 [14•] (UK)	Via patients participating in a feasibility RCT of a respiratory distress symptom cluster intervention	43 carers Age groups: <70yrs n=28 (65.1%) ≥70yrs n=12 (27.9%) Mean age 61.7yrs (SD=12.4) 28 women (65%), 15 men	Lung cancer (participating in a feasibility RCT of a respiratory distress symptom cluster intervention)	Quantitative: Cross-sectional secondary analysis of self-completed questionnaires from RCT
Carer impact	Dzingina et al, 2017 [15••] (UK)	N/A	N/A	Advanced disease (e.g. cancer, COPD, chronic heart failure, interstitial lung disease and motor neuron disease) and refractory breathlessness on exertion/ rest optimum treatment of	Quantitative: Cross-sectional secondary analysis of data from RCT Structured patient interviews

				underlying disease (participating in a RCT of a palliative breathlessness support service)	
Carer impact	Mansfield et al, 2016 [16] (n/a systematic review)	Various (systematic review)	Various (systematic review)	COPD	Systematic review
Carer support	Sampson et al, 2016 [17] (UK)	Used The Health Improvement Network (THIN: database of over 500 primary care practices) to identify cohabitees of patients who had died of cancer, dementia or	13,693 cohabitees COPD cohabitees (n=6041): Median age 77yrs (IQR 71-82) Women 71% (4,304)	Cancer, dementia or COPD	Quantitative: Retrospective cohort study using THIN

		COPD, as proxy for carers			
Carer support	Cramm et al, 2016 [18] (Netherlands)	N/A	N/A	COPD	Quantitative: Cross-sectional study of 411/981 patients enrolled in the Dutch COPD care program Kennemer Lucht and 62/97 HCPs
Carer support	Farquhar et al, 2016 [19•] (UK)	Via patients participating in RCT of a palliative Breathlessness Intervention Service	57 carers Mean age 62.2yrs (SD=13.39) Women 79% (n=45)	Advanced non-malignant disease (83% COPD) (participating in a RCT of a palliative Breathlessness Intervention Service)	Mixed method RCT: quantitative outcome measures and topic-guided interviews with all participants
Carer support	Ellis et al, 2016 [20]	Via patients participating in a	Purposive sample Three carers	Lung cancer	Qualitative:

	(UK)	feasibility RCT of a respiratory distress symptom cluster intervention	Two women, one man No age data	(participating in a feasibility RCT of a respiratory distress symptom cluster intervention)	nested qualitative study within a mixed method feasibility RCT
Carer support	Johnson et al, 2016 [21] (UK)	Via patients participating in a feasibility RCT of a handheld fan for refractory breathlessness	Only one carer (and 12 patients) recruited to the qualitative aspect of the study	Feasibility RCT sample's primary disease (intervention/control groups): COPD n=12 (50%) /n=11 (46%) Cancer/ heart diseases n=6 (25%)/ n=7 (29%) Others n=6 (25%) /n=6 (25%)	Qualitative: nested qualitative study within a mixed method feasibility RCT
Carer support	Figueiredo et al, 2016 [22•]	Family	56 family carers Mean age: 59yrs (SD=11.2)	COPD	Secondary analysis of mixed method RCT data

	(Portugal)	dyads (i.e. subjects with COPD and family carers) recruited to an RCT of a Family-Oriented Pulmonary Rehabilitation Program	Women 74% (n=29)		
Carer support	Man et al, 2016 [23] (UK)	N/A	N/A	N/A (no patients recruited, but target population for intervention COPD and chronic heart failure)	Stakeholder consensus methods
Carer support	Farquhar et al, 2016 [24•] (n/a systematic review)	Various (systematic review)	Various (systematic review)	Advanced disease - various (systematic review)	Systematic narrative review

Carer support	Farquhar et al, 2017 [25•] (UK)	Via patients in primary care and secondary care oncology or respiratory medicine departments	25 carers Mean age 68yrs (42-84) 21 women, 4 men	Cancer (n=13) or COPD (n=12) and troubled by breathlessness and intractable breathlessness in spite of optimisation of underlying illness	Qualitative: Topic guided interviews with carers (and patients)
Carer support	Ewing et al, 2016 [26•] (UK)	N/A	N/A	N/A (no patients recruited, but target population for intervention are carers of patients with breathlessness due to advanced disease)	Mixed methods: Online survey of 365 clinicians including fixed choice answers and free text responses
Carer support	Rosa et al, 2017 [27•] (n/a systematic review)	Various (systematic review)	Various (systematic review)	COPD	Systematic review

Carer views	Nakken et al, 2017 [28] (Netherlands)	Via patient participants who were attending secondary care respiratory clinics	188 partners Female partners (n=103): mean ae 65.4yrs (SD=8.6) Male partners (n=85): mean age 65.1yrs (SD=8.9)	Moderate to very severe COPD (GOLD II, III or IV)	Quantitative: Home visits collected data from 188 patient-partner couples using a range of questionnaires
Carer views	Alami et al, 2016 [29•] (France)	Via patient participants who were attending secondary care Pulmonary Arterial Hypertension clinics	4 relatives 2 women, 2 men Age range: 35-59yrs	Pulmonary Arterial Hypertension	Qualitative: Semi-structured interviews with 16 patients, 4 relatives and 9 practitioners
Carer views	Collier et al, 2017 [30•] (Australia)	Self-nominated carers of people using long-term oxygen therapy (LTOT) via specialist palliative care services	20 carers 13 women, 7 men No age data Spouses (n=14), friends (n=1), adult children (n=5)	People using LTOT for refractory breathlessness	Qualitative: Semi-structured interviews with carers

Carer views	Schmidt et al, 2016 [31] (France)	Patients and relatives screened for inclusion on discharge from Intensive Care Unit (ICU)	145 relatives (e.g. family member, partner, or close friend) who had visited relative at least once during a non-invasive ventilation (NIV) session Median age 59yrs (IQR 47–69) Men 38% (n=54)	Patients who had received NIV for more than 4 hours during their ICU stay, and had not been intubated before or after NIV	Quantitative: Prospective multi-centre questionnaire-based study involving 311 ICU physicians, 752 nurses, 396 patients, and 145 relatives from 32 ICUs