

# AMERICAN THORACIC SOCIETY DOCUMENTS

## Nursing Research Priorities in Critical Care, Pulmonary, and Sleep: International Delphi Survey of Nurses, Patients, and Caregivers An Official American Thoracic Society Workshop Report

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THIS OFFICIAL STATEMENT OF THE AMERICAN THORACIC SOCIETY (ATS) WAS APPROVED BY THE ATS BOARD OF DIRECTORS SEPTEMBER 2019

### Abstract

The objective of this workshop was to determine current nursing research priorities in critical care, adult pulmonary, and sleep conditions through input from consumer (patient, family, and formal and informal caregivers) and nursing experts around the world. Working groups composed of nurses and patients selected potential research priorities based on patient insight and a literature review of patient-reported outcomes, patient-reported experiences, and processes and clinical outcomes in the focal areas. A Delphi consensus approach, using a qualitative survey method to elicit expert opinion from nurses and consumers was conducted. Two rounds of online surveys available in English, Spanish, and Chinese were completed. A 75% or greater threshold for endorsement (combined responses from

nursing and consumer participants) was determined *a priori* to retain survey items. A total of 837 participants (649 nurses and 188 patients, family, and/or caregivers) from 45 countries responded. Survey data were analyzed and nursing research priorities that comprise 23 critical care, 45 adult pulmonary, and 16 sleep items were identified. This project was successful in engaging a wide variety of nursing and consumer experts, applying a patient-reported outcome/patient-reported experience framework for organizing and understanding research priorities. The project outcome was a research agenda to inform, guide, and aid nurse scientists, educators, and providers, and to advise agencies that provide research and program funding in these fields.

**Keywords:** nursing; Delphi survey; nursing research priorities

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This project was supported by an American Thoracic Society (ATS) Assembly Project Grant (Multiple Principal Investigators: M.G., C.H., and M.C.) and the ATS.

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This article has an online supplement, which is accessible from this issue's table of contents at [www.atsjournals.org](http://www.atsjournals.org).

Ann Am Thorac Soc Vol 17, No 1, pp 1–10, Jan 2020

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DOI: 10.1513/AnnalsATS.201909-705ST

Internet address: [www.atsjournals.org](http://www.atsjournals.org)

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## Introduction

Establishing health research priorities is a concept of increasing interest internationally, with nursing as one of the first healthcare professions to engage in this process (1–3). Identifying research priorities for evidence-based healthcare planning and delivery is central to effective and efficient health services that improve outcomes (4). Gaining consensus about which research efforts are most likely to advance science, inform best practices to improve the outcomes and experiences of patients and caregivers, and identify gaps in knowledge is central to this goal. Although research priorities have traditionally been set by researchers and clinicians (5), engaging patients and informal family and formal nonfamily caregivers has been found to establish research agendas that are “more just, more accountable, and more responsive to patients’ needs and values” (6). The James Lind Alliance’s guidelines on the methods of establishing priority setting partnerships (PSPs) have been important in engaging clinicians, policy makers, patients, and caregivers in setting research agendas that accelerate patient-centered research (7, 8). Others have used consensus-building approaches, such as Delphi survey method, to solicit expert opinions from clinicians, patients (9, 10), researchers, and advocacy groups (11, 12). There is also increasing support for the use of patient-reported outcomes (PROs) and patient-reported experiences (PREs) in research to support patient-centered care and educational improvements (13–15).

Although the American Thoracic Society (ATS) has a long history of supporting the identification of nursing research priorities, previously this was accomplished by creating a taskforce of expert nurse clinicians and scientists in the United States to develop and refine research priorities in 1990, 1998, and 2006 (3, 16, 17). In 2016, an international group of expert nurse researchers and clinicians recognized a need to update these priorities. Driving this need was the identification of new and emerging threats to lung health, widening health inequities, deployment of new models of care delivery, and recognition that patients with multiple chronic conditions require increasingly

complex care. There was also an acknowledgment that research funding was more competitive, and that international perspectives were needed. Today’s research benefits from the broader perspectives of international nursing colleagues by focusing attention on global lung health threats that could be reduced by nurses’ contribution to the care, education, and investigation of the human experience of health and disease in different care delivery systems around the world.

The previous development of ATS nursing research priorities did not include input from patients or caregivers, despite the value of patient and public involvement in improving patient outcomes and experiences. Because greater quality and clinical relevance of health research is the goal of nursing care, education, and research, it is appropriate that patients and caregivers contribute their unique perspectives to this project. Thus, the aim of this ATS report is to share the results of the workshop project (i.e., research priorities) identified by a consensus-building Delphi process called the International Nursing Critical Care, Adult Respiratory Health, and Sleep project.

## Methods

We employed a multiphase approach that included identifying a unifying, integrated, theoretical framework to guide and confirm research priorities specific to the three pillars of the ATS: pulmonary, critical care, and sleep. This framework, which included PROs, PREs, care processes, and clinical outcomes, offered flexibility in capturing the many ways in which nurses influence health. Phase 1 focused on the selection and approval of candidate survey items for the development of a global Delphi survey. Phase 2 included the implementation and analysis of two Delphi survey rounds. This project was supported by an ATS assembly project grant funded January 2016 through December 2019.

We aimed to bring together an international group of nurses and patients to identify patient-centered nursing research priorities that have broad global applicability across education, practice, and research. This workshop provided an opportunity for experts to review the literature, hear from key stakeholders, and

begin the process of selecting candidate survey items for the global Delphi.

### Phase 1. Selection and Approval of Candidate Survey Items

**Workshop agenda.** The project co-chairs (M.G., C.H., and M.C.) invited an inaugural group of 22 international expert nurse scientists, clinicians, and educators to contribute their expertise in critical care, pulmonary, or sleep conditions. Invitees represented the United States, Spain, England, Iceland, Australia, New Zealand, and China. Participants committed to make substantive contributions, not only at the workshop, but also on conference calls and e-mail communications throughout the project’s implementation phase.

It became apparent early in the collaborative process that the expert nurses did not unanimously define themselves as “respiratory nurses,” but rather as scientists, clinicians, and educators engaged in efforts to improve patient outcomes and experiences in the context of critical care, lung health (rather than pulmonary disease), and sleep. Therefore, it was agreed that research priorities should reflect this conceptualization and encompass the broader construct of health, care, service delivery, therapeutic patient education, and research, rather than being characterized as research priorities in respiratory nursing.

This group initiated the process of selecting candidate items before the May 2016 workshop. Three members (R.T.D., D.E.H., and G.N.) conducted a review of the literature to analyze and summarize what was known about PREs and PROs in pulmonary, critical care, and sleep, and to identify gaps in knowledge or existing impediments to the translation of research into practice. These literature reviews were then presented at the workshop, allowing the group to quickly identify potential items for the survey.

**Recruiting patient participants.** Patient participants were recruited to represent perspectives from each of the three ATS pillars. They presented their experiences with pulmonary, sleep, or critical care in a panel discussion after the literature review presentations to ensure the candidate research priority items were relevant to clinicians, individuals who live with these

conditions, and those who experience care in a specific health care environment, such as a critical care setting.

**Selecting candidate items.** To identify candidate items, the workshop concluded with small group meetings of patients and nurses organized by the three topic areas and facilitated by nurse experts in those areas (J.G., D.E.H., and G.N.). This work continued using e-mail and by teleconference until December 2016, when the final items were identified for the three surveys: critical care, pulmonary, and sleep. Items were organized within each survey by sections (e.g., PROs and PREs, care processes, and clinical outcomes, if applicable).

**Ethics approval.** As the selection of candidate items was nearing completion, a committee co-chair (M.C.) submitted the project to the Institutional Review Board of the University of Rochester (Rochester, NY) for review. In October 2016, the Institutional Review Board determined that the project did not constitute human subjects research according to the U.S. federal guidelines.

**Internal ATS review and approval.** The items for the three surveys were submitted for internal review to the ATS Survey Screening Subcommittee in January 2017 and approved in April 2017. The surveys then moved to the ATS Survey Review Subcommittee, and were approved with minor revisions in June 2017.

**Creation of final survey versions.** Upon receipt of internal approval, surveys were created in a beta version for committee review before opening the survey to participants using SurveyMonkey, an open-source survey software program (18). Patient/caregiver versions were created for two of the surveys (critical care and adult respiratory health) by reducing jargon, lowering literacy demands, and providing definitions of nursing or medical terms. This resulted in five survey versions: separate nurse and patient/caregiver versions for critical care, separate nurse and patient/caregiver versions for adult respiratory health, and a single version for sleep nurses, patients, and caregivers with/knowledge of sleep conditions.

All five versions were translated into Spanish and Chinese using native-speaking volunteer committee members (C.H. and Z.C.). With the assistance of the Spanish Respiratory Scientific Society nursing assembly, the Spanish versions were pilot tested with 10 nurses, 5 patients, and 2

caregivers, and needed revisions made. This process was limited in that no back translations were performed for either Spanish or Chinese, and no piloting of the Chinese language version was done. Links to the surveys were housed on the homepage of the ATS Nursing Assembly, and could be accessed after screening was done to determine “expert” status of participant (*see DEFINING WHO IS AN EXPERT AND PARTICIPANT RECRUITMENT*). Participants also had the option of navigating links for background information and disclaimers before proceeding to the Delphi survey.

## Phase 2. The Delphi Approach

**Methodological considerations.** The Delphi approach is an established method to incorporate expert opinion using sequential rounds to obtain consensus (19, 20). The Delphi survey is a particularly appropriate method when seeking consensus from geographically diverse participants. In multiple rounds of queries, “experts” respond to items by either ranking items (e.g., very important, important, unimportant, and not at all important) or by seeking consensus about whether an item should be included or discarded (endorsed or not endorsed). Consensus can be achieved by majority (>50%) or by any other number up to 100% (19). Defining consensus *a priori* is considered the most important methodologic consideration for Delphi surveys (20). We made the decision *a priori* to use 75% as the cut-off point, in part because it is the most commonly used median threshold to define consensus (21). The number of participants can be as few as 10, but may be much larger.

Most importantly, participants should be recognized as experts in their field or as having credible experiences with the phenomenon (22).

**Defining who is an expert and participant recruitment.** The landing pages of the survey screened participants for “expert” status. Nurses who self-identified as scientists, clinicians, and educators working in the field of critical care, adult respiratory health, or sleep could proceed to the survey. Likewise, adult patients who self-reported a history of receiving care in an intensive care unit or having a respiratory or sleep condition or self-identified adult caregivers (formal or informal) could proceed to the survey. However, individuals who selected the option for “other,” indicating that they

were not a nurse, patient, or adult caregiver with personal or professional experience in critical care, adult respiratory health, or sleep were redirected to a page thanking them for their interest, but were prevented from continuing to the survey, as they could not be defined as an expert. No restrictions were placed on multiple responses from a single internet provider address to allow participation of colleagues or relatives using the same device. Individuals who wanted to participate in the second round could enter their e-mail address for contact at Round 2.

**Nursing and patient advocacy networks.** The committee members obtained nurses’ e-mails from unrelated academic or professional partnerships and conducted outreach to international nursing and medical societies (pulmonary and critical care). The committee also partnered with the Public Advisory Roundtable of the ATS and the European Lung Foundation for dissemination of the survey. The Public Advisory Roundtable is composed of more than a dozen patient advocacy groups representing persons affected by respiratory diseases, sleep conditions, or critical illnesses in the United States. The European Lung Foundation is a nonprofit organization that partners with other European patient and respiratory organizations, patients, the public, and respiratory professionals to positively influence lung health. In addition, the committee used personal contacts to recruit global participants. We also contacted all the scientific societies that partner with ATS, as well as the nursing assemblies within those societies (if established) to advertise the project.

**Social media.** In consultation with the larger committee, one nurse expert (B.H.) spearheaded an ATS-compliant social media sharing strategy that was employed for the second (final) round of the Delphi. This included sharing information and the survey link via Facebook and Twitter. One committee member (Z.C.) used WeChat, a Chinese multipurpose messaging and social media app, to distribute the survey link to the Chinese community.

## Data Collection and Delphi Analysis

Two Delphi survey rounds were conducted: Round 1 was open for 6 weeks (November–December 2017) and Round 2 for 8 weeks (September–November 2018). Respondents had four selection options for each item:

agree; disagree; not sure; and no opinion. The committee elected to use the dichotomous approach of endorsed/not endorsed (as opposed to rankings); only “agree” responses were counted as endorsement. A 75% or greater threshold for endorsement (combined responses of nurses, patients, and caregivers) was set to determine if an item should be retained.

**Results: Summaries and Findings**

As described subsequently here, our results demonstrate that there is convergence between nurse and patient/caregiver perspectives as to research priorities in pulmonary, sleep, and critical care internationally.

**Round 1**

**Delphi participants.** As shown in Table 1, most (88%) of the 412 nurse respondents were female and 88% held a college or post-graduate degree. A total of 63% worked in a hospital setting, 65% had received training in their specialty area, and 38% reported 10<sup>+</sup> years in their field. Table 2 provides the characteristics of the 154 participating patients and caregivers. Most (87%) were female and over the age of 55 years (73%), with 57% reporting a sleep or respiratory diagnosis, or critical care experience, in the past 10 years.

**Participating countries.** As seen in Table E1 in the online supplement, 264 (46.6%) participants provided data on their country of origin; demonstrating representation from 23 different countries.

Most Round 1 participants were from Asia (*n* = 96; 36.3%), Europe (*n* = 89; 33.7%), and North America (*n* = 65; 24.6%) (Figure 1, shown in blue).

**Performance of Round 1 Delphi Survey Items**

**Critical care items.** Totals of 20 critical care-focused PROs and 5 PREs were identified for Round 1—nurses’ version (Table E2). Only 19 PROs were included in the patient/caregiver version (Table E3), as the patient/caregiver version did not differentiate between pharmacologic and nonpharmacologic treatment of dyspnea, whereas the nurse version had this distinction. All items were endorsed at 75% or greater.

**Adult respiratory health items.** Totals of 22 adult respiratory health-focused PROs, 22 PREs, and 3 care processes/clinical outcome items were identified for Round 1—nurses’ version (Table E4); corresponding items were asked in the patient/caregiver version (Table E5). All 22 PRO and the 3 clinical/process outcomes were endorsed; 4 of the 18 PREs were discarded (see Tables E4 and E5).

**Sleep items.** Totals of 11 sleep-focused PROs and 5 sleep-focused PREs were identified for Round 1—combined nurses’, patients’, and caregivers’ version (Table E6). One PRO item and all 5 PREs were discarded for lack of endorsement (see Table E6).

**Table 1.** Characteristics of nurse expert participants (Round 1 *n* = 412; Round 2 *n* = 237; *N* = 649\*)

Characteristics	Round 1 <i>n</i> (%)	Round 2 <i>n</i> (%)
Sex		
Female	362 (88)	199 (84)
Male	50 (12)	38 (16)
Age, yr		
<34	133 (34)	53 (22)
35–44	99 (24)	64 (27)
45–54	94 (22)	66 (28)
55 <sup>+</sup>	62 (18)	54 (23)
Nurse education		
Postgraduate degree	190 (44)	127 (54)
University degree	174 (44)	92 (39)
Nursing degree from nonuniversity program	37 (9)	—
Nurses employment		
Full time in nursing	249 (83)	184 (78)
Part time in nursing	26 (23)	13 (5)
Care setting		
Hospital	260 (63)	108 (46)
Academic/university	56 (13)	37 (16)
Primary care clinic	22 (5)	33 (14)
Specialty care clinic	50 (12)	32 (14)
Home care	12 (3)	16 (7)
Time employed as nurse, yr		
<10	150 (39)	51 (22)
10–20	96 (23)	57 (24)
20 <sup>+</sup>	151 (34)	124 (52)
Time employed in specialty area, yr		
<10	224 (54)	99 (48)
10–20	85 (21)	73 (31)
20 <sup>+</sup>	71 (17)	54 (23)
Received training in specialty area		
Yes	266 (65)	133 (56)
No	146 (35)	104 (44)
Research experience in specialty area?		
Yes	158 (38)	123 (52)
No	254 (62)	114 (48)

\*Categories do not equal 100 due to missing responses and rounding.

**Round 2**

**Delphi participants.** A total of 237 nurses provided data for Round 2 (Table 1). Like Round 1, most (84%) were female, with high rates of holding a college or post-graduate degree (93%), reporting training in their specialty area (56%), and having 10<sup>+</sup> years of experience in their specialty field (64%). A total of 34 patients, family, and caregivers participated. Again, most (89%) were female, although there were fewer respondents (44%) of 55<sup>+</sup> years of age. Similar numbers (56%) reported a respiratory or sleep diagnosis or critical care experience in the past 10 years (Table 2).

**Participating countries.** Responses came from 267 of 271 (99%) participants (Table E1), representing 31 different countries. As shown in Figure 1 (yellow), the majority were from Europe (*n* = 157; 58.8%),

**Table 2.** Characteristics of patient and caregiver expert participants (Round 1,  $n = 154$ ; Round 2,  $n = 34$ ;  $N = 188^*$ )

Characteristics	Round 1 $n$ (%)	Round 2 $n$ (%)
Sex		
Female	134 (87)	27 (79)
Male	20 (13)	7 (21)
Age, yr		
<34	6 (4)	7 (21)
35–44	13 (8)	7 (21)
45–54	23 (15)	5 (15)
55 <sup>+</sup>	113 (73)	15 (44)
Patient/family/caregiver education		
High school or less; trade school	33 (21)	6 (18)
Some college, no degree	27 (17)	9 (26)
University degree (2 or 4 yr)	45 (29)	9 (26)
Postgraduate degree	41 (27)	9 (26)
Patient/family/caregiver employment		
Full-time work	27 (17)	19 (56)
Retired	76 (49)	8 (24)
Time since diagnosis/critical care stay, yr		
<5	44 (28)	13 (38)
5–9	45 (29)	6 (18)
10–20	41 (27)	8 (24)
20 <sup>+</sup>	16 (10)	4 (12)

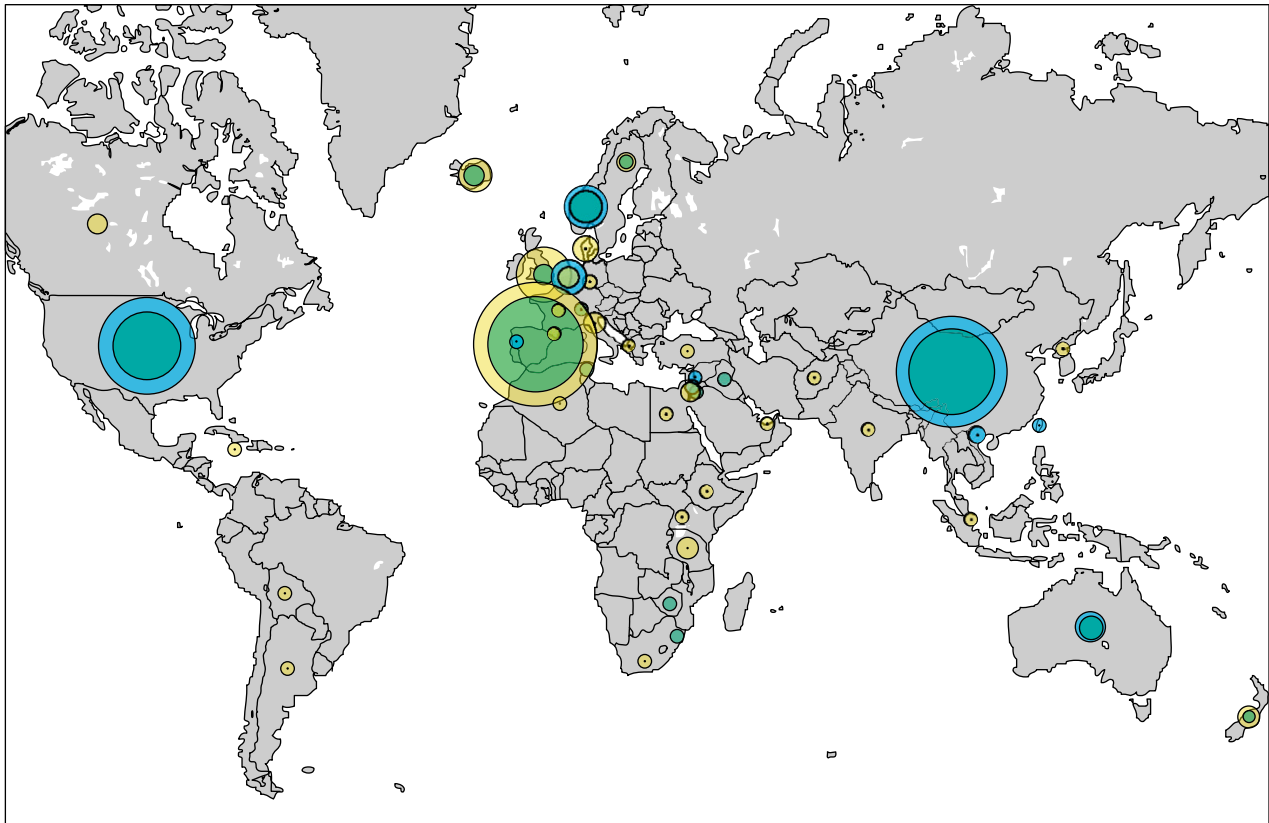
\*Categories do not equal 100 due to missing responses or rounding.

Asia ( $n = 51$ ; 19.1%), and North America ( $n = 33$ ; 12.4%).

**Preparation of new or revised items.** Free text open responses in Round 1 allowed participants to propose items they felt had been missed or to recommend changes to existing items for Round 2. These open responses were analyzed by committee members within each specialty area (M.C., C.H., J.G., and G.N.). Those items or revisions that were deemed critical by the committee members were included in Round 2, and all versions were revised with new translations into Spanish and Chinese, as needed.

**Critical care items (20 PROs and 5 PREs).** No changes were made.

**Adult respiratory health items (24 PROs and 20 PREs).** Items were revised to clarify that when “family” was used, it was meant to encompass formal and informal family and nonfamily caregivers. Analysis of the open responses identified two PRO items to be added in Round 2, for a total of 24 PROs (22 original PROs plus the 2 additional items).



**Figure 1.** Details are shown for countries. Size shows sum of Round 1 in blue and sum of Round 2 in yellow.

**Table 3.** Nursing research priorities in critical care—final items endorsed by all nurses, patients, and caregivers

## Patient-reported outcomes

1. Development and evaluation of interventions to reduce the incidence and/or duration of delirium
2. Development and evaluation of assessment tools to identify dyspnea (breathlessness/shortness of breath)
3. Development and evaluation of interventions to manage dyspnea (breathlessness/shortness of breath)
4. Promotion of routine assessment of common symptoms, such as anxiety, thirst, breathlessness/dyspnea, and fatigue
5. Development and evaluation of nonpharmacologic interventions to manage anxiety
6. Development and evaluation of nonpharmacologic interventions to manage dyspnea (breathlessness/shortness of breath)
7. Describe relationships or clusters among critically ill patients' symptoms (e.g., dyspnea, anxiety, pain, etc.)
8. Describe the relationship between patient symptoms or experiences during critical illness and patient outcomes and recovery
9. Description of fear (feeling scared) during critical illness
10. Development and testing of nonpharmacologic interventions to manage pain or discomfort
11. Evaluation of assessment tools to measure sleep during critical illness
12. Evaluation of fatigue during critical illness
13. Development and evaluation of nonpharmacologic interventions to improve sleep during critical illness
14. Evaluation and description of emotional responses during critical illness such as anger, grief, or sadness
15. Development of a pre-hospital discharge or pre-ICU discharge intervention or tool to identify potential challenges during recovery (e.g., decreased physical, psychosocial, or cognitive function)
16. Identification and testing of interventions during acute hospitalization/ICU to improve recovery from critical illness (e.g., improve physical, psychosocial, cognitive, or quality-of-life outcomes)
17. Identification and testing of interventions for after the ICU to improve recovery from critical illness (e.g., improve physical, psychosocial, cognitive, or quality-of-life outcomes)
18. Evaluation and description of sleep disturbances during recovery from critical illness
19. Evaluation and description of fatigue during recovery from critical illness

## Patient-reported experiences

1. Integration, into routine care, of interventions to enhance patient communication during mechanical ventilation
2. Evaluation of patient outcomes related to communication ability during mechanical ventilation
3. Identification and evaluation of communication/advocacy interventions to promote patient/family engagement and participation in decision-making
4. Description and impact of patients' feelings such as depersonalization, uncertainty, and vulnerability experienced during critical illness

*Definition of abbreviation:* ICU = intensive care unit.

Open responses also identified 2 items to be added to the PRE items, bringing the total number of PRE items to 20 (after removing 4 PRE items not endorsed in Round 1 and adding the 2 new items). Language was slightly revised for one of the care processes/clinical outcomes items (see Table E7, nurses' version, and Table E8, patient/caregiver version).

**Sleep items (12 PROs and 1 PRE).** Totals of 2 PRO items and 1 PRE item were added based on analysis of the open responses, for totals of 12 PRO items (after removing 1 PRO item not endorsed in Round 1 and adding 2 new items) and 1 PRE

item (after removing 5 PRE items not endorsed in Round 1 and adding 1 new item).

### Performance of Round 2 (Final) Delphi Survey Items

In Round 2 analysis, final items were retained if they were endorsed by 75% or more nurses, patients, and caregivers.

**Nursing research priorities in critical care.** Table 3 identifies the final items and reflects the deletion of 1 PRO item and 1 PRE item from Round 2, for a total of 19 PRO and 4 PRE items endorsed. Participants endorsed items that focused on the multiple co-occurring

psychophysiological symptoms and emotional responses associated with recovery from critical illness, life-sustaining treatments, and experience with a complex illness trajectory. These items are inherently patient centered, and are thus slightly different than the intensive care top 10 research priorities identified by a John Lind Alliance PSP (23) that focused more broadly on psychological support, comfort, and critical care interventions that favorably impact outcomes. Our items also added detail on specific symptoms of interest that should be targeted in future studies (e.g., anxiety and dyspnea). The need for nursing research on assessing and improving patient–family communication, advocacy, and engagement in critical care setting (e.g., during mechanical ventilation) was recognized previously as a nursing research priority (3, 17). Although there has been progress in this area (24–30), well-designed trials are clearly needed to advance this complex area of critical care science.

**Nursing research priorities in adult respiratory health.** Table 4 highlights the final items and reflects the deletion of 2 PRO items from Round 2; all remaining items were endorsed, for a total of 22 PROs, 20 PREs, and the 3 care processes and clinical outcomes items. Most items that were endorsed reflected priority items identified in previous ATS efforts (3, 16, 17) and in regional Delphi surveys (31). These included the need to prioritize nursing research focusing on disease and symptom self-management, quality of life, patient–provider communication, health promotion and behaviors, technology, care delivery, risk reduction, and patient education. However, our items differed from an asthma PSP in that the PSP identified research needs more focused on clinical and educational effectiveness (32). Several of our items appeared to be novel, including endorsement of research into the burden of multiple chronic conditions, personalized care, advanced care planning, decision-making, and health beliefs.

**Nursing research priorities in sleep.** As seen in Table 5, all items from Round 2 (12 PRO items and 1 PRE item) were endorsed. Participants in the sleep Delphi survey prioritized the need for enhanced patient and provider education about sleep and the need for more skills training in, and knowledge about, sleep self-management, mirroring the recommendations of an earlier ATS statement on sleep (33).

**Table 4.** Nursing research priorities in adult respiratory health—final items endorsed by nurses, patients and caregivers

## Patient-reported outcomes

1. Health-related quality of life (e.g., physical and mental health)
2. Functional status (e.g., ability to perform normal daily activities to meet basic needs, fulfill usual roles, and maintain health and well-being)
3. Symptom reduction (e.g., how patients can have fewer symptoms)
4. Adherence (e.g., having closer agreement between what the patient wants to do for self-care and what they have been advised to do, such as taking medicines and quitting smoking)
5. Quitting smoking and staying quit
6. Risk reduction (e.g., identify what things will help decrease risk for a complication, a disease, or other unwanted outcomes)
7. Patient education focused on risk reduction (e.g., teaching patients and families how to decrease risk for a complication, a disease, or other unwanted outcomes)
8. Ways to motivate health promotion/health-seeking behaviors (e.g., enabling people to increase control over, and to improve, their health)
9. Symptom overlap—better management strategies for symptoms that have multiple underlying causes (COPD and CHF exacerbation)
10. Technology to support self-care (e.g., telehealth and home spirometry)
11. Effective communication by the health care team (e.g., using plain language to explain diseases, medical tests, and treatments)
12. Effective communication between patients and families and the health care team
13. Personalized care (e.g., care that is tailored to help patients and families better understand the direction or course of their particular lung disease)
14. Personalized care (understanding which models of care are appropriate and which treatments are effective at different time points across the trajectory of illness)
15. Advance-care planning. This is a negotiated plan that tells the health care team what patients want for care if they are unable to speak for themselves. It is based on their own values, preferences, and discussions with their loved ones
16. Anticipatory grief. This means learning how best to give patients and families bad news early and how best to respond to patient/family grief (e.g., refer to support groups or mental health specialists in end-of-life care)
17. Presymptom management. This is the effectiveness of services aimed at preventing or slowing the development of lung disease or its symptoms (e.g., pulmonary rehab in early stage COPD)
18. Low-cost simple treatments in places where resources are limited or unavailable (e.g., community walking programs instead of pulmonary rehab)
19. Social support (e.g., helping friends/family to maximize quality outcomes in their loved ones)
20. Nonpharmacologic interventions. These are ways to help patients with lung disease besides using medicines (e.g., pulmonary rehabilitation, psychological support, and handheld fans)
21. Effectiveness of support groups early in progression (long-term impact on cost; online vs. face to face)
22. Effectiveness of shared decision-making in improving outcomes

## Patient-reported experience

1. Quitting smoking and staying quit
2. The impact of interventions that promote health
3. How patients and families/caregivers make decisions about health
4. The burden of having more than one illness
5. Patients' and families'/caregivers' health beliefs
6. How patients and families/caregivers think, understand, learn, and remember
7. How patients and families/caregivers get, process, and understand basic health information and services to arrive at a health decision
8. What families/caregivers understand about what patients need in order to take care of their disease or symptoms
9. What patients and families/caregivers understand about the progression or prognosis of lung disease (e.g., will the symptoms get worse or will the disease never be cured?)
10. What it is like for patients and families/caregivers to live with the uncertainty of what the future holds because of a lung disease diagnosis
11. What it is like for patients and families/caregivers to create an advanced-care plan. This is a negotiated plan to tell the health care team what care they want if they are unable to speak. It is based on their values, preferences, and discussions with loved one
12. What patients and families/caregivers have found to be helpful in motivating them to care for their disease or symptoms
13. What it has been like for patients and families/caregivers to prepare for loss. This means responding to bad news (e.g., a disease cannot be cured or that symptoms will get worse)
14. How families/caregivers can be helped to better understand what patients are experiencing
15. What it is like for patients and families/caregivers to be diagnosed with a lung disease and to accept the diagnosis
16. How much social support patients and families/caregivers have, or do not have, and how that impacts health
17. How scientific evidence, patients' and families'/caregivers' values, preferences, and needs lead to certain health behaviors
18. How patients and families/caregivers experience good and poor communication with the health care team
19. The role of patients and patient associations in therapeutic education programs and caregiver support
20. The impact of loneliness on outcomes in lung disease

## To better understand the experience of the patient/family, nurses should:

1. Use clinical data (e.g., emergency/hospitalization) in conducting research
2. Conduct more longitudinal studies and more studies of greater length
3. Use research frameworks like the chronic-care model (care)

*Definition of abbreviations:* CHF = congestive heart failure; COPD = chronic obstructive pulmonary disease.

Likewise, there was consensus between our respondents and sleep specialty societies about the need for improved access to sleep care, including the use of telehealth (34, 35).

The need to understand how sleep interacts with and affects other symptoms over the course of a chronic respiratory illness, and the need to develop assessment measures for

sleep disturbances and nonpharmacologic interventions to improve sleep during and after critical illness, were also endorsed; these have also been reported before

**Table 5.** Nursing research priorities in sleep—final items endorsed by nurses, patients and caregivers

Patient-reported outcomes

1. Effective communication (what providers do with the information from the patients related to sleep)
2. Adherence (agreement between patient preference and prescribed treatment of their sleep disorders or disturbances)
3. Access (patient barriers to access care for sleep disorders or disturbances)
4. Trajectory (how the need for sleep assessment and treatment changes over the course of a chronic illness)
5. Risk reduction (how sleep disorders or disturbances influence the trajectory of the chronic illness)
6. Functional status (how sleep disturbances affect other symptoms, such as problems breathing and the ability to do valued daily activities)
7. Prevention (whether a change in sleep pattern comes before or signals an acute exacerbation of a lung disease)
8. Access (level of access to sleep care)
9. Self-management (knowledge and technology skills to support sleep health)
10. Sleep health education (evidence-based education for patients and providers)
11. The use of technology/telehealth to support the diagnosis and treatment of sleep conditions\*
12. The use of population health information for the identification of those with undiagnosed sleep conditions\*

Patient-reported experiences

1. Psychological support that is needed for sleep conditions\*

\*New item added after analysis of open responses.

(36, 37). Adherence to sleep treatments was also seen as a nursing research priority area that may provide an opportunity to examine adherence to less-studied disorders, such as insomnia or sleep-related movements.

**Conclusions**

The ATS mission is to improve health worldwide by advancing research, clinical care, and public health in respiratory disease, critical illness, and sleep disorders (38). This Workshop Report details the results of an effort to update nursing research priorities in critical care, pulmonary and sleep conditions by engaging nurses, patients and caregivers using a global Delphi survey. A total of 649 nurses and 188 patients, family and/or caregivers (*N* = 837) from 45 countries participated. The proposed research agenda developed from this study is timely, responsive, and proactive, serving as a roadmap to inform and guide the implementation of research strategies and requests for proposals aimed at developing and implementing evidence to improve patient outcomes and experiences of care.

Four areas were broadly endorsed across the three surveys: communication, education, risk reduction and psychological support. This was to be expected given that these areas are strongly identified with

the practice of nursing and are responsive to nursing interventions. It should also be noted that there was considerable agreement between nurses, patients and caregiver as to research priorities suggesting that nurses understand the patient and caregiver experience. Given the proximity of nurses to patients and their caregivers and the intimate knowledge they have of their health-related experiences, this is not surprising. However, it underscores the importance of including nursing’s point-of-view in various healthcare issues, especially those that impact patients and caregivers. Unique differences among the three surveys are likely a function of the groups working independently to identify candidate items. For example, only the sleep group focused on access and only the pulmonary group focused on quality of life, motivation, patient-centered care, advanced/anticipatory planning, alternatives to care, shared decision-making and health beliefs.

Although many of the items endorsed by our respondents do not constitute new research priorities, having international perspectives as well as patients’ and caregivers’ endorsement provides added legitimacy and urgency to items that are part of a future nursing research agenda. Such collaborations narrow the gap between what matters most to patients and what funders and researchers think are the most

important or expedient paths to improving PROs and PREs. In an era of patient-centered care, it seems only fitting that the type of collaboration used in this project be codified as the preferred model for setting funding priorities, making clinical decisions and prioritizing the educational needs for professional practice and patient care. ■

This official workshop report was prepared by an *ad hoc* subcommittee of the American Thoracic Society Assembly on Nursing.

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**Author Disclosures:** M.G. served as a consultant AstraZeneca, Mylan, and Teva; served on an advisory committee for AstraZeneca; served as a speaker for Teva. M.B.H. has copyright for the SPEACS-2 communication training program; received non-financial support from VidaTalk, LLC (communication application on NIH grant). N.S.R. served as an editor for Elsevier Publishers. C.H., S.S., G.N., M.C.K., M.C., J.G., R.T.D., D.E.H., L.L.C., Z.C., B.H., A.F.H., H.J., H.S.-C., M.F., and J.Y. reported no relevant commercial relationships.

**Acknowledgment:** The authors thank the following for their assistance: the patient members of the Critical Care, Adult Respiratory

Health, and Sleep working group for their early support and commitment to situating our work in the patient, family, and caregiver experience; the American Thoracic Society (ATS) Public Advisory Roundtable and ATS staff member, Courtney White, for assistance with survey dissemination to their patient and caregiver network; the European Lung Foundation for assistance with survey dissemination to their patient and caregiver network; the Nursing Group of the Spanish Respiratory Society for their contribution to translation and dissemination of the surveys to all nursing members, and Paz Vaquero, R.N. (Chair of the nursing group) for piloting of the Spanish version to all nursing members; Ms. Mirjam Hillenius for her assistance with translation; ATS staff members, John Harmon and Kimberly Lawrence, for their tireless administrative support of the Delphi survey and assembly project; Leanne Aitken, Ph.D., R.N., for her assistance with survey dissemination; Nina Bracken, M.S.N., A.C.N.P.-B.C., for her help with web hosting the Delphi survey on the ATS

Nursing Assembly homepage; Mengying Bu, M.S.N., R.N., for assistance with Chinese translations; Jayun Choi, Ph.D., R.N., for her assistance with data analysis of Round 2 participants; Columbia University School of Nursing's Office of Global Initiatives' Director Jennifer E. Dohm, D.N.P., C.N.M., F.A.A.N., and Assistant Director Yu-Hui Ferng, M.P.A., for facilitating contact with African and Middle Eastern collaborators; DorAnne Dornesky, Ph.D., R.N., for her assistance in recruiting patients to participate; Qianhui Ma, M.S.N., R.N., for assistance with Chinese translations; Jin Yan, Ph.D., R.N., Sharon McKinley, Ph.D., R.N., and Elizabeth Scruth, Ph.D., M.P.H., R.N., C.C.N.S., C.C.R.N., F.C.C.M., for their contributions to the workshop planning and survey dissemination; Hui Yang, M.S.N., R.N., for assistance with Chinese translations; and Dandan Sun, M.N., R.N., for assistance in the translation of the Chinese version of the surveys.

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