The American Alliance for Healthy Sleep (AAHS), a national non-profit membership organization comprised of patients with sleep disorders, medical providers, and others interested in healthy sleep, is dedicated to improving the lives of patients with sleep disorders as well as furthering healthy sleep for all through advocacy, awareness, community, collaboration and services.

BACKGROUND

The AAHS has recognized that access to care is critical to assuring patients with sleep disorders achieve long-term treatment of their disorder and maintain the highest quality of life possible. The AAHS launched the Access to Information...Access to Care awareness campaign in September 2018 to increase awareness for the spectrum of sleep disorders and urge individuals suspecting they may have a sleep disorder to speak with a physician. The campaign also focused on the strategies and benefits of healthy sleep for all populations.

The AAHS is focused on improving access to care for individuals suffering from sleep disorders; to fully address this issue and define areas where change or improvement is needed, insight into the difficulties of accessing care is needed from all individuals, including those with a sleep disorder.

The AAHS's ultimate goal for this survey is to establish how the AAHS may improve access to care for patients with sleep disorders based upon issues identified by both sleep patients and the general public in relation to sleep care issues and information; to accomplish this, the AAHS used this survey to discover: 1) the barriers to sleep care that patients with sleep disorders, as well as the general public, face, 2) how the public/patients find information on sleep and sleep care, and 3) what resources are still needed to ensure the public understands the path to healthy sleep and patients with sleep disorders have the resources needed to both seek diagnosis and treatment and manage their disorder long-term. The survey focused on:

- Access to health/sleep care from a financial perspective, with questions on insurance, coverage for sleep services, and whether cost affects health decision-making
- Access to health/sleep care from a provider perspective, with questions on the availability of sleep services with both primary care physicians and specialists
- Access to sleep care and treatment for patients with sleep disorders
- Access to information related to health/sleep information
- Other comments regarding access to information or sleep care

This survey served to answer these questions to inform future AAHS activities, resources and advocacy related to access to care issues.

METHODOLOGY

The survey was provided online as a SurveyMonkey survey and was distributed through a number of weblinks, including ads placed on social media, a dedicated webpage on the AAHS website (www.sleepallies.org), press releases distributed to various media/sleep outlets, and emails to AAHS members and others in the sleep community. The survey was comprised of 20 questions; all participants were asked a set of 14 questions; the following were asked additional questions:
Those who indicated they had insurance were asked three additional questions. Those who indicated they did not have insurance were asked one additional question. Those who indicated they were diagnosed with a sleep disorder were asked two additional questions.

Participants were also asked an additional seven optional demographic questions. Individuals who completed the survey (including those who did not answer the demographic questions) were offered a free two-year AAHS membership ($25 value).

RESULTS

289 individuals started the survey; 225 answered the majority of questions (including those on insurance and availability of services); 204 answered all general survey questions; 199 answered all demographic questions.

The survey found that most respondents (89%) had insurance, but many were unaware of whether sleep services are covered. Cost of healthcare affected a large majority of individuals’ decision to seek care. Most respondents have a primary care or family physician that they see regularly; however, almost half indicated that their primary care physician has never asked about their sleep health. Most felt that sleep services are readily available, but comments revealed that lack of access as a result of long waiting times, physical distance or lack of knowledge of available services, as well as prohibitive costs, inhibit individuals from seeking care.

Almost half of the survey respondents have a diagnosed sleep disorder; of those the large majority (80%) use medication or equipment to manage their sleep disorder; for those that do not use medication/equipment, many were not prescribed treatment, or they felt that treatment was not effective, or, again, cost of treatment was prohibitive.

The survey found that most individuals find medical or health information from medical professionals or the internet, as well as family or friends.

CONCLUSIONS

The survey clearly demonstrates that there are a variety of issues affecting individuals’ ability to access quality sleep care including:

- Cost of care and coverage by insurance companies
- Access to providers, including both primary care providers who are educated on all sleep disorders and readily available specialists
- Limitations of currently available treatments
- Access to accurate information online or from medical professionals

RECOMMENDATIONS

To improve access to sleep services for those suffering with sleep disorders, as well as improve awareness with general populations that would benefit from increased information or access to sleep care, additional education is needed with both the public and medical providers. The results demonstrate the importance of having medical professionals who are aware of sleep disorders and address sleep health with their patients, as well as the importance of reliable, accurate sleep health information available online. Advocacy is needed for increased research into sleep disorder treatment and insurance coverage or decreased cost for sleep services.

The AAHS Board of Directors will review the survey results to determine long-term recommendations for the organization in addressing the findings of this survey to address barriers and increase access to care for sleep patients and would welcome collaboration with other organizations working towards the same goal of improving the lives of patients with sleep disorders.