NURSING
YEAR IN REVIEW
# ATS 2019 – DALLAS

## Nursing Year in Review

**Bibliography**

Monday, May 20

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PATIENT ENGAGEMENT: PATIENT EXPERIENCE


Summary
Safety and acceptability of sedative self-administration by patients receiving mechanical ventilation is unknown. This pilot study aimed to determine if self-administration of dexmedetomidine by patients is safe and acceptable for self-management of anxiety during ventilatory support. Seventeen intubated ICU patients were randomly assigned to dexmedetomidine and 20 to usual care. Dexmedetomidine was administered for patient-controlled analgesia, with a basal infusion titrated by the number of patient-triggered doses. Safety parameters related to heart rate and blood pressure were established a priori. Acceptability was based on patients’ self-reported satisfaction and ability to administer the sedative. A 100-mm visual analog scale was used daily to assess patients’ anxiety. The sample was 59% male and 89% white. Mean values were age, 50.6 years; score on the APACHE III, 60.1; and protocol duration, 3.4 days. Five dexmedetomidine patients had blood pressure and/or heart rate lower than safety parameters, necessitating short-term treatment. Nurses’ adherence to reporting of safety parameters was 100%; adherence to the dexmedetomidine titration algorithm was 73%. Overall baseline anxiety score was 38.4 and did not change significantly. Most dexmedetomidine patients (92%) were satisfied or very satisfied with their ability to self-administer medication. For select patients, self-administration of dexmedetomidine is safe and acceptable.

Comments
1. This study demonstrated that dexmedetomidine is safe as defined by a priori criteria for a select sample of patients during the later, more stable part of mechanical ventilation.
2. Patient self-administration of sedative therapy aligns with current sedation management guidelines that state patients should be as alert as medically feasible and able to participate in their own care.
3. Subjects were satisfied with their ability to self-administer the medication and were able to use dexmedetomidine according to their own individual sedation needs.
4. No patients in the intervention group experienced delirium after enrollment, whereas four patients in the usual care group did; further evaluation of this intervention in regards to delirium is needed.
5. Subsequent studies are needed to determine whether patient-controlled sedation can achieve clinically relevant outcomes such as shorter duration of mechanical ventilation, decreases in patients’ psychological symptoms, prevention of delirium, and improved recovery after critical illness.

PATIENT ENGAGEMENT: PATIENT COMMUNICATION


Summary
Ineffective communication during mechanical ventilation and critical illness is distressing to many patients. This study aimed to describe the scope of communication content of ventilated critically ill patients. The investigators conducted a prospective qualitative interview study in a multidisciplinary ICU. Ten alert, orientated adult patients who previously underwent mechanical ventilation for at least 24 hours and were able to speak at the time of interview were recruited. Semi-structured interviews with stimulated recall technique were conducted. A descriptive thematic analysis was performed of the patient-generated content using a free coding technique, where recurrent themes and subthemes were noted, coded and analyzed. Patients’ communication content included medical discussions with clinicians; communication with family to provide advice or comfort, make requests and plans, express feelings and convey personal perspectives on medical care; and expression of their own psychoemotional needs. The scope of communication content of ventilated ICU patients was broad, extending far beyond task-focused subject matter. Content ranged from conveying symptom-related messages to active participation in medical discussions, to conversing with family about a range of complex multidimensional issues, to sharing their own psychoemotional experiences.

Comments
1. Patients’ intended scope of communication content was multidimensional spanning multiple domains and topics.
2. Patients expressed a desire to actively participate in their own medical discussions with physicians and communicate with their families to provide and receive support as well as to share their own experience.
3. The broad scope and complexity of patients’ communication content is not adequately addressed by the communication tools and strategies most commonly used (i.e. mouthing words, writing, typing, communication boards, etc).
4. These study findings suggest there are unmet needs in regards to the content that ventilated patients want to communicate as well as highlight the importance of providing communication tools that enable patients to engage in complex discussions rather than just simple symptom or task related topics.

**FAMILY ENGAGEMENT: FAMILY PRESENCE**


**Summary**

There is a lack of recent studies exploring ICU patients’ families’ preferences regarding family-witnessed resuscitation. Exploring families’ perspective contributes to a better understanding of what patients’ relatives expect. A descriptive qualitative design was used to describe preferences of intensive care patients’ family members regarding the idea of an inpatient family-witnessed cardiopulmonary resuscitation. Twelve family members of former intensive care patients took part in individual semi-structured interviews. Data were analyzed using thematic analysis. The thematic analysis resulted in two main themes with four subthemes each: (Theme 1) Being more involved and engaged in patient’s care in case of cardiopulmonary resuscitation, with subthemes: (a) Having an option to decide, (b) Being in physical proximity to the patient, (c) Feeling like having more control and impact and (d) Having a better idea about the situation. (Theme 2) Being cared for and treated respectfully during possible cardiopulmonary resuscitation, with subthemes: (a) Need for more support and understanding from the staff, (b) Uniqueness of the family – patient relationship, (c) Need for staff to be more humane and less mechanical and (d) Professional and highly qualified staff. Results of this study suggest a possible gap in family-centered care delivery in intensive care settings.

**Comments**

1. There are a number of preferences that family members of critical care patients hold regarding their expectations towards family-witness resuscitation.
2. Patients’ relatives desire to be more involved in patients’ care during possible in-hospital cardiopulmonary resuscitation of their loved-one, generally receive more support, and be better treated by the ICU staff.
3. Taking into account patients’ relatives’ voices can help the intensive and critical care nurses to understand families’ experiences and improve care deliver to them.
4. Mapping out or/and updating local family-centered care guidelines can initiate local organizational change in the ICU and enable desired implementation of family-witnessed resuscitation.
5. System changes are necessary to increase nurses’ awareness of patients’ families’ preferences and successfully implement recommended family-witnessed cardiopulmonary resuscitation.

**FAMILY ENGAGEMENT: RECEIVING INFORMATION AND HAVING NEEDS MET**


**Summary**

Relatives of ICU patients suffer emotional distress that impairs their ability to acquire the information they need. This randomized, parallel-group trial evaluated whether providing relatives with a list of important questions was associated with better comprehension on day 5. 302 relatives of mechanically ventilated patients were included from 14 hospitals in France. A validated list of 21 questions was given to the relatives immediately after randomization. The primary endpoint was comprehension on day 5. Secondary endpoints were satisfaction and symptoms of anxiety and depression. Day-5 family comprehension was adequate in 68 (44.2%) and 75 (50.7%) intervention and control group relatives (P = 0.30), respectively. Over the first five ICU days, median number of family–staff meetings/patient was 6 [3–9], median total meeting time was 72.5 [35–110] min, and relatives asked a median of 20 [8–33] questions including 11 [6–13] from the list, with no between-group difference. Satisfaction and anxiety/depression symptoms were not significantly different between groups. The only variable significantly associated with better day-5 comprehension was a higher total number of questions asked. Providing relatives with a list of questions did not improve day-5 comprehension, secondary endpoints, or information time.

**Comments**

1. Giving the list, compared to no list, was not associated with any significant changes in comprehension on day 5, family satisfaction, or presence in relatives of symptoms of anxiety and/or depression.
2. There were no significant differences between groups for the number of family meetings, total staff-family meeting time, or number of questions asked by relatives, or for the number of questions asked that were on the list.
3. The more time relatives and staff spent speaking together, the greater the level of relative comprehension.
4. The investigators did not assess whether and how the list of questions was used by the relatives; thus having a staff member...
or facilitator go through the questions with relatives might have produced a different result.

5. Additional research, specifically qualitative interviews with subjects who receive the list of questions, is needed to identify methods to improve ICU relatives' comprehension.

FAMILY ENGAGEMENT: DECISION MAKING


Summary
Surrogate decision makers of ICU patients often struggle with decisions related to goals of care, which causes psychological distress that leads to treatment that does not align with patients' preferences. This stepped-wedge, cluster-randomized trial involving 1420 ICU patients and their surrogates compared a multicomponent family-support intervention delivered by an interprofessional ICU team with usual care. Outcomes included the surrogates' mean score on the Hospital Anxiety and Depression Scale (HADS) at 6 months, mean scores on the Impact of Event Scale (IES), the Quality of Communication (QOC) scale, and a modified Patient Perception of Patient Centeredness (PPPC) scale, as well as the mean length of ICU stay. There was no significant difference between groups in the surrogates' mean HADS score at 6 months or mean IES score. The surrogates' mean QOC and PPC scores were better in the intervention group. The mean length of stay in the ICU was shorter in the intervention group. The intervention did not significantly affect the surrogates' burden of psychological symptoms, but the surrogates' ratings of the quality of communication and the patient- and family-centeredness of care were better and the length of stay in the ICU was shorter with the intervention group.

Comments
1. A low cost decision support intervention delivered by an interprofessional ICU team did not significantly affect surrogates' burden of psychological symptoms at 6 months.
2. Surrogates ratings of the quality of communication the patient and family-centeredness of care were better and the length of stay in the ICU was shorter with the intervention than with usual care.
3. It is feasible to train members of the existing interprofessional ICU team to deliver a family support intervention.
4. The intervention resulted in significant improvements in makers of the quality of decision-making, including the patient- and family-centeredness of care and the quality of clinician-family communication.
5. The intervention allowed surrogates to transition a patients' treatment to comfort-focused care when doing so aligned with the patient's values.

FAMILY ENGAGEMENT – CONTRIBUTIONS TO CARE


Summary
Parental involvement in care might result in improved outcomes for preterm infants’ and their parents. This pilot randomized controlled trial evaluated the effectiveness and safety of a family centered care intervention in a Chinese neonatal ICU. Premature infants (n = 61) and their parents (n = 110) were enrolled from a tertiary children's hospital in China with a 60-bed neonatal ICU. The intervention included a parent education program followed by parents' participation in care as primary caregiver for the infant until discharge for a minimum of 4 hours per day. Infants in family-centered care group (n = 31) had higher weight gain, less neonatal ICU length of stay in days, and decreased readmission rate at 1 week and at 1 month compared with the control group (n = 30). Total Mean Parental Stress and Anxiety scores were lower in the family centered care group, mean satisfaction rates in family-centered care group were higher compared with control group, and parents in the family centered care group had better educational outcomes related to neonatal specialized care skills. The results suggest that involving parents in the daily care of their infants is feasible and should be promoted by neonatal ICU clinicians.

Comments
1. Family centered care may provide beneficial effects on infants’ clinical outcomes and parent-reported outcomes and skills without additional harm.
2. The family centered care intervention was associated with greater weight gain at discharge, better breastfeeding rates, lower readmission rates and favorable neurologic outcomes.
3. Patients in the intervention group experienced less anxiety and depression while satisfaction scores increased.
4. Involving parents in the care of their infant in a NICU contributed to a better understanding of parent's clinical knowledge, decreased stress levels, and increased satisfaction.
5. Results suggest that working collaboratively with parents is feasible and contributes the quality and safety of NICU services.
OTHER ARTICLES OF INTEREST


NURSING YEAR IN REVIEW

SELF-MANAGEMENT OF OBSTRUCTIVE SLEEP APNEA

Summary
Obstructive sleep apnea (OSA) has been linked to increased risk for Alzheimer's disease (AD), but little evidence exists on the effects of OSA treatment in preclinical AD. This study was designed to determine if continuous positive airway pressure (CPAP) treatment adherence predicts cognitive and everyday function after 1 year in older adults with mild cognitive impairment (MCI) and to determine effect sizes for a larger trial. This quasi-experimental pilot clinical trial included older adults, aged 55 to 89 years, with an apnea-hypopnea index of 10 or higher. The groups included people with MCI and OSA who were CPAP adherent (MCI +CPAP), n = 29; and people with MCI and OSA who were non-adherent to CPAP (MCI -CPAP), n = 25. The investigators found statistically significant improvements in psychomotor/cognitive processing speed in the MCI +CPAP group vs the MCI -CPAP group at 1 year after adjustment for age, race, and marital status. There were small to moderate ESs for memory, attention, daytime sleepiness, and everyday function (ES 0.50, 6 mo) favoring the MCI +CPAP group vs the MCI -CPAP group. Controlling for baseline differences, 1 year of CPAP adherence in MCI +OSA significantly improved cognition, compared with a nonadherent control group, and may slow the trajectory of cognitive decline.

Comments
1. Obstructive sleep apnea has been increasingly found to be associated with cognitive impairment and the development of AD, but there have been few clinical trials to determine if treating OSA might improve cognition, especially in people who are at high risk.
2. This quasi-experimental study is among the first to show the potential benefits of CPAP among people with mild cognitive impairment
3. People who were more likely to be adherent were older, white and married than those who were non-adherent
4. Adherence was determined by a mean of > 4 hours of CPAP use per night over one year, based on evidence-based recommendations, but a higher adherence may have better outcomes
5. Authors recommend future large scale randomized controlled trials.


Summary
Sleep apnea has major neurocognitive, cardiovascular and metabolic risks. Treatment is often suboptimal because of variable adherence to CPAP. This trial compared positive airway pressure (CPAP) adherence among patients who were provided active patient engagement (APE) technology vs those who received usual care monitoring (USM). The primary outcome was the US Medicare definition of adherence. Adherence data from two cloud-based databases (Airview and Myair) were collected and propensity matched in a 1:2 ratio (APE:UCM) based on baseline patient characteristics. The investigators analyzed data from 128,037 patients. APE was associated with more patients achieving adherence criteria (87.3%) compared with UCM patients (70.4%; p < .0001 for the difference). Average therapy usage was 5.9 h per night in the APE group vs 4.9 h per night in the UCM patients (p < .0001). Patients with sleep apnea “struggling” with therapy adherence had a 17.6% absolute improvement in adherence using APE compared with UCM. The authors concluded that robust therapy adherence rates can be achieved by adding modern technology to usual care. Advances in technology in care management may allow more effective and efficient treatment of sleep apnea.

Comments
1. A primary barrier to the effectiveness of CPAP for sleep apnea is patient adherence, but past interventions to promote adherence have had inconsistent results.
2. The Airview system provided multiple reminders and prompts to promote CPAP use after patients selected to use this system and was delivered electronically.
3. The intervention was not theory-based. Thus, the behavioral mechanisms for the effects on adherence cannot be determined from these data, and the use of multiple components make it difficult to determine the active ingredients of the intervention.
4. Patients were self-selected and this may bias the results.
5. The data suggest that cloud-based patient engagement may improve CPAP adherence, but future well-controlled randomized clinical trials are needed.

PATIENT ENGAGEMENT WITH SLEEP IN THE ACUTE AND CRITICAL CARE SETTING


Summary
Patients in the intensive care unit (ICU) frequently have sleep deprivation that may contribute to ICU delirium. Experts recommend sleep promotion to prevent or shorten periods of delirium, but ICU sleep promotion protocols are difficult to implement. The purpose of this study was to describe the development, implementation, and revision of a medical ICU sleep promotion protocol (“naptime”), a clustered-care intervention to provide a rest period between 00:00 and 04:00. The investigators developed a protocol and piloted it. Using stakeholder feedback, they revised it and adapted it for unit-wide implementation. Investigators identified sound, patient care, and patient anxiety as important sources of overnight disturbance. The pilot protocol altered the timing of routine care with a focus on medications and laboratory draws. There were frequent protocol violations for laboratory draws and for urgent care. Stakeholder feedback supported revision of the protocol with a focus on providing 60- to 120-minute rest periods interrupted by brief clusters of care between 00:00 and 04:00. Four-hour blocks of rest may not be possible for all medical ICU patients, but interruptions can be minimized to a significant degree. Involvement of all stakeholders and frequent protocol reevaluation are needed for successful adoption of an overnight rest period.

Comments
1. The problem of sleep deprivation in the ICU has been documented for many years, but to date, few clinical trials have been conducted to address this problem.
2. Multiple environmental and patients care interactions contribute to sleep deprivation, and these are complex to address, requiring the cooperation and input of multiple members of the intensive care team.
3. This paper documents the process of engaging stakeholders in the ICU setting into the development and implementation of a protocol to improve sleep deprivation in this setting and addressing barriers and facilitators to unit-wide change to promote sleep.
4. This study provides important foundational information to support the development of a randomized controlled trial of a unit-wide protocol to promote sleep in the ICU.

SLEEP IN THE SETTING OF PALLIATIVE CARE


Summary
There are high rates of sleep-wake difficulties in patients with cancer receiving palliative care. Pharmacotherapy is the most frequently used treatment option to manage these difficulties despite numerous adverse effects and the absence of empirical evidence of its efficacy and innocuity in palliative care. The purpose of this pilot study was to assess the feasibility and acceptability of a cognitive-behavioral and environmental intervention (CBT-E) to improve insomnia and hypersomnolence in patients with poor functioning and to collect preliminary data on its effects. Six patients with cancer receiving palliative care who had insomnia and/or hypersomnolence, received 1 CBT-E individual session at home. They applied the strategies for 3 weeks. Patients completed the Insomnia Severity Index, the Epworth Sleepiness Scale, a daily sleep diary, and 24-hour actigraphy at pretreatment and posttreatment, in addition to a semi-structured interview. Participants found strategies easy to apply most of the time, and none was rated as impossible to use because of their health condition, but adherence and satisfaction toward CBT-E were highly variable. Results were heterogeneous, but improvements were observed in patients with persistent insomnia. The CBT-E was fairly well received and suggested positive outcomes in some patients, particularly those with an insomnia complaint alone.

Comments
1. This small pilot study focused on behavioral intervention for sleep-wake difficulty in cancer patients receiving palliative care, and important, but understudied symptoms.
2. Responses to the intervention were highly variable.
3. People with persistent insomnia were most likely to benefit from the intervention.
4. Efforts should be pursued to adapt CBT-E and develop other non-pharmacological interventions, in order to provide an alternative to pharmacotherapy for sleep-wake difficulties in this population.
SLEEP AND SMOKING CESSION


Summary
Declining national rates of current tobacco use represent a public health victory. However, smoking rates are approximately of 50% among high-risk, low-income populations. Current FDA-approved treatments for nicotine dependence are ineffective with between 70-95% of treatment-seekers relapsing within the first year of attempted abstinence. Identification of novel intervention targets to optimize response to currently available treatments for nicotine dependence is critical. Insomnia is a clinically verified nicotine withdrawal symptom but, to date, addressing insomnia or other sleep disturbance symptoms as an adjunctive smoking cessation therapy has yet to be fully considered. This manuscript presents a narrative review of: (1) sleep continuity and architecture in smokers versus nonsmokers; (2) effects of nicotine abstinence on sleep; (3) possible mechanisms linking sleep with smoking cessation outcomes; (4) plausible adjunctive sleep therapies to promote smoking cessation; (5) possible treatments for unhealthy sleep in smokers; and (6) directions for future research. This narrative review presents a comprehensive discussion of the relationship between habitual sleep and cigarette smoking. The extent to which unhealthy sleep in smokers may be a viable intervention target for promoting response to smoking cessation treatment is considered. Sleep therapy may be an adjunctive treatment for tobacco cessation.

Comments
1. Smokers have poorer sleep continuity than non-smokers, more restless sleep, and more daytime sleepiness.
2. Poor sleep, if not addressed may contribute to relapse after attempts to quit smoking.
3. Cognitive behavioral therapy for insomnia may assist with treating insomnia and preventing relapse.
4. FDA-approved treatments for smoking cessation, such as varenicline impair sleep.
5. Research is needed in the effects of smoking on sleep and vice versa and the extent to which pharmacological and non-pharmacological strategies may influence sleep and in turn influence tobacco cessation.

OTHER ARTICLES OF INTEREST

SELF-MANAGEMENT OF OBSTRUCTIVE SLEEP APNEA


PATIENT ENGAGEMENT AND SLEEP IN THE ACUTE AND CRITICAL CARE SETTING


TOBACCO AND SLEEP

SLEEP AND PALLIATIVE CARE
TRANSITIONAL CARE AND SELF-MANAGEMENT OF COPD


Summary

Hospital readmissions are common after COPD exacerbations. The purpose of this single-site randomized controlled, patient-centered trial (the BREATHE Program) was to evaluate a combined transition and long-term self-management program that was initiated during the hospitalization and continued at home. The researchers hypothesized that compared with participants who received usual care, participants randomized to the BREATHE Program would have fewer COPD-related acute care events and better HRQOL at 6 months after discharge from the hospital. The 3-month study intervention was co-developed with persons who have COPD, caregivers and other stakeholders. It comprised 3 components: transition support, individualized COPD self-management support and facilitated access to community services. Nurses provided the intervention at sessions held at the hospital before discharge and at home or by telephone after discharge. COPD participants (n=240) were randomized to the BREATHE Program or usual care. Usual care included assigning a general transition coach to follow the patient for 30 days after discharge, focusing on adherence to the discharge plan, and connecting to outpatient care. Participants in The BREATHE Program had significantly fewer COPD-related hospitalizations and ED visits and better HRQOL at 6 months.

Comments

1. This study was focused on engaging patients and caregivers. Patients with co-morbidities were not excluded from the study.
2. Initiating the study in the hospital may have increased patient engagement in care.
3. Providing home or telephone support increased outreach to patients who found it difficult to leave home.

PATIENT AND FAMILY ENGAGEMENT IN COPD

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PATIENT AND FAMILY ENGAGEMENT IN COPD


Summary

This study aimed to assess the effect of the Living Well with COPD (LWWCOPD) intervention on behavioral changes and disease-specific health-related quality of life (HRQOL) in persons receiving primary care for COPD (n=71), compared to a control group of patients with COPD from a Dutch and Swiss primary care cohort (n=396). The primary care LWWCOPD program included three main dimensions: knowledge, skills and the confidence and motivation to use the skills. There was a focus on reactions to patient health deterioration, based on a written action plan that was included as part of a personal diary. Participants recorded the date and types of symptoms that worsened, and the action taken according to the action plan. The action plan instructed patients to increase inhalation therapy, start systemic steroids or antibiotics, contact the care team, seek clinical care and when necessary, seek hospital admission. The researchers emphasized the importance of regular physical activity, and strength, endurance and breathing exercises in the action plan. The program consisted of six group modules, including: 1) what is COPD; 2) pharmacological treatment and correct inhalation techniques; 3) breathing techniques and coping strategies aimed at symptom control; 4) how to manage daily activities; 5) the health benefits of physical activity and how to determine barriers and enablers of regular physical activity; and 6) what is an exacerbation and how to prevent, recognize and adequately manage worsening symptoms. Participants took part in group sessions with the aim of increasing confidence, enhancing inner motivation to adopt healthy lifestyle behaviors, and empowering patients to improve COPD self-management on a day-to-day basis. They also received 2 or 3 individual coaching sessions to identify individual needs, barriers, goals and views about living with COPD. The LWWCOPD intervention improved HRQOL to a clinically relevant extent and reduced COPD exacerbations. Participants in the LWWCOPD group gained confidence in recognizing early signs of worsening condition and using the action plan in a timely fashion, which improved exacerbation outcomes.
Comments
1. The intervention included cognitive behavioral and motivational components that addressed self-efficacy and provided tools for developing self-management skills.
2. Results showed the impact of effective self-management on health outcomes.
3. Confidence in being physically active increased during the first 6 months of the intervention. This suggests the optimal time to provide support and encouragement for finding preferred physical activities.

PHYSICAL ACTIVITY COACHING

Summary
Sedentary behavior is associated with poor outcomes in persons with chronic obstructive pulmonary disease. The purpose of this secondary analysis of the Chronic Obstructive Pulmonary Disease Self-Management Activation Research Trial (COPD-SMART) was to examine the effectiveness of a behavioral lifestyle physical activity intervention combined with chronic obstructive pulmonary disease self-management education to promote lifestyle physical activity and prevent high-cost health care utilization. During a six-week run-in period, all participants (n=325) received COPD self-management education by a trained health coach via telephone. They were then randomized to the physical activity intervention or usual care. The goal of the physical activity intervention was accruing at least 30 minutes of moderate intensity physical activity per day. The intervention included a 25-chapter workbook supported by tailored telephone health coaching. Health coaches made calls every other week over 20 weeks and standardized automated telephone health coach messages were made on alternate weeks to reinforce the workbook activity for that week. The active intervention phase was followed by a 10-month maintenance phase. The lifestyle physical activity intervention plus COPD self-management education and usual care increased self-reported physical activity compared with usual care in participants with both moderate and severe COPD. The risk of urgent care or emergency room visits or hospitalizations was reduced by 40% compared with COPD self-management education plus usual care.

Comments
1. This study had a larger sample size than many previous studies in persons with COPD.
2. The longer followup period may have allowed time for behavioral change to take place.
3. The study provides evidence of the need to address physical activity in COPD self-management programs.

ADVANCED CARE PLANNING

Summary
The objective of this study was to systematically review advanced care planning (ACP) practice in chronic respiratory disease, attitudes of patients and health care providers and barriers and facilitators related to engagement in ACP. The researchers searched twelve electronic databases for studies on ACP in adults with chronic respiratory diseases. Twenty-one of 2509 studies were eligible – of these, 10 were quantitative studies. Advanced care planning was defined as the process of discussion of end-of-life care, clarification of related values and goals, and embodiment of preferences through written documents and medical orders. The researchers included studies with interventions, programs or activities that were labelled as ‘advanced care planning’ by the authors or studies addressing one or more core elements of ACP. The search strategy was developed with the aid of a biomedical information specialist of the Erasmus MC medical library. Extracted data included study characteristics, elements and effects of ACP and patient and HCP attitudes towards ACP. Barriers and facilitators were defined as predisposing factors reported by either patients, HCPs or both that hamper or facilitate engagement in ACP. Only barriers and facilitators that were endorsed by at least 10% of the participants of the particular study were included in the review. Of 4031 potential studies, 2264 studies were excluded, mostly because ACP was not the focus of the study. Two hundred forty-five remaining studies were assessed for eligibility and 21 studies were included in the systematic review. Results support that the concept of ACP is not widely known or used in chronic respiratory disease. The majority of the studies did not include the clarification of patients’ values and goals in their studies. There was minimal involvement of family caregivers. Results suggest three explanations for a discrepancy between the expressed interest in ACP discussions and the actual discussions. The explanations include unpredictable disease course, HCPs’ fear of taking away hope and system-related barriers such as time constraints and lack of continuity of care.
Comments
1. Patients find advanced care planning acceptable, but ACP discussions are limited.
2. The complex disease course and hesitation of persons with COPD and health care providers are barriers to engagement in ACP.
3. Identification of optimal times to discuss ACP, HCP training and system changes may help minimize barriers preventing patient engagement in ACP.

OTHER ARTICLES OF INTEREST


DISSEMINATION OF PATIENT ENGAGEMENT STRATEGIES INTO PRACTICE


Summary
Although SDH has demonstrated efficacy towards improving patient engagement and health outcomes, dissemination has been slow and inconsistent. The ability to implement SDM strategies into practice settings has been found to be complex. Current evidence suggests that successful implementation of SDM models of care is optimized when efforts are coordinated, providers educated with the knowledge and skills to engage patients in SDM and feedback is ongoing during practice facilitation. In this study investigators used a clustered randomized control design to compare the uptake of an asthma SDM intervention into primary care practices using three different dissemination approaches: (1) facilitator-led, (2) lunch and learn and (3) usual care control. The facilitator-led approach was evidence based and utilized a 12-week rollout plan that included weekly, hour-long meetings, a core team (champion, practice manager, health coach nurses and registration staff) an SDM toolkit, ongoing episodic needs-based contact by the facilitator and a refresher session one year after implementation. The practice was also assisted with tailoring the adoption of the SDM intervention to the culture of their practice. The lunch and learn dissemination approach included a lunchtime presentation describing the SDM toolkit to practice staff members and access to the toolkit materials via the internet. Usual care (control) received no intervention or active dissemination.

Comments
1. Seventy Four percent of patients indicated they participated equally in decision making at facilitator led practices compared to 66.3% from the lunch and learn practices.
2. No significant differences were found for patient outcomes by implementation group in emergency department visits, hospitalizations oral steroid prescription orders or exacerbations.
3. Clinical outcomes may be explained by the fact that a concurrent state-wide asthma intervention was being implemented in study practices.
4. Additional studies are needed to determine both sustainability of SDM models and clinical implications.

THE OLDER ADULT WITH ASTHMA AND PATIENT ENGAGEMENT


Summary
Patient engagement is increasingly expected as a part of health care, yet little is known about the patient’s desire for this type of involvement. Older adults often have multiple chronic medical conditions with multiple treatment options making engagement in shared decision-making more complex than for younger age groups. In this study, investigators analyzed data from persons participating in an ongoing randomized control trial prior to randomization. The purpose of this study was to determine patient preferences for involvement in medical care (autonomy) and to assess the association with asthma related outcomes in persons > 55 years diagnosed with persistent asthma. Additional metrics included the Autonomy Preference Index (API), Geriatric Depression Scale scores and asthma severity. Other measures were spirometry, the Asthma Control Test (ACT), and Quality of Life using the Mini Asthma Quality of Life Questionnaire (AQLQ). Asthma exacerbations were assessed by proxy indicators of corticosteroid use, hospitalizations, emergency department (ED) visits and unscheduled or urgent physician visits during the prior 12 months. The API measures autonomy in two domains (1) decision-making preferences and (2) information-seeking preferences. There were 189 participants, 49 (25.9%) were men, the mean age was 66 years, 60 (31.8%) were black and the median educational level was 4 years of college.

Comments
1. Higher scores on the API subscale, Decision-making preferences were positively correlated with being female (P=.007), higher educational level (P=.01), lower depression scores (P=.04), and higher AQLQ scores (P=.01).
2. Decision-making preference scores were also found to be a significant positive predictor for AQLQ, educational level, sex race, and depression score using regression analysis.
3. API scores were not significant predictors for spirometric values, asthma exacerbations or ACT scores.
LOW INCOME URBAN POPULATIONS AND PATIENT ENGAGEMENT


Summary
Purpose: To evaluate and compare patients’ sense of empowerment, engagement and acceptability of experiences with routine care vs. having assistance from a patient advocate (PA). In this report investigators used qualitative methods to obtain participant feedback at the end of a feasibility study. Participants were randomized to two groups, PA intervention or minimal intervention (MI) control group. Overall participants in both arms of the study were satisfied and would recommend the study to friends with asthma. Themes in the data analysis were Improved: health care adherence, and appointment preparation and communication. Both groups reported gaining knowledge regarding asthma medications and the importance of adherence. Participants also reported improvements in their preparation for a medical visit and communication with their provider. Feedback revealed perceived improvement empowerment and engagement in asthma care. While the intervention group received personal support from a PA, the control group received feedback on questionnaires completed during data collection sessions. Study investigators reported a positive effect on the MI group. This finding was attributed to the benefits of personal attention and accountability. Qualitative results suggest the need for additional investigations into the influence of facilitated support in asthma care and the role of active versus passive support and the association with patient engagement.

Comments
1. Patient advocates may play a unique role in health care that has not been fully explored.
2. Patient engagement is associated with improvements in asthma medication adherence, appointment keeping and communication with a health care provider.
3. Urban Minority patients are satisfied with and benefit from both intense and minimal levels of personal support and education to facilitate health care engagement.

PATIENT ENGAGEMENT: HOW DO WE TEACH THIS HEALTH

CARE STRATEGY TO NURSES


Summary
As an active participant in care, patients engage in shared decision-making to develop goals of care and the actions necessary to achieve goals. This process evaluation used mixed methods to explore training experiences of practice nurses in a Dutch primary care setting in health coaching and the patient experience in response to coaching. The training included educational session, on the job coaching and follow up meetings to provide feedback, answer questions, and reflections on actual experiences. Nurses found the training to be valuable as a means of obtaining greater insight into the patients’ personal issues relevant to realistic person-centered goal setting. However, nurses struggled to consistently integrate the approach into their current practice.

Fifty percent of patients (N=10) that were the recipients of the coaching intervention reported an awareness of a difference during encounters with nurses. Some patients reported a sense that the nurse asked more questions and listened more than during previous visits. Two patients reported greater insight into their personal situation which influenced their ability to set more realistic concrete goals. Most patients had limited or no recall of active participation in goal setting, and half reported no active engagement in developing a plan of care.

Comments
1. Health care providers require training to develop skills to engage patients in care
2. Consistent use of patient engagement may require more time for a clinic visit than a traditional office visit.
3. Patients perceive provider interactions that promote engagement as positive.

PATIENT ENGAGEMENT USING REMOTE DIGITAL CONNECTIONS


Summary
Engagement of patients with a chronic disease such as asthma is central to the achievement of quality health outcomes. Patients that are engaged in treatment decisions have been found to be more knowledgeable of their
disease, have better communication interactions with health care providers, and are better able to manage their disease. Often brief office visits are inadequate in time and responsiveness to promote patient engagement which requires frequent reminders and reinforcement to sustain positive health behaviors long after the clinic visit is over. With the increased availability and access to remote digital devices, barriers to patient engagement can often be overcome. In this study a remote digital coaching engagement program was implemented to improve asthma outcomes by providing frequent remote coaching. This was a 12-week prospective study that enrolled 51 adults diagnosed with uncontrolled asthma. Each participant was provided instructional print asthma self-management materials and a personal health advisor/coach who communicated with the participant weekly by telephone, text messaging or email. The coach provided support, motivation, additional education and accountability checks. Participants set small weekly goals during coaching sessions and received follow up text messages several times throughout the week to encourage or remind the patient or to hold them accountable for their goal.

**Comments**
1. Patient reported controller medication adherence improved, but there was no difference in FEV1 or FEV1/FVC.
2. A statistically significant decrease in periods of acute asthma worsening not requiring an acute care visit (p=0.028) was achieved as were best peak flow rates.
3. The Asthma Severity Index improved and was statistically significant and met the minimum clinically significant difference (>0.09).
4. The mean increase in the Asthma Control Test score was statistically significant but did not achieve the minimum clinically important difference of -4.0.
5. Remote digital patient coaching holds promise as a means of supporting and sustaining patient engagement in health care management.

**PATIENT ENGAGEMENT: PATIENT AND PROVIDER PERCEPTIONS**


**Summary**
The purpose of this descriptive study was to assess and compare asthma patient and provider perceptions of factors associated with effective partnerships and patient engagement. A survey was administered immediately prior to a local education session attended by 40 physicians and 334 adult patients with asthma recruited from the respective practice sites. The mean age of the patient participants was 46 years and 70% were women. Physician participants came from allergy and immunology practices based in community settings. Physicians knowledge about patients was primarily related to their medical condition. They had limited knowledge regarding personal patient centered factors. A comparison of treatment goals selected by patients differed significantly from goals selected by providers. Physicians treatment goals were primarily focused on clinical outcomes while patient goals focused on personal challenges related to asthma. Physicians were also more likely to provide patients with medical information i.e. medication options and how to respond to an asthma exacerbation as opposed to exercise training and nonpharmacologic therapies. However, patients believed they had a high level of involvement in decision making (76%). When it came to understanding barriers to asthma medication adherence patients most frequently cited forgetting and feeling fine without medications, while providers perceived side effects, insurance issues, cost and absence of symptoms as barriers.

**Comments**
1. Results indicate differences in the perceptions held by patients and their treating physician on factors important to building partnerships that may support patient engagement.
2. Patient centered care will require health care providers to be knowledgeable about personal factors in addition to medical factors that may influence health outcomes.
3. Findings reinforce the importance of openly communicating treatment goals of both patients and providers.

**OTHER ARTICLES OF INTEREST**


Simmons LA, Wolever RQ, Bechard EM, Snyderman R. Patient engagement as a risk factor in personalized health care: a systematic review of the literature on chronic disease. Genome Medicine, 2014. 6, 16 retrieved from http://genomemedicine.com/content/6/2/16


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