

Experiences of older adult with chronic pulmonary disease using longterm home oxygen therapy in romantic and sexual relationships

- Giovanna Hass Bueno¹ ID
- Claudinei José Gomes Campos¹ (D)
 - Egberto Ribeiro Turato²
 - Ilma Aparecida Paschoal²
 - Luiz Cláudio Martins¹

Abstract

Objective: To understand the meanings attributed by older adult with Chronic Obstructive Pulmonary Disease (COPD) using the Long-Term Home Oxygen Therapy (LTOT) regarding romantic relationships and sexual practice. Method: Qualitative study in which seven semi-structured interviews were carried out with patients with a confirmed diagnosis of COPD and using LTOT, treated in an outpatient service. The content analysis technique was applied with the support of the WebQDA2.0 software license. COREQ criteria were used to report method and outcome. Results: Two categories emerged: 1- Destabilization in the romantic relationship and in the sexual life of the LTOT user: : revealed that therapy causes relationship breakup, change of partner after prescription of the LTOT or even the idea of looking for an extramarital person; 2- Experience and meanings of COPD and oxygen therapy during sexual intercourse: suffering with physiological problems, how much the patient feels short of breath to have sexual intercourse and the impact of this on performance and frequency, reducing these moments with the partner. Conclusion: The perception of elderly people with COPD using LTOT indicates that oxygen therapy had an impact on sexual practice and romantic relationships. Having good quality in relationships and sexual practice is a fundamental condition for health promotion.

Keywords: Qualitative Research. Oxygen Inhalation Therapy. Aged. COPD. Sexuality.

Research funding: Coordenação de Aperfeiçoamento de Pessoal de Nível Superior - Brasil (CAPES) - Código de Financiamento 001.

The authors declare no conflict in the conception of this study.

Correspondence Giovanna Hass Bueno giovannahassbueno@gmail.com

Universidade Estadual de Campinas, Faculdade de Ciências Médicas, Programa de Pós-Graduação em Gerontologia. Campinas, SP, Brasil.

Universidade Estadual de Campinas, Faculdade de Ciências Médicas, Programa de Pós-Graduação em Clínica Médica. Campinas, SP, Brasil.

INTRODUCTION

Aging, in the biological condition, is associated with molecular and cellular damage¹. These losses can increase the risk of contracting various diseases and, frequently, Chronic Noncommunicable Diseases (NCDs)² occur. One of the common NCDs that affects the older population is Chronic Obstructive Pulmonary Disease (COPD), which has its highest prevalence in people over 40 years of age³ and worsens over time.

COPD is an inflammatory disease of the lungs, resulting from pathological changes in the peripheral airways and lung parenchyma, represented by airflow limitation³. When the patient is diagnosed in a severe stage of COPD, Long-term Home Oxygen Therapy (LTOT) is prescribed³.

LTOT results in clinical improvement and increased survival of the user, but also entails physical and psychosocial limitations², highlighting changes in love relationships and sexual practice. Having a good sexual quality is a fundamental condition to promote health and quality of life⁴, because aging does not mean becoming asexual.

In today's society, sexual intercourse in older people is still seen with prejudice, taboo and myths, both by the older people and by the population of other age groups⁵. Even if older people have a decrease in sexual practice or even if they have negative stereotypes of their sexuality, the theme should be addressed in health services and guidelines, building new concepts about the sexual practice of the older population⁶.

It is necessary not only to treat the patient's chronic disease, but to have a holistic view of them. Knowledge of these changes is essential to offer humanized care to the patient and improve patients' adherence to treatment, without having to choose between LTOT and a romantic relationship, providing them with quality of life.

This study is justified by the search for knowledge about the perception of strengths and challenges in the use of oxygen therapy associated with a loving relationship and sexual practice. This understanding is important, as it can help health professionals to better

manage the difficulties of adherence to treatment, improve the assistance provided, so that they can assist users in the management of this treatment, creating strategies in which health guidelines do not reach. This issue should be addressed in health services and guidelines, as there is a lack of material in the literature on the subject to support professionals.

The objective of this study is to understand the meanings attributed by the older person with COPD using the LTOT regarding the love relationship and sexual practice.

METHOD

This is a qualitative study, approved by the Research Ethics Committee of the Faculty of Medical Sciences/UNICAMP, under opinion number 2658702.

Study participants are patients treated at the Pulmonology outpatient clinic of the Hospital das Clínicas da UNICAMP (HC/UNICAMP), with a diagnosis of COPD, according to the *Global Initiative for Chronic Obstructive Lung Disease* (GOLD) guidelines³. The inclusion criteria in the research were: being on long-term home oxygen therapy for \geq one year; being aged \geq 60 years and be able to communicate verbally, oriented and aware.

The sample closure happened by theoretical saturation. This means that the inclusion of new participants was suspended because the data obtained showed repetition and redundancy, failing to contribute significantly to the research⁷. The study included 7 patients, from P1 to P7.

Before starting data collection, the researcher and student observed and interacted with the local health team and patients during the 1st half of 2019. The purpose of this interaction would be the setting, a technique used to avoid bias in data collection, in addition to understanding how the service works and being able to adapt before collection.

Data collection took place in the 2nd half of 2019 and the beginning of the 1st half of 2020. Due to COVID-19, the interviews were suspended in certain periods, but this did not interfere with the study findings.

The participants were informed that the interviews would be recorded and subsequently analyzed and, upon agreeing, they signed the Free and Informed Consent Form.

Semi-structured interviews were carried out before the appointment at the outpatient clinic, in a reserved environment and alone with the researcher, with the following guiding questions: "What feelings or impressions do you have about your body image?", "How are you in relation to affection?", "How do you feel pleasure?", "What does it mean for you to use oxygen during sexual activity?", "Talk about the quality of your sexual relationship after you started using LTOT?"

To characterize the population, a questionnaire originated by the study was carried out, with sociodemographic data (age, gender, occupation, religion, education, marital status), and history of LTOT use (number of hours/day and how long it has been in use of O₂, flow, number of hospitalizations and attendance at emergency services due to lung problems in the last 12 months) and sexual behavior (active sex life, steady partner, stopped having intercourse after LTOT, frequency of sex in the week before and after LTOT).

A WebQDA2.0® Software license was used, which served as a support tool for data organization and analysis8. A word cloud was also built, which is a tool that shows the most used words during the participants' speeches.

The methodological technique used for data analysis was Content Analysis by Lawrence Bardin⁹,

which is divided into three stages, pre-analysis, material exploration and treatment of the obtained results and interpretation9. Data validation was carried out by peers and judges, specialists in this methodology.

For the analysis of the results, two theoretical references were used, Medical Psychology¹⁰, which approaches the patient in a holistic way, having biopsychosocial relationships and with the inserted environment and Psychosomatic Medicine^{11,12}, study of mind and body relationships. The *Consolidated criteria for reporting qualitative research* (COREQ) were used to report the method and results¹³.

RESULTS

The sociodemographic data can be found in Table 1. The variables related to the use of oxygen (O_2) are the time of use of O_2 , which was between 1 and 13 years (mean of 3.5 years), and the daily hours of use, which were between 18h and 24h (mean of 23 hours). As for the number of hospitalizations and attendance at the emergency room in the 12 months prior to the interview, three patients were hospitalized and five sought the emergency room due to lung problems².

As for the elements related to sexual behavior: four individuals have an active sex life and have steady partners, two patients stopped having sexual intercourse with their partner after the LTOT was prescribed and four patients changed the frequency of sexual intercourse, before oxygen therapy they had more moments of intimacy with the partner.

Table 1. Biosociodemographic characteristics of the studied sample, Campinas, São Paulo, 2020²

SOCIODEMOGRAPHIC DATA						
Patient	Sex	Age (Years)	Schooling	Former occupation	Religion	Marital status
P1	F	60	Illiterate	Home maker	Catholic	Has lived with the partner
P2	F	63	High school	Bath and groom pet shop	Catholic	Has lived with the partner
P3	M	73	Primary	Worked with cellulose	Atheist	Lives with the partner
P4	M	63	Primary	Construction	Catholic	Lives with the partner
P5	M	76	Primary	Truck driver	Catholic	Lives with the partner
P6	F	60	Technical	Administration at city hall	Catholic	Has lived with the partner
P7	M	73	Basic	Mechanic	Catholic	Lives with the partner

In the qualitative analysis, two categories emerged from the interviews: 1- Destabilization in the love relationship and in the sexual life of the LTOT user revealed that the therapy causes disturbance in relationships; 2- Experience and meanings of COPD and oxygen therapy during sexual intercourse.

In the first category, patients reported changing partners after the LTOT was prescribed or even the idea of looking for an extramarital person, as in the cases of P1 and P6.

"I even told him, go and look for someone on the street for you. He said "why if I have you?" (P1).

"When I started using oxygen, I was with my partner. After a year, I saw that things had changed too much, I asked and he said he had found another partner, that he would live with her and left. After 35 years of being married to him. I was already feeling very bad, I got worse. I think that when he saw me with oxygen, he saw that our relationship was over, he didn't wait to see how I adapted. He already got another woman. Oxygen was the end of our relationship." (P6).

It also highlights the concern of family members with the therapy, preventing P2 from being alone with his partner.

"I stopped having sex because of myself. My son started to spend more time with me, I decided to pay more attention to my son" (P2).

In the second category, suffering with physiological issues is reported, how much the patient feels short of breath to have sexual intercourse and the impact of this on performance and frequency, reducing these moments with the partner, as in the case of these patients:

"I don't have sex with my partner because of the shortness of breath. I felt very bad, I felt like I was going to die. It's once a month, and far off, once in a while." (P1).

"I felt a lot of shortness of breath in the relationship. So, in order not to look bad, I preferred to go out with my head held high and dedicate myself to my health" (P2).

"Because by the time I finish having sex, I think I'm going to die of shortness of breath. I have much less sex, before putting on oxygen it was every week, now with oxygen every 3 to 4 weeks to have sex. I even keep thinking, in the past I had nothing, right? No problem, I could. Now I can't, I'm so tired. Before, I was much better than with oxygen" (P3).

"This is difficult, I can't have sex anymore, no. I have sex very little, once a week, in the past it was 2 to 3 times a week, that burdens our bodies too, right?" (P5).

"After the oxygen we had no more. He didn't look for me anymore" (P6).

P1 and P5 also refer to the sensations and feelings that arise in this circumstance, such as fear of having intercourse and feeling sick, shame in using oxygen during the act and respect for the partner, because of his moment and the disease.

"I don't have sex with my partner because of the shortness of breath, and also because I feel ashamed, right? Ah, this thing on me, right? It's ugly. I feel ashamed. I have sex with him, but he doesn't force me, it's when I want to" (P1).

"She says she doesn't look for me anymore to have sex because she's afraid I'll feel sick, run out of air" (P5).

This category also presents the users' attitudes towards the therapy, P4 using the LTOT during sex and P3 and P7 not using it or using it differently from what was prescribed by the doctor.

"I don't use oxygen to have sex, I don't think you need it, right? But then you have a lot of shortness of breath, it hits you! I feel very bad afterwards, I'm too tired. Because by the time I finish, I think I'm going to die. I seem to be looking for air, it's a dang problem. Then I put on the oxygen, after about 2 to 3 minutes I get better. I don't put it on because that hose gets in the way of having sex" (P3).

"Having sex makes me feel short of breath. I didn't use it to have sex, I felt sick and had to be hospitalized. I stayed 10, 15 days there. To have

sex, it's with him, because any effort, it goes down and I feel short of breath. But it recovers soon, because I'm using oxygen" (P4).

"I sometimes feel that shortness of breath when I'm having sex, but I think it's normal, right? Everyone feels that shortness of breath, it seems that the air is going to run out, we take a deep breath. I don't use oxygen, I can have sex without it. This is not effort, I can do it. You can have sex without (P7).

The study also originated the Word Cloud, presenting the most frequent terms used by the participants during the interview (Figure 1).

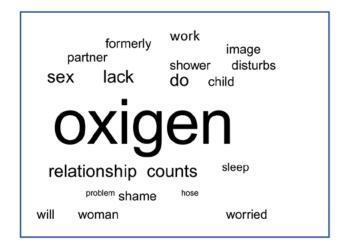


Figure 1. 20 most referenced words in the speeches of the studied sample, Campinas, São Paulo, 2020².

DISCUSSION

This study clearly indicated that oxygen is at the center of these participants' lives. It demonstrates alterations in love and sexual relationships, in routine activities, and in the representation of the body in the mind. Participants use the word formerly, as if the use of LTOT was the mark of a new life. The word lack is also used a lot and shows how much they see LTOT as deprivation.

Given these results, it is essential to involve the spouse in the treatment, as the partner maintains intimate relationships with the patient, which involve feelings and physiological needs¹⁴. It is necessary to have holistic care for this patient, to prevent the feeling of intimacy and friendship with the partner from diminishing or even disappearing, as well as the identity of marital union.

Living with an older patient with COPD using LTOT is not easy, and as the degree of dependence

increases, the greater the dedication, negatively impacting several dimensions of the spouse's life¹⁵, feeling forced to live a life different from the one planned, with the possibility of breaking up the marriage¹⁵, as was the case with P6, who was unable to sustain all the changes and all the feelings.

The user going through situations of choosing between therapy and romantic involvement may not adhere to the treatment as prescribed by the doctor. The resistance to using the LTOT often triggers marital tensions, the lack of patient and caregiver communication, isolating the patient from the spouse^{16,17}, also suffering changes in the couple's intimate moments, leading to changes in the individual's libido and sexuality.

The sexual function of the older people with COPD is more affected than in healthy older people¹⁸. There is a greater loss of libido and erectile dysfunction is more pronounced, due to debilitating systemic inflammation in terms of functional limitations,

hormonal imbalance, chronic hypoxia, intolerance to efforts and the use of medications^{19–21}. The relationship between erectile dysfunction and COPD is recent, since the first data published on the subject were in 1982 and, since then, there have been few studies^{19,21,22}.

Some patients in this study reported how much the disease had repercussions on sexual intercourse, both due to shortness of breath and fear of feeling sick during intimate moments. There are changes in sexual relations or total abstinence due to patients' physiological and emotional symptoms^{15,23}.

The individual needs to feel desired, take pleasure in their own body, to have their well-being²⁴. Changes in the image are not formed only by neurological information, but also by psychic and libidinal issues²⁵. In the case of P6, she suffers from the change in her body figure, decreasing libido, feeling unwanted, losing her sexuality. With all this process, the patient represents with signs of mourning, which can trigger melancholy and various feelings of suffering²⁴.

It is necessary to understand this patient in psychological distress to provide comprehensive care, as we cannot rule out sexual issues and treat only COPD. The idea that there is no sex life in old age and that problems are only linked to age is unacceptable. It is necessary to consider the whole scenario in which the person is inserted. Interventions are necessary to support spouses and are essential to promote a better adjustment to the disease and prevent couples from drifting apart¹⁵. Including the family in the treatment is essential and benefits everyone¹⁷.

Studies show that the health team feels embarrassed and ashamed to address this issue with patients^{26,27}, but it is necessary to improve adherence to treatment and not impact the quality of life of these older people, as sexual activity is possible and beneficial for health. This subject is little discussed between the health team and the patient, and professionals need to be aware that these patients need sexual assessment¹⁹. COPD guidelines need to delve deeper into correlating the disease with sexual activity and include a sex counseling document for these patients and their spouses¹⁹.

The limitation of the study was the difficulty of accessing the participants, as most of them used

public transport to go to the consultations, having a time to arrive and leave.

CONCLUSION

In light of the study's findings, the perception of older people with COPD using LTOT indicates that oxygen therapy had an impact on sexual practice and romantic relationships. Patients had their lives changed, with changes in habits, physiological changes and family reorganization.

Faced with such results, the health team needs to help the family and the patients to reorganize themselves in the new routine, meeting the demands and encouraging them to continue taking care of themselves, without depriving the patient and the spouse. Only then can they be partners in the treatment, avoiding turmoil, minimizing the suffering caused by the process of becoming ill in the whole family, bringing benefits to all.

Having good quality relationships and sexual practice is a fundamental condition for promoting health. Aging does not mean becoming asexual. The issue should be addressed in health services and guidelines, using health education, building new concepts about the sexual practice of the older population and love relationships.

AUTHOR CONTRIBUTIONS

- Giovanna Hass Bueno Administration of Project, Writing – First draft, Writing – Review and Editing
- Claudinei José Gomes Campos Formal Analysis, Methodology and Conceptualization
- Egberto Ribeiro Turato Methodology and Validation
- Ilma Aparecida Paschoal Formal Analysis
- Luiz Cláudio Martins Formal Analysis, Data Curation, Securing of Funding, Resources and Supervision

Edited by: Maria Luiza Diniz de Sousa Lopes

REFERENCES

- Organização Mundial da Saúde. Relatório mundial de envelhecimento e saúde.https://sbgg. org.br//wp-content/uploads/2015/10/OMS-ENVELHECIMENTO-2015-port.pdf. Published 2015.
- Bueno GH, Campos CJG, Turato ER, et al.
 Experiences in elderly people with chronic obstructive pulmonary disease in relation to the use of long-term home oxygen therapy: a qualitative study about feelings attributed to therapy. BMC Pulmonary Medicine. 2022;22(1):96. doi:10.1186/s12890-022-01891-6
- Global Initiative for Chronic Obstructive Lung
 Disease (GOLD). Global strategy for the diagnosis,
 management, and prevention of chronic obstructive
 pulmonary disease (2023 report). Global Initiative
 for Chronic Obstructive Lung Disease GOLD.
 Accessed April 25, 2023. https://goldcopd.org/2023-gold-report-2/
- Souza Júnior EV de, Silva Filho BF da, Silva C dos S, et al. Sexualidade como fator associado à qualidade de vida da pessoa idosa. Esc Anna Nery. 2022;27:e20220228. doi:10.1590/2177-9465-EAN-2022-0228pt
- de Souza Júnior EV, Fernandes da Silva Filho B, Pires Cruz D, et al. Efeitos da Sexualidade na Funcionalidade Familiar e na Qualidade de Vida de Pessoas Idosas: Estudo Transversal. Revista Cuidarte. 2022;13(1). doi:10.15649/cuidarte.2296
- Souza Júnior EV de, Cruz DP, Siqueira LR, et al. Efeitos da sexualidade nos transtornos mentais comuns e na qualidade de vida de pessoas idosas. Cogitare Enferm. 2022;27:e83253. doi:10.5380/ce.v27i0.83253
- Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. Qual Quant. 2018;52(4):1893-1907. doi:10.1007/s11135-017-0574-8
- 8. WebQDA Qualitative Data Analysis Software. webQDA Qualitative Data Analysis Software. Accessed April 25, 2023. https://www.webqda.net
- 9. Bardin L. Análise de Conteúdo. São Paulo: Edições 70.; 2011.
- Marco MA de, Abud CC, Lucchese AC, Zimmermann VB. Psicologia Médica: Abordagem Integral Do Processo Saúde Doença. 1a Ed. Artmed; 2012.
- 11. Filho J de M, Burd M. Psicossomática Hoje. 2a Ed. Artmed; 2010.
- 12. Fava GA, Cosci F, Sonino N. Current Psychosomatic Practice. Psychother Psychosom. 2017;86(1):13-30. doi:10.1159/000448856

- Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care. 2007;19(6):349-357. doi:10.1093/intqhc/mzm042
- Rubio-Rask SE, Farver-Vestergaard I, Hilberg O, Løkke A. Sexual health communication in COPD: The role, contents and design of patient information leaflets. Chron Respir Dis. 2021;18:14799731211020322. doi:10.1177/14799731211020322
- CastrO O, Lima RS, Sanches RS, Dázio EMR, Gomes RG, Fava SMCL. Significado de ser cuidador de pessoa com oxigenoterapia domiciliar: grounded theory. Rev enferm Cent-Oeste Min. Published online 2020:3607-3607.
- Balint M. O Médico, Seu Paciente e a Doença. 2a Ed. Atheneu; 2005.
- 17. Perestrello D. A Medicina Da Pessoa. 4a Ed. Atheneu; 1996.
- 18. Zysman M, Rubenstein J, Le Guillou F, et al. COPD burden on sexual well-being. Respir Res. 2020;21(1):311. doi:10.1186/s12931-020-01572-0
- Dias M, Oliveira MJ, Oliveira P, Ladeira I, Lima R, Guimarães M. Does any association exist between Chronic Obstructive Pulmonary Disease and Erectile Dysfunction? The DECODED study. Revista Portuguesa de Pneumologia (English Edition). 2017;23(5):259-265. doi:10.1016/j.rppnen.2017.04.005
- Alcalá-Rivera N, Díez-Manglano J. Erectile dysfunction in patients with COPD. A systematic review and metaanalysis. Revista Clínica Española (English Edition). 2023;223(3):165-175. doi:10.1016/j.rceng.2023.02.003
- 21. Marinelli L, Lanfranco F, Motta G, Zavattaro M. Erectile Dysfunction in Men with Chronic Obstructive Pulmonary Disease. J Clin Med. 2021;10(12):2730. doi:10.3390/jcm10122730
- 22. Fletcher EC, Martin RJ. Sexual Dysfunction and Erectile Impotence in Chronic Obstructive Pulmonary Disease. CHEST. 1982;81(4):413-421. doi:10.1378/chest.81.4.413
- Farver-Vestergaard I, Frederiksen Y, Zachariae R, Rubio-Rask S, Løkke A. Sexual Health in COPD: A Systematic Review and Meta-Analysis. Int J Chron Obstruct Pulmon Dis. 2022;17:297-315. doi:10.2147/ COPD.S347578
- 24. Freud. Luto e Melancolia. 1a Ed. LeBooks; 1917.
- Jeammet P, Reynaud M, Consoli S. Manual de Psicologia Médica. 2a Ed. Medsi; 2000.

- 26. Barbosa CSP, Bezerra VP, Oliveira GP de, Nogueira JA, Moreira MASP. Sexualidade da pessoa idosa: Vivências de profissionais de saúde e idosos. Cogitare Enferm. 2022;27:e83845. doi:10.5380/ce.v27i0.83845
- 27. Ezhova I, Savidge L, Bonnett C, Cassidy J, Okwuokei A, Dickinson T. Barriers to older adults seeking sexual health advice and treatment: A scoping review. International Journal of Nursing Studies. 2020;107:103566. doi:10.1016/j.ijnurstu.2020.103566