

Developing Community-Appropriate Sleep Apnea Messaging Through Appreciative Inquiry and Boot Camp Translation: A Qualitative Study

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Abstract

Undiagnosed sleep apnea is a substantial burden in the United States, leading to negative health impacts and unnecessary costs. Diagnosing sleep apnea is challenging due to a lack of evidence to justify universal screening and discomfort associated with sleep studies. This study used semi-structured, individual interviews ($N = 12$) to examine how community members with sleep apnea become diagnosed and identify effective strategies to manage their condition. Findings from these interviews, in turn, were used to develop messaging campaigns intended to increase community members' awareness of undetected sleep apnea. Influences from a variety of social and health care-related sources helped participants identify effective treatment strategies. Delays occurred at multiple points in the diagnostic process from symptom recognition through treatment, and finding effective treatment required trial and error. There is room to improve sleep apnea screening and diagnosis efforts in ambulatory care settings to better address high rates of undiagnosed sleep apnea. Community- and clinic-based strategies to incorporate sleep into patient-provider discussions and screen more broadly for sleep disorders could reduce the prevalence and duration of untreated sleep apnea.

The burden of undiagnosed sleep apnea is substantial in the United States, leading to negative physical and mental health impacts and unnecessary costs. Addressing untreated sleep apnea has great potential to improve the health of millions of people, but multifactorial barriers hinder efforts to (a) identify people who are at risk, (b) formally diagnose sleep apnea, and (c) manage the condition. Using interviews with individuals who have been diagnosed with sleep apnea and successfully adopted methods of treating it, this study aimed to examine common elements of the diagnostic and treatment process, from obtaining an initial diagnosis to identifying effective strategies to manage the condition.

Up to 80% of people with sleep apnea have not been formally diagnosed (Finkel et al., 2009; Singh et al., 2013), representing more than 20 million individuals in the United States. Sleep-disordered breathing resulting from untreated sleep apnea is associated with increased risks of depression, hypertension, stroke, coronary artery disease, and death (Punjabi et al., 2009; Young et al., 2009), which in turn drive excessive costs from comorbidities, accidents, and lost productivity (American Academy of Sleep Medicine, 2016). When sleep apnea is diagnosed and treated, numerous health benefits ensue. For example, continuous positive airway pressure (CPAP)

treatment has been shown to improve patients' blood pressure (Navarro-Soriano et al., 2019). Some studies have also indicated improvements in measures of insulin resistance associated with CPAP therapy (Muraki et al., 2018). Lastly, treatment has been shown to improve several patient-oriented outcomes, such as mood, physical functioning, sleepiness, and work absenteeism (Zhao et al., 2017). These health benefits highlight the great potential to improve individuals' lives by addressing their undiagnosed sleep apnea. However, numerous barriers exist to the successful diagnosis and treatment of the condition.

Since the most apparent symptoms of sleep apnea occur during sleep, they may not be obvious to sufferers. Screening for obstructive sleep apnea is not yet sufficiently accurate or effective to justify universal screening (Bibbins-Domingo et al., 2017; Jonas et al., 2017); there is uncertainty about the balance of risks and benefits associated with screening in asymptomatic patients (Jonas et al., 2017). Research supports testing symptomatic adults as part of primary care, so clinicians must rely upon a case-finding approach in order to accurately identify patients with sleep apnea (Pendharkar & Clement, 2017). However, patients are unlikely to volunteer information about sleep-related symptoms to their primary care clinician (Mold et al., 2011), sleep-related complaints may

not receive follow-up investigation (Grover et al., 2011), and physicians may lack specific knowledge about sleep disorders (Hayes et al., 2012). These factors compound the difficulty of detecting undiagnosed sleep apnea. Once sleep apnea is diagnosed, further challenges may surface in accepting the sleep apnea diagnosis, trying CPAP therapy, adhering to CPAP therapy over time, and integrating CPAP therapy into one's lifestyle (Matthias et al., 2014). Nonadherence to CPAP therapy may hinder treatment efforts (Sawyer et al., 2010); challenges that impede CPAP use include problems during the initial use of the equipment, mask discomfort, difficulty sleeping, inconvenience while traveling (Almeida et al., 2013; Luyster et al., 2016), and factors stemming from the health care system (Shapiro & Shapiro, 2010).

Despite the need for more widespread diagnosis of sleep apnea, little research has qualitatively explored patients' experiences of sleep apnea diagnosis and treatment. A better understanding of the process by which people become diagnosed and eventually adopt effective management and treatment approaches could inform strategies to address the high proportion of individuals with sleep apnea who remain undiagnosed. Learning from successful cases of diagnosis and treatment, rather than exploring further barriers, may provide insight on best practices for promoting symptom recognition, identifying patients at risk for sleep apnea, and adopting treatment. Such an approach has the potential to help alleviate the high prevalence and corresponding long-term health impacts of untreated sleep apnea in the United States.

This study examined how people become diagnosed with sleep apnea and identify strategies to effectively manage it, with the objective of identifying messages and strategies that can be useful in diagnosing and treating undetected sleep apnea in others. As part of a larger methods award funded by the Patient Centered Outcomes Research Institute (PCORI), community advisory council members identified sleep apnea as one priority topic. A success-focused approach called appreciative inquiry (AI) was used to frame data collection. Boot Camp Translation (BCT) was then conducted to translate findings from AI interviews into messaging campaigns designed to be accessible and relevant to specific communities. This paper describes AI interview findings and corresponding community-developed messages on the topic of sleep apnea.

Participants and Methods

This was a qualitative, exploratory study consisting of an initial data collection phase guided by AI followed by a BCT phase (AI/BCT). The AI/BCT method is designed to address community-identified priority areas, gather information about community members' or patients' successes in those areas, and translate those successes into evidence and interventions that are relevant for the local community (Nease et al., 2020). AI/BCT is a highly localized and success-focused approach to equitably collaborating with communities on research that matters to them, building on local strengths, and involving partners in dissemination and application of findings, consistent with a community-based participatory research approach (Israel et al., 2013). The overall study is described elsewhere (Nease et al., 2020).

Setting

The Department of Family Medicine at the University of Colorado Anschutz Medical Campus partnered with 2040 Partners for Health (2040), a community-based nonprofit organization in Aurora, Colorado, to conduct exploratory research on the topic of sleep apnea using AI/BCT. 2040 uses community-based participatory approaches to implement research and educational programs in collaboration with community residents, nonprofit organizations, health care providers, and faculty and student researchers.

Sampling and Recruitment

A purposeful sampling strategy was used to recruit individuals for AI interviews who (a) resided within 2040's service area, (b) had received a sleep apnea diagnosis, and (c) had identified and adopted treatment that alleviated the interference of sleep apnea symptoms in their everyday lives. Research team members, including both community and academic partners, conducted participant recruitment. Recruitment efforts consisted of sending individuals on 2040's email listserv a project overview, description of eligible interviewees, and request to follow up by telephone or email; conducting brief presentations about 2040 and the study at partners' community health events; and placing flyers with study information in University of Colorado health care facilities in Denver and Aurora. Two members of the research team, the community organization director (GPJ) and a family physician (MS),

screened potential participants for inclusion criteria prior to confirming study eligibility and scheduling an interview.

AI Interviews

AI originated in the field of organizational change as a method to explore successes rather than focusing on barriers and problem-solving (Hammond, 2013). The AI approach seeks out successful events and explores the context and factors that contributed to the success, with the ultimate goal of replicating positive outcomes on a regular basis (Bleich & Hessler, 2016; Hammond, 2013). Recently, AI has been applied in health care research as a strengths-based approach (Moore & Charvat, 2007). In the current study, AI took the form of individual, in-person interviews conducted by two research team members using a semi-structured interview guide. Interviewees were invited to share their experiences with this initial question: “Tell us the story about when you were properly diagnosed with sleep apnea and successfully treated. What is the story about how you were diagnosed and treated successfully?” Interviewers probed for details from participants, including any symptoms they experienced, how social support influenced their health care-seeking behaviors, which specific factors facilitated their eventual diagnosis, the timeframe for diagnosis and treatment, their personal feelings and attitudes related to sleep apnea, strategies they used to manage their condition, which modes of treatment they had considered and tried, and the outcomes of treatment efforts, particularly those they found most beneficial. Interview recruitment continued until multiple waves of outreach efforts yielded no additional eligible participants and overarching concepts described by participants in interviews began to reach saturation, with limited new information emerging.

Data Analysis

The analysis team consisted of the director of 2040 and community research liaison (GPJ), a family physician with public health and research training (MS), and a public health-trained research assistant with special expertise in qualitative inquiry (TH). The analysis team used a grounded editing approach (Addison, 1999) to analyze AI interview data and then developed a matrix of all stories and codes to further organize findings (Miles et al., 2014). The process was assisted by the use of ATLAS.ti (Version 7.5), a qualitative data analysis software program. One member of

the analysis team (TH) first reviewed all interview transcripts to become familiar with their contents. The analysis team then selected three interviews to read together to generate an initial list of codes for analysis. Through a series of four meetings over 6 weeks, the analysis team applied the identified coding structure to interview transcripts, refining the structure by adding and condensing codes as analysis progressed. The analysis team continued to discuss, reread, and code interview transcripts until team members came to consensus around a stable and relevant coding structure. The final coding structure consisted of 12 codes related to the diagnosis and treatment of sleep apnea and interview participants’ characteristics and context. The code dictionary is presented in Table 1.

The research assistant coded the remaining transcripts according to the determined coding structure, remaining open-minded to the emergence of additional themes. The analysis team then organized notable aspects of and illustrative quotes from each story into a matrix display of themes grouped by interview. This matrix display was presented to the entire research team for review and discussion to identify common themes and contrasting elements across stories. It was then used to map commonalities in the sequence of steps from symptom identification through successful diagnosis and treatment of sleep apnea.

BCT

The BCT method works to engage community members and health care professionals in translating evidence-based medical practice into messages meant for local dissemination. BCT was first developed as part of a Centers for Disease Control and Prevention grant to increase screening rates for colorectal cancer in rural, eastern Colorado. Using principles of community-based participatory research, BCT takes formal evidence-based guidelines and recommendations and adapts them into a format that is accessible and engaging for local patients and community members. The materials and messages developed through the translation process are then disseminated to the community under the guidance of the participants in the group. BCT has been utilized to spread information about a variety of health topics, including asthma, hypertension, and the patient-centered medical home (Allison et al., 2014; Norman et al., 2013; Westfall et al., 2013; Westfall et al., 2016; Zittleman et al., 2009). For instance, a BCT program focused on hypertension engaged members of a rural Colorado community

Table 1. Code Dictionary Applied to Transcripts of Interviews With Individuals Who Had Been Diagnosed With and Adopted Treatment for Sleep Apnea (*N* = 12)

Code	Definition
Symptoms	Signs demonstrated by participant and noticed by self or friends that contributed to awareness of need to seek care for sleep disorder (e.g., snoring, fatigue)
Diagnosis	Steps leading up to being diagnosed with sleep apnea, including sleep study (clinic or home-based); feelings associated with diagnosis and condition
Treatment methods	Description of approaches to treatment of sleep apnea utilized by participant from time of diagnosis through the present, including less effective methods used prior to current mode (e.g., CPAP machine, surgery)
Challenges	Factors that hindered sleep apnea diagnosis or identification of effective mode of treatment (e.g., discomfort with sleep study or CPAP equipment)
Navigating success	Activities and development of skills to manage the condition of sleep apnea and fit into lifestyle, including caring for and traveling with equipment
Health care	Process of seeking help for sleep symptoms and managing condition, including type of health care providers, relationship with clinicians and technicians, and insurance coverage or lack thereof
Turning point	The point at which the participant had a realization of the seriousness of their sleep apnea and factors leading to this point
Current success	Specific examples of ways in which the participant is currently successful in managing their sleep apnea
Timeline	Sequence and duration of key events in the process of seeking health care, being diagnosed with sleep apnea, and identifying effective treatment approaches
Social factors	Family history (if any), family and friends' influence on symptom recognition and adherence to treatment, general social support, condition's negative influence on social factors
Other health conditions	Other chronic diseases with which participant is diagnosed (e.g., obesity, hypertension)
Demographic characteristics	Participant characteristics including gender, age, and race and/or ethnicity

in developing a home-based blood pressure monitoring and tracking program (Just Check It; <https://justcheckit.org>).

For this project, the community BCT group convened for two in-person meetings and three telephone calls to apply the themes gleaned from interviews with members of their own community to the development of messages to encourage sleep apnea diagnosis and treatment. A local clinician-researcher specializing in sleep disorders provided a general presentation on the condition of sleep apnea, including typical symptoms, diagnosis methods, modes of treatment, and the overall importance of sleep to health and well-being. Then, the research assistant presented the interview

findings to the BCT participants. Through structured discussion and activities in an iterative process of conference calls, in-person meetings, and other asynchronous communication, the community group created a set of key messages and materials focusing on sleep health.

Funding and Institutional Review Board

This study was funded through a PCORI methods award and approved as exempt from human subjects review by the Colorado Multiple Institutional Review Board. All study participants provided informed consent for their participation. The funding agency had no involvement in the design or execution of this study.

Results

Interview Participants

AI interviews were conducted with 12 community members from the greater Denver metropolitan area who had been diagnosed with chronic, obstructive, or complex sleep apnea and adopted an effective treatment regimen. The group of interviewees included eight female and four male adults and seniors who identified as African American, White, and/or Hispanic. All participants had some form of health insurance coverage.

BCT Participants

Fourteen community members residing in the urban neighborhoods served by 2040 participated in the BCT process. Of the participants, 10 were female and four were male, and three had participated previously in AI interviews. BCT participants represented a variety of self-identified backgrounds and included retired professionals, employees of community organizations, neighborhood volunteers, and family caretakers; about half reported residing in the Denver metropolitan area for multiple decades.

Themes: Sleep Apnea Diagnosis and Effective Treatment

In this section, we detail common aspects of the process from symptom identification through diagnosis and treatment of sleep apnea, followed by overarching themes that recurred across the experiences of individuals who had adopted effective sleep apnea management or treatment modes. Among the 12 interviewees, multiple sources often influenced interviewees to progress toward identifying an effective mode of treatment for sleep apnea, delays occurred at multiple points from symptom recognition through diagnosis and treatment, and finding an effective treatment mode required trial and error. These themes are described in more detail below, followed by Table 2 containing illustrative quotes for select themes.

Influences from multiple sources are often needed for patients to be diagnosed with sleep apnea and recognize the need for treatment. In general, participants' paths to sleep apnea diagnosis and treatment began when they noticed symptoms independently or as a result of input from friends or family. A combination of influences from health care providers and social circles led participants to become aware of their sleep apnea symptoms or their significance, see a health care provider, and/or resume seeking treatment. For instance, family or friends made participants

aware of snoring habits or intermittent breathing during sleep or urged them to make the initial doctor's visit or follow up on a sleep study referral. Once symptoms were identified, participants were referred to sleep studies along one of two distinct paths: Some informed a health care provider of their sleep apnea symptoms as a chief complaint, while others were referred after an unrelated doctor's visit at which the physician incidentally noticed the relevance of the patient's symptoms or risk factors to sleep apnea.

Participants described journeys to diagnosis and treatment that included multiple health care providers. Several participants were referred to a sleep study by a primary care provider, but it was just as common for the referral to come from a specialist such as a cardiologist, pulmonologist, or neurologist. Multiple participants described a turning point in their understanding of the seriousness of their condition or the importance of sleep and good health following conversations with a health care provider or loved ones. Participants often needed both social influences and advice from a health care provider to recognize the significance of their symptoms, go through the diagnosis process, or persist to identify an effective mode of treatment.

Delays are possible at multiple points from symptom recognition through diagnosis and treatment. Participants experienced delays at multiple points in the process of obtaining diagnosis and treatment. Many participants delayed their decision to seek health care simply because it took time for them to become aware of their symptoms, such as snoring or breathing problems while sleeping, or to recognize the significance of signs like daytime fatigue and headaches. After informing a health care provider about relevant symptoms, some participants described hesitating for months before following through with their sleep study referral or visiting their physician to discuss sleep study results. Once participants were formally diagnosed, it took them some time to identify comfortable equipment and to get in the habit of using it regularly as part of their sleeping routines. These delays were long: Several participants reported that 2 to 5 years passed between recognizing symptoms and seeking health care. The longest duration between noting symptoms and diagnosis was 15 years. Reasons for such delays included costs associated with testing and equipment, even after taking into account health insurance coverage, and physical discomfort associated with a sleep study or wearing a CPAP device.

Finding an effective treatment mode requires trial and error. Participants utilized trial and error strategies to find types of treatment or equipment that minimized the interference of sleep apnea symptoms with their daily lives. All but one participant utilized a CPAP device as part of their treatment regimen (this participant instead opted for surgical treatment.) Participants tried multiple brands and varieties of devices to find ones that effectively relieved their symptoms and fit comfortably. Some participants received assistance from a health care provider in identifying a CPAP mask that fit properly or in communicating with device manufacturers to order appropriate equipment. However, others noted that interactions with health care providers were not particularly useful in selecting equipment and that they mainly relied on personal research or recommendations from friends and family with sleep apnea to inform this decision. Participants highlighted enhanced sleep quality, increased alertness and energy, less snoring, and improved breathing as a result of adopting effective treatment.

BCT Messages

Once data collection and analysis were complete, the research team convened the BCT group for discussion and message development. BCT attendance rates were high, with most of the 14 participants attending all meetings. Following the presentation of information about sleep apnea and the interview findings, the facilitation team (GPJ, MS) led BCT participants in a discussion of their reflections and reactions. BCT participants provided input as to what community members would need to hear in order to more rapidly seek a diagnosis for sleep apnea, and they brainstormed specific messages to disseminate to their community. In response to the expert presentation, they expressed the importance of framing sleep apnea as a chronic medical condition that can be improved through treatment. Interview findings about the combined influence of social circles and health care providers on the sleep apnea diagnosis and treatment journey led BCT participants to share that sleep was rarely discussed in their own health care encounters. Based on the finding that interviewees commonly faced delays in the diagnosis and treatment process, BCT participants discussed the importance of accelerating the transitions between recognizing symptoms, seeking care, and identifying an effective mode of treatment. The combination of interview findings, information from an expert about sleep apnea and associated risks, and BCT

participants' own experiences led them to decide on a broad messaging approach that focused on the consequences of poor sleep rather than specifically mentioning sleep apnea. The BCT group arrived at the following key messages:

- Sleep is an important part of health and well-being.
- Poor sleep can lead to numerous health issues and poor quality of life.
- If you are not sleeping well, then you ought to talk to your doctor.

The BCT group also developed several ideas for disseminating these key messages. First, since they recognized that sleep apnea has a higher prevalence in older adults, they wanted to emphasize the use of media that would reach this demographic. As such, they felt that posters and other written communications posted in venues such as recreation centers would be effective. Additionally, they advocated for peer education in which individuals who had been diagnosed with sleep apnea could share their experiences with people in the process of seeking diagnosis and treatment.

Discussion

Along the way to identifying an effective mode of treatment for sleep apnea, people often experience delays, need guidance from social circles and multiple health care providers, and undertake trial and error of several treatment devices. These themes are consistent with previous research demonstrating the contribution of symptom awareness to the decision to seek health care and the importance of social support to treatment adherence (Sawyer et al., 2010). Building on previous studies that demonstrated the role of partners and spouses in identifying and managing sleep apnea (Henry & Rosenthal, 2013; Luyster et al., 2016), these findings indicate that influence from wider social circles and health care providers can also contribute to symptom recognition and adherence to treatment. Given the common substantial delays between one's awareness of sleep apnea symptoms and diagnosis of the condition, strategies should be explored to accelerate conversations about sleep between patients and primary care providers, including conversations about the importance of sleep initiated by a health professional or patient-initiated discussion of sleep-related symptoms in the course of an unrelated visit. Identification of patients at risk for sleep apnea in primary care is feasible with more effective and systematic screening approaches (Grover et al., 2011; Mold et al., 2011).

Table 2. Select Illustrative Quotes for Notable Themes From Interviews With Individuals Who Had Been Diagnosed With and Adopted Treatment for Sleep Apnea ($N = 12$).

Theme	Illustrative quotes
Influences from multiple sources are often needed for patients to be diagnosed with sleep apnea and recognize the need for treatment.	"One day I came out of surgery from having all my toes operated on, and the surgeon told my family that they need to have me call the pulmonary department, the breathing department as soon as possible . . . and I had noticed a large part of my adult life, my husband and my closest friends was telling me I snored hardly [sic], and I believe that was a sign that during all those years I didn't even realize it . . . "I think it was the doctor that scared the stew out of me . . . He scared the entire family because he said I was losing my breath and it could endanger me and cause other medical problems." (Participant 2) "I had four grandchildren, and when they were young they loved me enough to put up with my snoring, but as they got older they was like, 'We'll sleep downstairs.' So I didn't realize how bad the snoring was. I thought I'd never get a husband because I snored . . . I literally snored that bad [laughter], and so between not being able to rest, the weight gain, and the snoring my doctor said, 'Let's do a sleep study,' and it was just that piece of the conversation." (Participant 6)
Finding an effective treatment mode requires trial and error.	"The first mask they got didn't work, so I had to go back to the doctor, and then he wrote an order that said, pretty much, 'Try it until it fits. Let her try it until it fits.' . . . They sent me [sigh], God they sent quite a few of them. It was just atrocious. I mean [laughing] and they're trying because you're communicating with the [company] people over the phone, and so they're asking you these questions about your head size and your nose and your this and your that, and I'm like, yeah, okay." (Participant 6) "I had a really hard time adjusting to it at first because the headgear, they always give you this thing that fits clear over your whole face and you feel totally claustrophobic and oh this is awful . . . I have changed headgear maybe six times. I finally found some headgear that I can tolerate, and even that wants to leak at night a lot." (Participant 5)
Delays are possible at multiple points from symptom recognition through diagnosis and treatment.	"I've always been a bad snorer, but I never knew it until me and my wife moved in together, so it was probably 12 years ago. She always told me I snored bad . . . so finally she set me up with somebody because she wanted me to get it checked out. They had me do a sleep study test at the house or I don't know if it was at the doctor's office. Weird, it was like this little room, and they made me sleep for half the night, and they came in and put a mask on me, and then tried it after that, and I never followed up. That was probably 5 years ago. . . . "I never followed up with that, and then I did get a primary care provider two years ago. . . . She had me sign up for a home test, and they sent that to my house, so it was an oxygen sensor in your finger and then it wraps around you, and it was two oxygen things that go in your nose . . . so it was cool. They just put it on the door of your house, and then in the morning you just [put it] out there and they pick it up. It took most of the month for me to hear from them. Which, I forgot about it. Then my wife kept asking because I snore a lot, so [laughing] they finally got me the results, and said you do have apnea. . . . "They set me up with a place to get my CPAP, and even though it was covered by insurance it was still like \$500 upfront, and then \$91 a month for 13 months. So I didn't do it right away. I said, 'No, I'm not going to do this. It's too expensive.' Finally after 2 months of always being tired and snoring, and we have a daughter that's 16 months now, so not being there . . . you know falling asleep on the couch while she's crying. My wife's like, 'You need to call them. It doesn't matter how much it costs.'" (Participant 7) "I guess the general theme is you ought to listen to your partner [laughs]. By that I mean probably 15 years ago in Chicago my wife would wake me up in the middle of the night and say, 'Hey you've stopped breathing or you're gasping for air,' and I wouldn't believe her, and so I ignored it for a good 12 years until we actually moved up to Colorado, which as you know we're at 10,000 feet." (Participant 8) "For the first 2 years I didn't really know what was going on. I just knew that I would wake and sometimes I'd be scared, but usually I was gasping for breath." (Participant 10)

This study involved intentional recruitment of participants who were effectively managing their sleep apnea and interviews focusing on successful navigation of the process from symptom recognition through diagnosis and treatment. Despite this positive study framework, participants experienced common barriers, including delays in obtaining diagnoses and treatment and challenges in finding a comfortable device. In other words, participants who successfully navigated the process of sleep apnea diagnosis and treatment had to demonstrate persistence through barriers at each stage. Better understanding these common barriers, particularly those that arise early in this process, could help address the large proportion of undiagnosed sleep apnea sufferers in the United States.

While some messages developed by the community group mentioned sleep apnea, most broadly emphasized the importance of good sleep for all. This more expansive approach may better inform and capture patients who do not have a current diagnosis of sleep apnea but who are suffering from poor sleep. Furthermore, the community's call to action encouraged individuals to discuss their sleep symptoms with their doctor, which is a critical step in successfully diagnosing individuals with sleep apnea.

Findings suggest that the detection of sleep apnea in general may be fairly haphazard, as each study participant came to be diagnosed in a unique way. As the AI/BCT approach attempts to "make the random the usual" (Nease et al., 2020), it has the potential to help translate the experiences of individuals who were successfully diagnosed with sleep apnea into interventions to encourage and expedite the process of obtaining sleep apnea diagnoses in others. The community-derived messages from the BCT are intended to accomplish this goal; however, subsequent testing of these messages in the community setting is needed.

This study benefited from a strong community-academic partnership, which ensured that community members felt empowered and represented throughout the entire research process from the identification of the research topic to analysis and dissemination of the findings. The 2040 community advisory council identified sleep apnea as a priority health topic, and the executive director of 2040 (GPJ) participated in the development of the interview guide, recruitment of study participants, analysis of interview data, and facilitation of the BCT. The community developed the key messages through BCT, an iterative process

that facilitates colearning between community members and researchers (Norman et al., 2013). By recruiting individuals from the community who had demonstrated success with sleep apnea diagnosis and treatment, the study leveraged community strengths and gathered local data about sleep apnea, enhancing the relevance of the topic to the community. In this regard, this study exemplified numerous principles of community-based participatory research (Israel et al., 2013).

Limitations

These findings represent a limited number of Colorado residents diagnosed with sleep apnea and are not necessarily representative beyond this population. The effectiveness of the messages developed by BCT participants in this study is unknown, as they have not been disseminated or pilot tested. Future work will focus on testing the effectiveness of these messages at increasing the successful diagnosis of sleep apnea in this community.

Conclusions

There is room to improve sleep apnea screening and diagnosis efforts in ambulatory care settings to better address high rates of undiagnosed sleep apnea. Diagnosis is impeded by several factors: Widespread screening of the general population for sleep apnea is not supported by the evidence, patients are unlikely to initiate discussions about sleep with their primary care clinicians, symptoms may go unnoticed or unreported, and both diagnosis and treatment are often perceived as cumbersome by patients. The underdiagnosis of sleep apnea is a major health concern because the condition is associated with many comorbidities, such as hypertension, heart disease, diabetes, mental health concerns, and increased mortality. Study findings have practical implications for communicating with and supporting patients to shorten the amount of time between sleep apnea symptom awareness, diagnosis, and implementation of effective treatment. Incorporating sleep into patient-provider discussions, developing more effective screening approaches, and screening more systematically for sleep disorders when appropriate could reduce the prevalence and duration of untreated sleep apnea.

References

Addison, R.B. (1999). A grounded hermeneutic editing approach. In B.F. Crabtree & W.L. Miller (Eds.), *Doing qualitative research* (2nd ed., pp. 145–161). Sage Publications.

- Allison, C., Zittleman, L., Ringel, M., Felzien, M., Bennett, C., Cowart, S., Flores, M., Hernandez, M., Norman, N., Rodriquez, M., Sanchez, N., Sanchez, S., Winkelman, K., Winkelman, S., Sutter, C., Gale, S., & Westfall, J.M. (2014). Translating the medical home into patient-centred language. *London Journal of Primary Care*, 6(6), 124–130. <https://doi.org/10.1080/17571472.2014.11494363>
- Almeida, F.R., Henrich, N., Marra, C., Lynd, L. D., Lowe, A.A., Tsuda, H., Fleetham, J.A., Pliska, B., & Ayas, N. (2013). Patient preferences and experiences of CPAP and oral appliances for the treatment of obstructive sleep apnea: A qualitative analysis. *Sleep and Breathing*, 17(2), 659–666. <https://doi.org/10.1007/s11325-012-0739-6>
- American Academy of Sleep Medicine. (2016). *Hidden health crisis costing America billions: Underdiagnosing and undertreating obstructive sleep apnea draining healthcare system*. Frost & Sullivan.
- Bibbins-Domingo, K., Grossman, D.C., Curry, S.J., Davidson, K.W., Epling, J.W., García, F.A.R., Herzstein, J., Kemper, A.R., Krist, A.H., Kurth, A.E., Landefeld, C.S., Mangione, C.M., Phillips, W.R., Phipps, M.G., Pignone, M.P., Silverstein, M., & Tseng, C.-W. (2017). Screening for obstructive sleep apnea in adults: US Preventive Services Task Force recommendation statement. *Journal of the American Medical Association*, 317(4), 407–414. <https://doi.org/10.1001/jama.2016.20325>
- Bleich, M.R., & Hessler, C. (2016). Appreciative inquiry and implementation science in leadership development. *Journal of Continuing Education in Nursing*, 47(5), 207–209. <https://doi.org/10.3928/00220124-20160419-04>
- Finkel, K.J., Searleman, A.C., Tymkew, H., Tanaka, C.Y., Saager, L., Safer-Zadeh, E., Bottros, M., Selvidge, J.A., Jacobsohn, E., Pulley, D., Duntley, S., Becker, C., & Avidan, M.S. (2009). Prevalence of undiagnosed obstructive sleep apnea among adult surgical patients in an academic medical center. *Sleep Medicine*, 10(7), 753–758. <https://doi.org/10.1016/j.sleep.2008.08.007>
- Grover, M., Mookadam, M., Armas, D., Bozarth, C., Castleberry, T., Gannon, M., Webb, D., & Dueck, A. (2011). Identifying patients at risk for obstructive sleep apnea in a primary care practice. *Journal of the American Board of Family Medicine*, 24(2), 152–160. <https://doi.org/10.3122/jabfm.2011.02.100193>
- Hammond, S.A. (2013). *The thin book of appreciative inquiry*. Thin Book Publishing.
- Hayes, S.M., Murray, S., Castriotta, R.J., Landrigan, C.P., & Malhotra, A. (2012). (Mis) perceptions and interactions of sleep specialists and generalists: Obstacles to referrals to sleep specialists and the multidisciplinary team management of sleep disorders. *Journal of Clinical Sleep Medicine*, 8(6), 633–642. <https://doi.org/10.5664/jcsm.2252>
- Henry, D., & Rosenthal, L. (2013). “Listening for his breath:” The significance of gender and partner reporting on the diagnosis, management, and treatment of obstructive sleep apnea. *Social Science & Medicine*, 79, 48–56. <https://doi.org/10.1016/j.socscimed.2012.05.021>
- Israel, B.A., Eng, E., Schulz, A.J., & Parker, E.A. (Eds.). (2013). *Methods for community-based participatory research for health*. Jossey-Bass.
- Jonas, D.E., Amick, H.R., Feltner, C., Weber, R.P., Arvanitis, M., Stine, A., Lux, L., & Harris, R.P. (2017). Screening for obstructive sleep apnea in adults: Evidence report and systematic review for the US Preventive Services Task Force. *Journal of the American Medical Association*, 317(4), 415–433. <https://doi.org/10.1001/jama.2016.19635>
- Luyster, F.S., Dunbar-Jacob, J., Aloia, M.S., Martire, L.M., Buysse, D.J., & Strollo, P.J. (2016). Patient and partner experiences with obstructive sleep apnea and CPAP treatment: A qualitative analysis. *Behavioral Sleep Medicine*, 14(1), 67–84. <https://doi.org/10.1080/15402002.2014.946597>
- Matthias, M.S., Chumbler, N.R., Bravata, D.M., Yaggi, H.K., Ferguson, J., Austin, C., McClain, V., Dallas, M.I., Couch, C.D., Burrus, N., & Miech, E.J. (2014). Challenges and motivating factors related to positive airway pressure therapy for post-TIA and stroke patients. *Behavioral Sleep Medicine*, 12(2), 143–157. <https://doi.org/10.1080/15402002.2013.778200>
- Miles, M.B., Huberman, A.M., & Saldaña, J. (2014). *Qualitative data analysis: A methods sourcebook*. (3rd ed., pp. 107–119). Sage Publications.
- Mold, J.W., Quattlebaum, C., Schinnerer, E., Boeckman, L., Orr, W., & Hollabaugh, K. (2011). Identification by primary care clinicians of patients with obstructive sleep apnea: A practice-based research network (PBRN) study. *Journal of the American Board of Family Medicine*, 24(2), 138–145. <https://doi.org/10.3122/jabfm.2011.02.100095>
- Moore, S.M., & Charvat, J. (2007). Promoting health behavior change using appreciative inquiry: Moving from deficit models to affirmation models of care. *Family and Community Health*, 30, S64–S74. <https://doi.org/10.1097/00003727-200701001-00009>

- Muraki, I., Wada, H., & Tanigawa, T. (2018). Sleep apnea and type 2 diabetes. *Journal of Diabetes Investigation*, 9(5), 991–997. <https://doi.org/10.1111/jdi.12823>
- Navarro-Soriano, C., Martínez-García, M.-A., Torres, G., Barbé, F., Caballero-Eraso, C., Lloberes, P., Diaz Cambriles, T., Somoza, M., Masa, J.F., González, M., Mañas, E., de la Peña, M., García-Río, F., Montserrat, J.M., Muriel, A., Oscullo, G., Feced Olmos, L., García-Ortega, A., Calhoun, D., & Campos-Rodríguez, F. (2019). Effect of continuous positive airway pressure in patients with true refractory hypertension and sleep apnea: A post-hoc intention-to-treat analysis of the HIPARCO randomized clinical trial. *Journal of Hypertension*, 37(6), 1269–1275. <https://doi.org/10.1097/HJH.0000000000002053>
- Nease, D.E., Jr., Simpson, M.J., Zittleman, L., Holtrop, J.S., Hall, T.L., Fisher, M., Felzien, M., & Westfall, J.M. (2020). Making the random the usual: Appreciative inquiry/boot camp translation—Developing community-oriented evidence that matters. *Journal of Primary Care & Community Health*, 11. <https://doi.org/10.1177/2150132720904176>
- Norman, N., Bennett, C., Cowart, S., Felzien, M., Flores, M., Flores, R., Haynes, C., Hernandez, M., Rodriguez, M.P., Sanchez, N., Sanchez, S., Winkelman, K., Winkelman, S., Zittleman, L., & Westfall, J.M. (2013). Boot camp translation: A method for building a community of solution. *Journal of American Board of Family Medicine*, 26(3), 254–263. <https://doi.org/10.3122/jabfm.2013.03.120253>
- Pendharkar, S.R., & Clement, F.M. (2017). Screening for obstructive sleep apnea: Important to find, but how hard should we look? *JAMA Internal Medicine*, 177(4), 463–464. <https://doi.org/10.1001/jamainternmed.2016.9538>
- Punjabi, N.M., Caffo, B.S., Goodwin, J.L., Gottlieb, D.J., Newman, A.B., O'Connor, G.T., Rapoport, D.M., Redline, S., Resnick, H.E., Robbins, J.A., Shahar, E., Unruh, M.L., & Samet, J.M. (2009). Sleep-disordered breathing and mortality: A prospective cohort study. *PLoS Medicine*, 6(8), Article e1000132. <https://doi.org/10.1371/journal.pmed.1000132>
- Sawyer, A.M., Deatricks, J.A., Kuna, S.T., & Weaver, T.E. (2010). Differences in perceptions of the diagnosis and treatment of obstructive sleep apnea and continuous positive airway pressure therapy among adherers and nonadherers. *Qualitative Health Research*, 20(7), 873–892. <https://doi.org/10.1177/1049732310365502>
- Shapiro, G.K., & Shapiro, C.M. (2010). Factors that influence CPAP adherence: An overview. *Sleep and Breathing*, 14(4), 323–335. <https://doi.org/10.1007/s11325-010-0391-y>
- Singh, M., Liao, P., Kobah, S., Wijeyesundera, D.N., Shapiro, C., & Chung, F. (2013). Proportion of surgical patients with undiagnosed obstructive sleep apnoea. *British Journal of Anaesthesia*, 110(4), 629–636. <https://doi.org/10.1093/bja/aes465>
- Westfall, J.M., Zittleman, L., Felzien, M., Norman, N., Tamez, M., Backlund-Jarquín, P., & Nease, D. (2016). Reinventing the wheel of medical evidence: How the boot camp translation process is making gains. *Health Affairs*, 35(4), 613–618. <https://doi.org/10.1377/hlthaff.2015.1648>
- Westfall, J.M., Zittleman, L., Sutter, C., Emsermann, C.B., Staton, E.W., Van Vorst, R., & Dickinson, L.M. (2013). Testing to prevent colon cancer: Results from a rural community intervention. *Annals of Family Medicine*, 11(6), 500–507. <https://doi.org/10.1370/afm.1582>
- Young, T., Palta, M., Dempsey, J., Peppard, P. E., Nieto, F.J., & Hla, K.M. (2009). Burden of sleep apnea: Rationale, design, and major findings of the Wisconsin Sleep Cohort study. *Wisconsin Medical Journal*, 108(5), 246–249.
- Zhao, Y.Y., Wang, R., Gleason, K.J., Lewis, E.F., Quan, S.F., Toth, C.M., Morrical, M., Rueschman, M., Weng, J., Ware, J.H., Mittleman, M.A., & Redline, S. (2017). Effect of continuous positive airway pressure treatment on health-related quality of life and sleepiness in high cardiovascular risk individuals with sleep apnea: Best apnea interventions for research (BestAIR) trial. *Sleep*, 40(4), Article zsx040. <https://doi.org/10.1093/sleep/zsx040>
- Zittleman, L., Emsermann, C., Dickinson, M., Norman, N., Winkelman, K., Linn, G., & Westfall, J.M. (2009). Increasing colon cancer testing in rural Colorado: Evaluation of the exposure to a community-based awareness campaign. *BMC Public Health*, 9, Article 288. <https://doi.org/10.1186/1471-2458-9-288>

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