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Sleepless nights and sleepy days - a qualitative study exploring the experiences of patients with chronic heart failure and newly verified sleep disordered breathing

Authors:
M Gullvag¹, KH Gjeilo¹, N Falun², TM Norekval², R Mo¹, A Brostrom³, ¹St Olavs Hospital, Department of Cardiology - Trondheim - Norway, ²Haukeland University Hospital, Department of Heart Disease - Bergen - Norway, ³School of Health Sciences - Jonkoping - Sweden,

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Background: Sleep disordered breathing (SDB) is a pathologic, nocturnal breathing pattern present in at least 50% of patients with chronic heart failure (CHF). SDB is categorized as central or obstructive, and both are associated with worsened prognosis, affects physical and mental capacity and influences quality of life. Knowledge of how SDB is experienced by patients with CHF is limited, and has not previously been addressed in qualitative studies.

Purpose: The aim of this study was to explore the experiences of patients with CHF and newly verified and untreated SDB.

Methods: The study used an inductive descriptive design, collecting data through semi-structured interviews analysed with qualitative content analysis. Twelve participants (9 men and 3 women, mean age 62 (range 41-80)) diagnosed with CHF and a newly objectively verified (i.e., by polygraphy) SDB (6 obstructive, 5 central and 1 mixed) were strategically selected from heart failure outpatient clinics at two Norwegian university hospitals.

Results: The participants’ descriptions fell into five categories:
Sleep disruption causing troublesome nights: Disruptive nights with sleep onset latency, frequent arousals and early morning awakenings caused frustration and a longing for a night of uninterrupted sleep.

Daily life challenges due to daytime sleepiness: Excessive tiredness led to a need for sleep during the day, overactivity to avoid tiredness, extra care when operating a vehicle, and a feeling that concentration and memory were impaired.

Involvement of a partner: The partners were described as being more affected by the sleep apnea than the participants, and it was apparent that the apneas caused fear and worry for the partners.

Self-care strategies: Use of a dark, quiet and well-ventilated bedroom and avoidance of actions that could impair sleep; i.e. daytime naps, coffee, or heavy meals before bedtime were described. Some participants discussed their sleep problems with their GP, but experienced that the problems were not examined in detail and sleep medication was a common, however unwanted, solution.

Awareness of SDB: Some participants were relieved as the finding of the SDB finally gave an explanation to their problems, while others were surprised by the result.

Conclusion: Patients with CHF and SDB experienced that sleep disturbances influenced their daily life. Raised awareness on sleep is needed for these patients. Possible underlying causes for disruptive sleep, such as SDB, should be identified in order to establish proper treatment strategies and follow-up care for the individual. Future studies on both medical and nursing strategies to improve sleep for patients with CHF and SDB are needed, and intervention studies should be prioritized.