

## A single qualitative study can show same findings as years of quantitative research: Obstructive sleep apnoea as an example

Howard Tandeter<sup>1</sup>, Yael Hershkovitz<sup>2</sup>, Lea Kacen<sup>2</sup>

1. Department of Family Medicine and Sial research centre for family medicine and primary care, Ben Gurion University of the Negev, Israel

2. The Spitzer Department of Social Work, Ben Gurion University of the Negev, Israel

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### RESEARCH

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#### Corresponding Author:

Howard Tandeter

Department of Family Medicine

Ben Gurion University of the Negev

POB 653, Beer Sheva 84105, Israel

Email: [howard@bgu.ac.il](mailto:howard@bgu.ac.il)

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### ABSTRACT

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#### Background

Many years of quantitative research led to our present knowledge of the symptoms and associated features (S&AF) of the obstructive sleep apnoea (OSA) syndrome.

#### Aims

1. To prove that a qualitative research approach may identify symptoms and associated features of OSA in less time/effort than that used in a quantitative approach; 2. To describe the experience of patients with OSA and the effects of the syndrome on their quality of life and that of their spouses and families (issues that quantitative methods fail to recognize).

#### Methods

We used a narrative inquiry methodology (qualitative research). The sample was selected using the “snowball sampling technique”. The sample included 10 patients with moderate to severe OSA who had good adherence to CPAP

and significant clinical improvement after treatment, and 3 of the patient’s spouses.

#### Results

The following issues were identified: A long pre-diagnosis phase of OSA (20 years in one of the patients); Characteristic S&AF of the syndrome as experienced by patients and their spouses; The need for increased awareness of both the public and the medical establishment in regards to this disorder; Premature ejaculation (not reported previously) and nightmares (non-conclusive in the literature) were identified and improved with CPAP therapy.

#### Conclusion

With the use of quantitative research methods it took decades to discover things that we found in one simple qualitative study. We therefore urge scientists to use more often these qualitative methods when looking for S&AF of diseases and syndromes.

#### Key Words

Qualitative research, obstructive sleep apnoea, symptoms

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#### What this study adds:

##### 1. What is known about this subject?

It took tens of years of quantitative research to learn about symptoms and associated features of OSA.

##### 2. What new information is offered in this study?

A simple qualitative study was able to recognize all these clinical associations in minimal time and add further insights.

##### 3. What are the implications for research, policy, or practice?

We urge scientists to use more often these qualitative methods when looking for S&AF of diseases and syndromes.

## Background

Our knowledge of obstructive sleep apnoea (OSA) has increased greatly in the last 20 years, as we recognized the epidemic proportions of this syndrome and its serious health effects. From a mean of 10 articles/year published until the end of the 20th century, publications skyrocketed to over 1000 articles/year in 2012. Some possible explanations for the exceptional growth in research in this area are the recognition of OSA's high prevalence, its serious health effects, and the development of diagnostic tools and effective therapeutic methods. Colin Sullivan's publication in the Lancet on the use of continuous positive airway pressure (CPAP) for the treatment of OSA,<sup>1</sup> paved the way to a better understanding of this syndrome. A causal relation between OSA and specific signs, symptoms, related events and pathologies can now be confirmed when these variables disappear or improve with CPAP treatment. Yet, despite the increased research attention and multiple findings, there are still many unsolved questions about OSA's diagnosis, treatment, clinical manifestations, natural history, and symptom burden.

With the use of quantitative research methods it took decades to discover the different components of this syndrome. We suggest that this puzzle could have been solved much easier and in less time by using a qualitative approach based on patient's narratives.

For this reason, we planned a study using the narrative inquiry methodology. It was designed to describe the experience and the effects on quality of life of OSA patients, their spouses, and their families.

## Method

### Research design and methods

To ascertain the subjective viewpoints of research participants we used a narrative inquiry methodology. Narrative inquiry uses interviews, narratives, family stories, and life experience, as the units of analysis to research and understand the way people create meaning in their lives as narratives.<sup>2</sup> The sample was selected using the "purposive sampling technique".<sup>3</sup> The sample included 10 patients with moderate to severe OSA who had good adherence to CPAP and significant clinical improvement after treatment, and 3 of the patients' spouses. All interviews and data analysis were facilitated by the second and third authors who are Social Workers in order to get rich narratives and strengthen trustworthiness of the research.<sup>4</sup> Theoretical Saturation has been achieved after 6

interviews when we identified redundancy of new knowledge.<sup>5</sup>

Using a "snowball sampling technique", a non-probability sampling technique where existing study subjects recruit future subjects from among their acquaintances, we recruited, the 10 subjects who presented. All those who contacted us were enrolled (nobody declined).

### Study group:

Participants were included in the study if they meet the following inclusion criteria:

1. Confirmed diagnosis of moderate to severe OSA
2. Good compliance with CPAP treatment
3. Significant clinical improvement with CPAP treatment
4. Partner of a patient consenting to participate in the study.

### Sampling:

The sample was selected using the "snowball sampling technique"<sup>6</sup> in which existing study subjects recruited future subjects from among their acquaintances. Subjects were known OSA patients treated with CPAP working at the local University and University Hospital. The PI, (H.T.) a family physician, recruited the first participants who were then asked to recruit others. The interviews were conducted within a year period, either in the patient's home or in the clinic, by the co-investigator (L.K.), a social worker. All participants were informed about the study's procedures and signed a consent form. The sample included 10 OSA patients and 3 of the patient's spouses.

### Interviews:

The semi structured interview included three sections:

(1) Initially, the participant was asked to tell the story as related to the development of OSA. This open ended question allowed the participant to choose what and how they wanted to tell us their narrative without interruption. At the end of the story, we asked them to provide a title for the story. This exercise gave the interviewee an opportunity to choose an individually perceived story-line.<sup>7</sup> (2) We then requested participants to elaborate on what they had told us in the first section, focusing their attention on what they had chosen to include and what details were missing. We encouraged them to use metaphors, proverbs and fables to illustrate their meaning. (3) Finally, we asked participants specific questions prepared in advance regarding the history of the chronologic appearance of symptoms and the diagnosis process. Socio-demographic details solicited

included age, marital status, employment, income, number of children, and health history.

#### Data analysis:

Interviews were recorded and transcribed. A twofold analysis was carried out by researchers in parallel to data gathering: Top-down analysis in which we looked for known and unknown OSA symptoms, and bottom-up analysis in which we inductively learned the influences of the OSA symptoms on the patient's and their partner's lives. For data analysis we utilized the method of Lieblich et al<sup>8</sup> which included a holistic approach and categorical analysis. Although the sample was small we evaluated saturation of findings.

#### Ethics:

Narrative inquiry data may expose intimate aspects of the participant's life.<sup>9</sup> In order to deal with the ethical dilemmas of this research we asked for the approval of the institution's Ethics Committee and ensured participant's privacy and anonymity at all stages of the research. Patients and spouses were interviewed separately and content of the interviews was not revealed to either one of the couple.

### **Results**

Here, we present the analysis of 10 interviews with OSA patients who were using CPAP at the time of the interview. The sample consisted of five physicians, one health management professor, a civil engineer and two medical secretaries. Only one interviewee was not from the health profession. Three spouses of physicians agreed to be interviewed. One participant was 80-years-old; all others were 45–58 years old. This analysis describes the experiences of 10 patients and three spouses. We use fake names in this manuscript.

Throughout the interviews we identified the following recurring themes as important within participant discourse:

1. A pre-diagnosis phase of OSA
2. Characteristic signs/symptoms of the syndrome as experienced by patients and their spouses
3. Changes that took place within the family unit after treatment with CPAP
4. The central role of the spouse in the diagnostic process of OSA
5. The need for increased awareness of both the public and the medical establishment in regards to this disorder

#### **Pre-diagnosis phase**

The time elapsed from the beginning of symptoms to the diagnosis of OSA was very long for all respondents. Seven participants mentioned reporting their symptoms to their family physician, which referred them to a sleep clinic. Four participants emphasized the significant contribution of their partner in identifying the illness. For example, Rafi, a physician in the university hospital, explained that he had suffered symptoms for ten years and that his wife diagnosed the illness almost by accident when listening to a radio program where a physician described the symptoms and side effects of OSA. The spouses whom were interviewed described the progress toward diagnosis as long and full of anxiety. They conveyed the stress of always watching the patient's fragmented and fitful sleep. Hana described this period with the following words:

*You just sit, you see a person continue to breathe, stop breathing, and their body shaking back and forth. It's really clear that it's not normal snoring. It's scary, but on the other hand you say well, there's some strange snoring but also some regular, again, there's no awareness. [Hana].*

Only after diagnosis, with the knowledge that he was suffering from a respiratory disorder, did her perspective change from looking at him as a man who snores, to a man with a severe health problem.

All the interviewees were able to report that the signs were present, but they were too involved in ignoring or denying the problem, attempting to interpret the symptoms to mean something else.

Many participants reported one event that acted as the catalyst, which finally led them to seek medical help and to the diagnosis of OSA.

Yoram, a physician, described the point that changed his life as "flipping a switch in my mind", after finding himself asleep in his car at a traffic light. This incident caused him to stop denying and acknowledge that he was suffering from a disorder. He realized that he could not disregard what was happening to him, that it was, in fact, of a question of life and death.

David, a family physician, who also suffered a car accident after falling asleep on the wheel, found that incident was not actually the final "switch" that made him look for medical help. He told the following story:

*Every evening, after a busy day at the clinic, I took the subway to leave downtown Toronto; every evening I fell asleep during the trip and woke up at the final station in the north end of the city. One evening I did not wake up, and I found myself back downtown. Then I said to myself, "That's it. It's time to go for a sleep study."*

David was diagnosed as suffering of severe OSA at age 38. Looking back at the development of his symptoms, he could recognize them from age 18 (a 20-years-gap between development of symptoms and diagnosis).

Yair, a specialist in medical management, realized one day that he missed a sentence during a lecture. His assistant told him that it looked as if he had fallen asleep for a moment.

Yona, a medical secretary, said that she dreamt horrible nightmares and woke up very tired every morning, until she finally decided to tell her family physician.

#### **Characteristic signs/symptoms experienced by patients and their spouses**

All respondents reported a subset of symptoms that dominated, and eventually disrupted their lives. Common symptoms were: constant fatigue, excessive daytime sleepiness, falling asleep while driving, loud snoring and disrupted breathing during sleep. Other symptoms that have been less or not explored at all in quantitative analyses were nocturia, sexual dysfunction and premature ejaculation, memory impairment, frequent nightmares and mood disturbances.

#### Constant Fatigue:

All of the participants complained of severe fatigue and excessive daytime sleepiness on a regular basis. Fatigue, in fact, determined and managed the patient's lives both at work and at home. For example, Yoram described how the fatigue had affected the quality of his relationship with his children:

*[Yoram] I have two children who are still the age where they want to run around and play with you, but you do not have the energy to do anything... you do not have it, you're tired, so forget about it. 'Constantly tired, Dad, you're constantly tired,' it's just a terrible feeling.*

Their constant fatigue led to the additional symptoms of falling asleep during the day, and, specifically, falling asleep while driving.

#### Excessive Daytime Sleepiness:

The patients' chronic fatigue/sleepiness created a constant struggle and effort to stay awake and function, mainly at work.

David, who is a physician, described his struggle to stay awake as an exhausting challenge and told an event that happened during work:

*[David] Once I fell asleep as I was taking someone's blood pressure. Try to imagine a situation for the patient as I'm rolling up the man's shirt, inflating the cuff, and suddenly I fall asleep; I wake up and see the pressure up to two hundred and something and the guy's turning blue!*

#### Falling Asleep While Driving:

Some of the respondents (7) referred to their struggles not to fall asleep at the wheel and their supreme effort to stay alert. Even their spouses referred to this with great anxiety. Participants described their stress and anxiety while driving and the measures they took to stay awake, from listening to music, to slapping and pinching themselves. David described that he had taught himself to fall asleep only while stopping at a red light. However, this habit failed over time, and on one of his trips to work, he fell asleep while driving and had an accident within a split second.

*[David] So one day in [nineteen] ninety-three I was on my way to work. It must have been about ten to five because that's the time that Avshalom Kor begins his program on the Hebrew language in the radio, and he has this music in the beginning. I remember the music exactly (hums the tune) and that's when I fell asleep. The road was one-way, two lanes. My car dropped to the other side of the road. I woke up with my car running through trees, like, rushing toward me. And then I hit a tree and that's where I stopped. In fact, there were no serious injuries... but the car was totally destroyed.*

Hana described how she used to watch her husband when he was driving, since she was afraid he will fell asleep. Most of the time she preferred that she drive instead of her husband.

#### Sleep Fragmentation and Disrupted Breathing:

This symptom came up frequently, sleep that was constantly fragmented and fraught with intense snoring. It was sleep characterized by multiple awakenings during the night, tossing and turning, extremely loud snoring and

breaks in breathing. Henia described her husband's sleeping experience as though it were a battlefield:

[Henia] *I guess it is very unpleasant to wake up and feel like you just spent eight hours in a kind of battlefield. Yes, I can tell you that the bed sheets were always out of place, because he was always tossing and turning.*

#### Nocturia:

Most respondents (9) mentioned nocturia (awaking several times a night to urinate) as a frequent symptom. David, Yair, Rafi and Sara talked about the need to urinate frequently during the night. This symptom disappeared after the initiation of CPAP therapy.

#### Sexual dysfunction:

Four participants stressed the connection between their illness and their sexual behaviour. Yoram explained:

*Even for sexual relations with your wife, you don't have any desire, none, this almost leads to impotence because you do not sleep at all and then that of course causes other things and then you have no desire so you keep avoiding it... [Yoram]*

David interpreted his problem of premature ejaculation as a symptom of the syndrome as it disappeared with the use of CPAP.

#### Dreams and nightmares:

Two of the respondents mentioned nightmares that disappeared when they started using CPAP, so they included nightmares as one of the symptoms of OSA. Zila, recounted:

*Among other things, I forgot to say that before using the device I had dreams, nightmares, and I always told my daughter that I have dreams that frighten me. I do not know what it is, but I was afraid to go to sleep at night because of these dreams... I had a lot of dreams and now I don't, it stopped, stopped altogether, I had nightmares that stopped after treatment. [Zila, age 80]*

Rafi also stated that all his nightmares disappeared immediately after he began CPAP treatment.

#### Memory Impairment:

Some of the participants described memory problems which improved after treatment with CPAP. Like Zila description:

*I started to have problems with memory then, I would forget things, forget to turn off the gas, forget to put something in the oven and then I would say maybe it's because of ageing. Then it got worse, so much worse, that I could not recognize people; there were people who worked with me and I didn't remember their names. [Zila]*

#### Changes in Quality of Life and mood disturbance after initiation of CPAP:

All patients, without exception, reported significant improvement in their quality of life and sleep after treatment with CPAP. Everyone reported that they now had uninterrupted night's sleep, vitality and alertness during the day, noticeable to not only themselves but their families and friends as well.

Yoram was so impressed by the intensity of the change in him that he named it "The life altering moment". He went on to explain:

*If you would ask me what has made the biggest change in my life, I would say that it's the day I started using the CPAP. Not marriage, or the birth of my first child, of course these events are important and not to be underestimated, but if you would ask me what was a life-changing move, I feel a little uncomfortable saying this, but for me, starting with the CPAP was more significant to me than when my first child was born. I think the day I got the CPAP it was like my life started over again. So much so, I have no doubt. That was the day when my life changed. No doubt. No doubt, it was that important issue in my life [Yoram].*

Yoram reported that after starting CPAP, his snoring intensity and breathing disruptions decreased and his wife was also able to sleep. He was able to work two jobs and stay out late, the fatigue he felt was normal and his sexual functioning returned. Long trips and the danger of falling asleep during the drive were no longer a threat, and his wife became relaxed and allowed herself to take a nap while he drove. He stopped having to wake up frequently at night to urinate, and he was able to wake up early and go to the gym. In general, he felt calm and not anxious, as he had prior to CPAP treatment.

Not only did the length of sleep increase to an average of six hours of continuous sleep, but also the quality of sleep improved. David remarked:



*Now I go to sleep lying on my side and wake up in the same position. This is impressive. The fact that using CPAP stopped my tossing and turning makes me understand that this was also a characteristic of my problem (OSA).*

David had suffered for many years from depression and mood swings. He had taken medication and received psychological and psychiatric treatment; these symptoms have disappeared since he began the CPAP therapy.

*Well, I connect the issue with mood swings. Hmm. And I want to believe it has to do with it [use of CPAP with decline in psychiatric medication usage], but I cannot say it's only because of that, the fact that I might be okay years without medication... that's saying something.*

Many respondents gave titles to their stories, highlighting the significance of the CPAP mask as life-saving. (Sara) "Life-altering," "(Zila) Resurrection of the Dead", "(Yoram) "You can live well with sleep apnoea" (Rafi) "Life and Death in the hands of the mask" and a spouse (Hana) who said her husband was "resurrected". All titles relate to life as opposed to death.

#### Implications of the mask on patient and spousal quality of life:

The fact that the device was given such names like "resurrection" and "life-altering" highlights the significant impact that the mask had on the patient, the family and even the public. In addition to the increased well-being that CPAP provided to the patient, marital communication and sexual functioning both improved. Henia, a patient's wife, spoke of the dramatic change that occurred in her husband's life and in the lives of those around him:

*Indeed his life changed, in part, also my life; we could finally sleep together without anger because I would always complain about his snoring. His life has changed, he really feels great with the CPAP and I do too because I can sleep.*

*I can only smile today. It is before and after. Life looks different from before CPAP to after. It's just a different life.*

Improvements in sexual function were also reported. David stated:

*Sexually, before treatment. Um. It was a long time. Maybe something like two years, of premature*

*ejaculation. That disappeared, completely. Completely, after treatment.*

#### **The role of the spouse in the diagnostic process**

The stories of the spouses of patients with sleep apnoea tell of the intimate experience of living together with someone with this condition, and their constant need to manage the complex aspects of the experience. The women's main experience was one of anxiety and fear; of what dangers may happen to her husband both during the day as well as during sleep.

Henia described her life of living with someone with this condition, as continuous anxiety, suffering from her fitful sleep, the stress resulting from the threat that her husband may stop breathing, and chronic fatigue and disturbed sleep because of her husband's snoring. In fact, the spouse may experience and feel things that the sufferer is unaware of, because she/he is asleep when they happen.

*I realized that I was waking up more and more because of his snoring. He would stop breathing and snore and snore and suddenly it stops, and I would move him and zzzz (makes a snoring noise) and he would wake up again and then I would make him aware of what had happened. [Henia]*

She feels that she is the "responsible adult" of the two, not daring to sleep during his driving, but must be on guard all the time. It made her angry and frustrated.

Over time, she realized that it was not up to him, and that he was not disrupting her sleep on purpose.

Although only three spouses (all of them were wives of physicians) agreed to participate in the study, we were able to learn a great deal from their interviews, that the partner's role is very significant both in identifying the condition and in follow-up post diagnosis, identifying trends in patient adaptation of the CPAP. This importance is emphasized in the title that Rafi gave to his story and dedicated it to his wife; "Listen to your wife" is the real title according to him, because it was his wife, neither he nor his doctors, who diagnosed his apnoea. Rafi gives this tip to other patients, telling them to listen to their wives. "It's very important. She knows the truth." "Even when Rafi was using the mask at night, his wife still monitored his sleep. When she noticed that he was having breathing disruptions she told him to begin using the CPAP again.

### Public and Medical Awareness

All of the participants were sure that people are not aware of the existence of OSA, and presumably, many who have the condition do not know that there is a solution to their problem. The respondents argued that until the seemingly random diagnosis of their condition, the couple and their family lived in a kind of bubble of ignorance and lack of awareness about the condition and its symptoms. Even physicians, according to the interviewees, lacked awareness and knowledge about sleep apnoea

Finally, all respondents believed that if they had been diagnosed at an earlier stage, much suffering and serious consequences could have been avoided, especially falling asleep at the wheel.

### Discussion

The present study shows that by using a simple qualitative method, we were able to identify the signs, symptoms, and related effects of a medical entity like OSA. This was done in a single study, interviewing a small number of diagnosed patients, and allowed us to recognize known features of this syndrome together with some new insights (not found in the literature).

As in a recently published study,<sup>10</sup> by using qualitative methods we were able to show the patients' and their partners' perspective of the disease and of the use of CPAP (a couple oriented approach).

In contrast to the simplicity of this qualitative method, research in OSA related to associated symptoms has been based in quantitative methods and it took many years to arrive to the understanding that could have been achieved by a simple qualitative method.

What we call today OSA was referred by Charles Sidney Burwell in 1956 as “the Pickwickian Syndrome”, based on the character of Joe, the “fat boy” who constantly falls asleep, in Charles Dickens’ book, *The Posthumous Papers of the Pickwick Club*.<sup>11</sup> Since then, until 2015, more than 7,000 articles have been cited in PubMed under the search “Sleep Apnoea Syndromes”[Mesh] (Limited to All Adults: 19+ years). During those 59 years, publications showed associations between OSA and certain symptoms and events. Still, the complete picture of OSA is being built by the summation of findings slowly recognized as a part of this syndrome. For example, it took until 1977 to find a relation between OSA and depression,<sup>12</sup> until 1987 with road accidents<sup>13</sup> and until 1997 with nocturia.<sup>14,15</sup>

Using qualitative methodology, we were able to identify the following characteristics of OSA: constant fatigue, excessive daytime sleepiness, falling asleep while driving that led to traffic accidents, loud snoring, disrupted breathing during sleep, multiple awakenings with nocturia, sexual dysfunction (including premature ejaculation), memory impairment, frequent nightmares and mood disturbances. These are the same symptoms and associations found in the past in the literature.<sup>16-29</sup> We also identified issues related to quality of life demonstrating that this syndrome not only affects the patient but also the spouse and the rest of the family. Patients emphasized the significant contribution of their partner in identifying the illness and the lack of recognition of the problem by the medical system. The time elapsed from the beginning of symptoms to the diagnosis of OSA was very long for all respondents in one case 10 years and in another 20. Disappearance of symptoms and associated events after treatment with CPAP demonstrate causality and was impressive for many symptoms (not simply improving sleepiness).

CPAP is an effective treatment of OSA that may be limited by poor adherence/high rejection rates<sup>30</sup> that varies between ethnic groups.<sup>31</sup>

Improvement of blood pressure, memory, nightmares, depression, nocturia, sexual dysfunction and premature ejaculation, and alertness during driving (that prevent motor vehicle accidents) are incredibly graphic, showing association with OSA and improvement with CPAP therapy. At least two of our findings were not reported previously or were non-conclusive in the literature: nightmares and premature ejaculation. Schredl in 2006 found that sleep apnoea syndrome severity did not correlate substantially with nightmare frequency;<sup>32</sup> we found no research addressing premature ejaculation. We suggest a possible causal relationship between the syndrome and these two symptoms that should be tested by further research.

### Conclusion

In summary, we showed that by using qualitative research methods one can define symptoms and events associated with a syndrome (in this case OSA), with less effort (less time and number of patients needed to arrive to the same conclusion). Obviously, qualitative methods can't replace quantitative ones in the discovery of etiology, pathophysiology and quantitative appreciation of data. But the narrative part of most diseases is seldom told and not properly studied in general. Therefore we suggest the use of both methodologies in order to get a more complete picture while researching disease. We also showed that after years

of quantitative research, this simple qualitative method was able to detect a new possibly associated symptom of OSA like premature ejaculation (not previously found in the literature) that, while disappearing after CPAP therapy, showed a possible causal relationship. Defining the long period elapsed from beginning of the syndrome until its definitive (medical) diagnosis was also easier to understand using narratives<sup>29</sup> and other qualitative techniques. One possible limitation of this study is the small number of women included (OSA may behave differently among men and women).

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## **ETHICS COMMITTEE APPROVAL**

The study was approved by the Helsinki Committee of the Soroka Medical Center (Approval # 10176).

## **PEER REVIEW**

Not commissioned. Externally peer reviewed.

## **CONFLICTS OF INTEREST**

The authors declare that they have no competing interests.

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