Selvadurai, et al. J Sleep Disor: Treat Care 2021, 10:6

Journal of Sleep Disorders: Treatment & Care

Research Article A SCITECHNOL JOURNAL

Exploring Barriers and Facilitators to Positive Airway Pressure Use Over Time Among Young Adults: A Qualitative Study

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Abstract

Objective: Effective treatment for Obstructive Sleep Apnea (OSA) in youth is challenging due to lack of adherence to Positive Airway Pressure (PAP). The study objective was to explore facilitators and barriers for PAP use among young adults with OSA transitioning from paediatric to adult care services.

Methods: This was a prospective, qualitative study using a modified grounded theory approach. Young adults, aged 18 to 20 years, diagnosed with OSA by polysomnography and initiated on PAP therapy in a paediatric sleep facility participated in the study. Semi-structured interviews were completed at: 1) baseline visit at the time of transfer from paediatric care and 2) follow-up visit after 12 months in adult care. Interview audio recordings were transcribed verbatim. Transcripts were reviewed, analysed and coded into themes related to barriers and facilitators to PAP.

Results: Eighteen interviews were conducted: 10 at baseline and 8 at follow-up. During both visits, participants described the importance of health education, support, and perceived benefits including restfulness and alertness despite experiencing discomfort with PAP use. Several challenges were also highlighted, including managing the stigma associated with PAP use and the physical design of the machine such as the interface discomfort and lack of portability.

Conclusion: Several facilitators and barriers to PAP adherence among young adults with OSA during transition were identified. Implementing an integrative healthcare approach with educational strategies and tools, family involvement and peer support is critical to optimize PAP use during young adulthood and the period of transition to adult care.

Keywords

Obstructive Sleep Apnea, Positive Airway Pressure, Young Adults, Qualitative

Introduction

Obstructive Sleep Apnea (OSA) is a common sleep-related breathing disorder, characterized by snoring, recurrent partial and/or complete obstruction of the upper airway and intermittent nocturnal oxyhaemoglobin desaturations and sleep disruption [1]. OSA affects 1-4% of otherwise healthy children, and adenotonsillar hypertrophy is a common etiologic risk factor for children, for which an adenotonsillectomy is typically curative [2]. During the last decade, there has been a marked increase in older adolescents diagnosed with persistent OSA following an adenotonsillectomy. This increase has been attributed to the obesity epidemic, as 25-60% of children and adolescents with obesity have OSA [3, 4] where an adenotonsillectomy is not curative for OSA in the majority of paediatric patients with obesity [2]. Moreover, additional management strategies such as weight loss have also shown to be difficult to achieve and maintain [5], increasing the likelihood of older adolescents having persistent OSA into young adulthood [6, 7].

Consequently, Positive Airway Pressure (PAP) therapy is commonly prescribed for the treatment of persistent OSA [3, 8]. PAP delivers pressurized air via nasal/oronasal interface to distend the upper airway and is required to be used on a nightly basis during sleep [8, 9]. While PAP has been shown to be effective in treating OSA, adherence is a significant challenge, whereby more than 50% of children and adults are unable to tolerate PAP [10-13]. As a result, many individuals with OSA remain untreated, predisposing them to potential adverse outcomes including increased cardiovascular and metabolic risk as well as neurocognitive and behavioural deficits [14-17].

Previous studies have highlighted factors associated with low PAP adherence among children and adolescents, including low maternal education, race, older age and decreased family social support [18]. Further, adolescents have reported that the physical design of the PAP machine, such as discomfort of the mask and the length of tubing, poses a significant challenge with using PAP [19]. Such challenges are perceived to be more difficult and outweigh benefits such as symptom relief [19]. Key facilitators for promoting adherence have also been identified, which include health education, peer support groups, family involvement and developmentally appropriate support strategies that are tailored based on individual and family experiences [20]. However, there remains a paucity of literature addressing PAP adherence among youth who are transitioning from paediatric to adult care. Adapting to PAP as a daily treatment regimen can be particularly difficult during the transition period from adolescence into adulthood, during which individuals undergo physical, psychosocial and cognitive maturation while coping with new experiences, including greater accountability for their own health, separating from their paediatric care team and navigating adult healthcare [21-23]. Thus, identifying key factors related to PAP adherence among transition-age youth will provide important information for promoting adherence and ensuring effective treatment of OSA throughout adulthood. The objectives of this study were to explore facilitators and barriers for PAP use among young adults who are transitioning from paediatric to adult care and to examine if and how these factors change during the initial 12-month period in the adult healthcare system.

Methods

Study Population

This was a prospective, qualitative study using a modified grounded theory approach. This approach involved generating a

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Received: June 07, 2021 **Accepted:** June 21, 2021 **Published:** June 29, 2021

set of integrated conceptual hypotheses systematically to produce an inductive theory based on the collected data in order to provide explanations for the phenomenon being explored [24]. Young adults, aged 18 to 20 years, who were diagnosed with OSA by polysomnography and initiated on PAP therapy in a paediatric sleep facility were invited to participate in the study. Patients with a neuromuscular disorder or significant developmental delay, and those who did not speak English were excluded from the study. Semi-structured interviews were completed at two timepoints: 1) baseline visit at the time of transfer from paediatric care and 2) follow-up visit after 12 months in adult care. Prior to transfer to adult care, both paediatric and adult sleep physicians attended the baseline clinical visit, but were not present during the interview session. Demographics and anthropometrics were recorded systematically at the time of the baseline visit.

Ethics Approval

Research ethics board approval was obtained from the University Health Network, Toronto, Canada (REB #17-5136).

Study Procedures

The research team consisted of sleep medicine, adolescent medicine, and qualitative methodology experts to ensure our approach and analysis were comprehensive, reflexive, and sensitive to the unique nature of this age group. A research team, external to the participant's medical team, conducted the semi-structured interviews for 45 minutes over the phone. A semi-structured interview guide with prompts was developed to explore topics such as 1) sleep hygiene, 2) quality of information provided regarding the need for PAP, 3) feelings and experience with using PAP at home, 4) social influences, perceptions of social norms and motivational factors related to PAP use, and 5) recommendations for patients, family members and the healthcare team (supplement E1). Similar questions were asked during both baseline and follow-up visits to assess changes in responses after a 12-month period in the adult healthcare system while minimizing potential bias. Interviews were audio-recorded and transcribed verbatim for analysis. The model of "information power" guided the study team regarding sample size. This principle suggests that for those studies where the aim of the research is focused and specific, smaller samples will provide sufficient data [25].

In the case of our study, sufficient information power was achieved with a sample size of 10 participants, where new themes or information relevant to the aim of the study were no longer identified.

Analysis

A series of meetings were held with the research team (U.M., A.H., C.R.) to discuss the transcripts and develop a framework for coding. A subset of transcripts was shared and discussed with the broader research team (I.N., A.T., S.S.) to further refine the coding framework. The codes were created by a data analyst based on the issues related to adherence to PAP and two research team members (R.C., U.M.) reviewed and coded all the transcripts. Research team meetings were held to review the interpretation of the data in terms of similarities and differences from participant experiences, and consensus was achieved through ongoing discussion; thereafter, a conventional content analysis was performed by an experienced qualitative researcher to structure codes into themes related to PAP barriers and facilitators (J.H.). Memos and meeting notes were maintained throughout the interview and analysis process.

RESULTS

A total of 10 participants were recruited and completed the interviews. All 10 participants completed the first interview during the baseline clinical visit. During the 12-month follow-up visit, 8/10 (80%) participants completed the second interview. Of the 10 participants, 6 (60%) were male and 5 (50%) were attending university/college. Seven (70%) individuals were Caucasian, 2 (20%) were African-American and 1 (10%) was of Asian ethnicity. The mean age and BMI (±SD) for the study population was 18.2 ± 0.9 years and 31.5 ± 10.3 kg/m2, respectively (Table 1). The median (±IQR) duration of PAP therapy prior to the baseline visit was 2.6 (1.5-4.1) years. Table 1 outlines PAP adherence data, which was downloaded from participants' PAP devices for a 30-day period prior to the interview. Of the 8 participants with follow-up interviews at 12 months, 3 had stopped PAP. Two participants did not complete the 12-month follow-up interview as they were no longer interested in participating. Of the two participants who failed to complete the follow-up interviews, one continued to use PAP, while the second participant did not.

Five key themes emerged in the analysis related to the experiences of young adults using PAP (Table 1): 1) health education and support, 2) balancing discomfort and restfulness, 3) managing stigma with Using PAP, 4) struggling with maintenance of the PAP Machine, and 5) physical design of the PAP machine.

Health Education and Support

The importance of education regarding the use and potential effectiveness of PAP was emphasized during both baseline and 12-month follow-up visits among 8/10 (80%) participants. Participants expressed that PAP adherence may be improved through building better awareness of PAP within their social circles and the broader societal context.

"It is better to talk about this to the parents and the people interacting with the person" (Participant #2 Baseline).

"Educating the public more about the sleep apnea and about the treatment" (Participant #2 Follow-Up).

During at least one of the visits, a sense of self-efficacy and independence with using the PAP machine was described by some participants, while also expressing appreciation and need for the help that their family provided with using PAP.

"They encourage me to put it on. I like it because it motivates me to wear it and helps me to sleep" (Participant #4 Baseline).

One participant, however, found that while parental reminders were initially beneficial, after 12 months, they became frustrated with the reminders, found them unhelpful, and attributed a lack of motivation to their poor PAP use.

Table 1: Baseline Demographics.

	Participants (N=10)
Age (years)	18.2 ± 0.9
Male Sex, n (%)	6 (60)
Body Mass Index (kg/m^2)	31.5 ± 10.3
Education/Work Status	
• High School	4 (40)
• University/College	5 (50)
• Working (Full/Part-Time)	1 (10)
Data presented as mean ± SD unless otherwise indicated.	

"My dad tells me every day to use it. I like it because it's helpful" (Participant #1 Baseline).

"It's annoying because my dad telling me to use it doesn't make a difference, I don't need a reminder, I just need motivation to use it" (Participant #1 Follow-Up).

Some participants emphasized that they did not require help with using PAP at both the baseline and follow-up visits, one of whom believed that they were "very independent" (Participant #3 Baseline) and that their "family does not help with [their] PAP therapy" (Participant #3 Follow-Up).

Balancing Discomfort and Restfulness

Despite feeling discomfort with using PAP, participants expressed acceptance of PAP use due to a perceived sense of restfulness. Across both interview timepoints, PAP use was viewed as an active negotiation between discomfort and restfulness. Particularly, 5/10 (50%) shared their thoughts regarding PAP being uncomfortable, but feeling more alert and rested after using PAP. "I feel more rested and less tired when using PAP" (Participant #1 Baseline).

"It helps me sleep. PAP is okay, it can be uncomfortable sometimes but not terrible" (Participant #1 Follow-Up).

"It's slightly uncomfortable when sleeping, but during the day, I feel more energetic" (Participant #4 Baseline).

"PAP bugs me on my face so I take it off. When I do wear it, I get a good night's rest and with it I feel more energized and clear-minded the following day" (Participant #4 Follow-Up).

Participants also perceived benefits using PAP with increased investment of time and commitment.

"Just get past first 6 weeks and [they'll] love it" (Participant #6 Follow-Up).

"At the beginning, it was harder to put on but now, it's much easier" (Participant #4 Baseline).

However, one participant, who had initially explained that PAP "was hard to get used to it but it changed how I feel during the day" (Participant #5 Baseline), had stopped using PAP by the time of the 12-month follow-up.

To alleviate discomfort and increase effectiveness, the opportunity to change mask type was also found as beneficial by one participant at baseline, explaining that while "not a fan for the full-face mask, I don't mind the nasal one" (Participant #10 Baseline).

Few participants did not perceive benefits during both baseline and follow-up visits. Rather, they perceived negative outcomes with PAP use, or did not experience a difference with PAP despite having knowledge that PAP provides benefits.

"It makes me feel tired the next day" (Participant #7 Baseline).

"Don't really feel a difference when I use it, it's kind of difficult to fall asleep with it on, it just keeps me up but overall it doesn't really bother me" (Participant #9 Baseline).

"Personally, I don't feel a difference but I know it benefits me" (Participant #9 Follow-Up).

Managing Stigma with Using PAP

A feeling of embarrassment with wearing PAP in the presence of others was expressed during both visits. Common concerns also included facial markings and indentations caused by PAP mask use.

"Wearing it by yourself is fine but when people sleep with me, they think I'm Darth Vader" (Participant #2 Follow-Up).

"I feel slight embarrassment since the straps create noticeable marks on my nose. I feel kind of embarrassed to take the PAP machine with me" (Participant #3 Baseline).

"PAP doesn't affect me much in social activities but it has made sleepovers more difficult" (Participant #3 Follow-Up).

Selective disclosure of PAP use was apparent among some participants, primarily during the baseline visit. Others were also indifferent towards other individuals having knowledge of their PAP use. Some participants found that social discomfort with using PAP can be alleviated by peers who have become accustomed to their PAP use.

"Some... friends... it is fine; I don't mind" (Participant #4 Baseline).

"Not many people know.... I don't really care if they know" (Participant #9 Baseline).

"Initially, my friends found the machine slightly strange but they are pretty supportive" (Participant #3 Baseline).

However, one participant's explanation of disclosing their PAP use changed, where few peers were aware of their PAP use during the baseline visit, but by the 12-month follow-up visit, the participant claimed that their PAP use was not known by anyone.

"Few friends know, doesn't really bother anything" (Participant #1 Baseline).

"No one knows. It's irrelevant to tell people, but no one asks" (Participant #1 Follow-Up).

Further, participants perceived the PAP machine as beneficial when other individuals acknowledged that PAP relieved symptoms such as snoring, resulting in greater use of PAP. Similarly, during both visits, several participants highlighted the importance of discussing the PAP machine as helpful and enabling, especially by family, friends and healthcare professionals.

"My dad does not like to see the PAP machine because for him it feels like I have a serious medical condition. And it gives him a hospital feel" (Participant #3 Baseline).

"It's important to not treat the PAP machine with shame, just refer to it as something that will better your sleep and make you more alert" (Participant #3 Follow-Up).

"My university roommate said I was quieter when I used it, so I used it more" (Participant #5 Follow-Up).

"I would tell the doctors to recommend PAP in a way that is more inviting and pleasing to use" (Participant #4 Baseline).

Struggling with Maintenance of the PAP Machine

Maintaining the PAP machine was described as one of the main challenges during both baseline and 12-month follow-up visits. Cleaning the machine was described as difficult among 7/10 (70%) participants. Particularly, handling the water was a considerable obstacle.

"One tricky thing is bringing the water container to and from the machine" (Participant #10 Baseline).

"Cleaning the device makes it a little harder to use but I was taught how to use it so that makes it easier" (Participant #2 Baseline).

"I do the machine mostly myself. I like it when they help, but I do most of it myself besides the water" (Participant #6 Follow-Up).

"Cleaning the machine is an issue and you have to take apart the mask and put it back together. I don't have trouble really, but I wish it was easier to maintain" (Participant #2 Follow-Up).

During the follow-up visit, one participant explained that they did not have the responsibility to clean the machine. Rather, during their paediatric care, the healthcare team cleaned the machine.

"Mom always cleaned it and we did not know how to pressure check. When we were at SickKids they did it for me" (Participant #5 Follow-Up).

The high cost of PAP was also identified as a source of stress with using the machine during both visits, for which cost-effective methods would be beneficial.

"Maybe talk about cost effective methods to reduce the price of the PAP device" (Participant #3 Baseline).

"The only stress I get from PAP is cost" (Participant #3 Follow-Up).

Physical Design of PAP Machine

An additional barrier for using PAP included the physical structure of the machine as expressed by 5/10 (50%) participants. During both visits, PAP was critiqued for its lack of portability due to the large size of the machine, resulting in reduced PAP adherence. As such, several participants recommended enhanced machine portability.

"Making it wireless and more portable could be good, right now it's hard when moving around" (Participant #1 Baseline).

"Traveling with the device was a pain. It made me less tired and feel less gross when I used the machine. When traveling I just didn't bring it" (Participant #5 Follow-Up).

One participant also described difficulty with handling and adjusting the mask and straps.

"PAP is easy to use because it's not complicated to put it on. Harder part is to keep it secure over time" (Participant #1 Baseline).

"Only thing that is annoying is all the straps as it's inconvenient but overall its really easy" (Participant #1 Follow-Up).

Change in Perceptions of PAP Use Over Time

Across the baseline and the 12-month follow-up period, participants reported similar perceptions regarding facilitators and barriers for PAP use. By the 12-month follow-up, most participants continued to highlight the importance of health education and support from parents, friends and healthcare professionals, while acknowledging the stigma and embarrassment associated with PAP use, and encountering similar challenges with the design and maintenance of PAP. Moreover, participants who either described benefits or negative outcomes with PAP at baseline reported similar perspectives after 12 months. Specifically among those who stopped using PAP, 2/3 (67%) described negative experiences with PAP, including a lack of benefits and disclosing PAP use to a limited number of people, during both visits. One participant who ceased PAP use by the 12-month follow-up was asymptomatic and repeatedly removed the mask while sleeping; however, the participant reported benefits with PAP use (e.g. sense of restfulness) at both visits, while also describing portability of the PAP machine as a significant challenge at the 12-month follow-up.

Discussion

Using qualitative interviews, this is the first study identifying facilitators and barriers to PAP use among young adults transitioning from paediatric to adult healthcare. It highlights the importance of health education and support, a perceived sense of restfulness despite feeling discomfort with using PAP, managing stigma, the time and effort required to maintain the machine, and challenges experienced with its physical design. Further, young adults demonstrated stability in their experiences with PAP therapy during the transition from paediatric to adult care. Such stability reflects the importance of the first year of adult care. At our institution, young adults and their parents were oriented to the adult healthcare, completed assessments relating to health (e.g., OSA-specific outcomes, quality of life, functional status, self-care skills), individual experiences of care (e.g., satisfaction, facilitators and barriers to care) and cost measures (e.g., gaps in care), with ongoing education relating to OSA and PAP therapy [23].

In our study, machine-related barriers, such as discomfort and lack of portability, were identified during both baseline and 12-month follow-up visits. Similar results were reported by Alebraheem et al (2018) and Luyster et al (2016), where interface discomfort and the sizing/weight of the machine were found as barriers with using PAP among adolescents and older adults, respectively [19, 26]. However, half of our participants described perceiving benefits with using PAP despite experiencing discomfort at both visits. Unlike adolescents where challenges with PAP tend to outweigh benefits of symptom relief [19], young adults may demonstrate greater recognition of symptom relief, including a sense of restfulness and alertness with less daytime sleepiness. Since disease and perception of treatment effectiveness can influence coping processes and adherence [27], healthcare providers should provide anticipatory guidance regarding the challenges with PAP for those with poor adherence by offering suggestions to address potential barriers, reiterating the benefits of PAP and discussing realistic expectations to facilitate PAP use.

The availability and accessibility of health education and support was identified as an important facilitator for PAP use at baseline and follow-up. As young adulthood is marked by a period of instability with individuals adjusting to major cognitive, behavioural and psychosocial changes [21], those dependent on medical technology may be especially affected emotionally, negatively impacted socially and academically, and have low self-esteem [28]. Although some young adults may express a sense of independence and accountability for managing their health needs, health education and parental involvement may be essential during the initial stages of PAP use in order to promote sustained adherence, similar to findings reported in adolescents [19, 20]. Especially during the transition process, young adults and families face several obstacles including anxiety associated with adopting an autonomous lifestyle, separating from their paediatric healthcare team, challenges forming a relationship with their adult provider, and inadequate institutional and family support [22, 23, 29]. Thus, more comprehensive ongoing education should be offered to families regarding the consequences of OSA and the importance of PAP, strategies and tools for overcoming common challenges with PAP and troubleshooting as well as cost-effective options for PAP [19, 20].

Social acceptance and affirmation from parents, peers and healthcare professionals were also found to be essential for promoting PAP use among young adults. Peer support, in particular, is highly valued as PAP use is often deterred by a desire to conform with peers [20]. Young adults tend to be selective with disclosing their use of PAP or using PAP in the presence of others, which negatively impacts adherence. As such, sharing experiences, concerns and challenges relating to PAP may be beneficial in providing a sense of reinforcement and comfort [30]. With the increasing utilization of hospital-moderated online forums and phone applications, such platforms can be adopted and implemented in transitional healthcare programs, providing a channel for young adult PAP users to share experiences with each other while exchanging solutions and recommendations for overcoming common barriers [19].

This study has several limitations. Firstly, selection bias is a common limitation inherent with qualitative interviews. Similarly, participants may demonstrate a social desirability bias, where they provide responses that are believed to be desired by the interviewer. Nonetheless, such biases were minimized by having professionals who were not involved in their clinical care conduct interviews while using a non-judgemental approach, and reinforcing that any shared experience, feeling, or opinion is acceptable and important to understand. Lastly, we did not collect data regarding the participants' socioeconomic status, parental education levels or family structure, which may also impact participants' PAP experiences.

Conclusion

The period of young adulthood represents a unique cohort with marked heterogeneity in underlying diseases, who face additional obstacles and challenges during their transition from paediatric to adult healthcare. Thus, healthcare professionals should implement an individualized and coordinated approach. While integrating health education, family involvement and peer support to develop ongoing mechanisms for addressing barriers and facilitating PAP use in youth with OSA. Providing and investing in such support through regular follow-up assessments of PAP regimens is critical for promoting short- and long-term PAP adherence among young adults.

Disclosure Statement: The authors report no potential conflict of interests or financial disclosures related to the manuscript content.

Funding Details: This work was supported by the Physicians' Services Incorporated Foundation under Grant # 16–29.

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