Original Research
Development of a Communication Instrument to Address Sexuality in COPD: COSY

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Abstract

Sexuality, an important aspect of quality of life (QoL), is often overlooked in COPD. Our aim was to develop an instrument that facilitates communication and counseling on sexuality in persons living with COPD.

We searched for publications on sexuality in COPD focusing on communication about sexuality and communication tools to support such communication. We also performed a survey asking 25 patients and 36 health care professionals (HCP) about their attitudes, experiences, barriers and facilitators when talking about sexuality. The survey showed that although patients and HCP wanted to talk about sexuality, it rarely happened due to communication barriers, lack of self-confidence and misconceptions on both sides. We set up a project expert team of HCP and three persons with COPD. In a half-day workshop, the team discussed the results of the literature review and the survey as a basis for the contents, the "when and how" to address communication about sexuality and the design of the communication instrument. In review rounds of the expert team, feedback on the drafts was collected and integrated into the final version of the communication instrument COSY (COmmunication about SexualitY in COPD).

The COSY instrument resulted in four tools: a communication leaflet, an application guide, a pictorial representation of the spectrum of intimacy for HCP and a comprehensible, picturized information booklet for patients.

Addressing sexuality in persons living with COPD should not be neglected. The COSY instrument could help to start and shape communication and consultations about sexuality and a more holistic consideration of QoL.

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Introduction

Quality of life is a widely accepted, if not the most relevant outcome measure, for persons with a chronic illness, such as chronic obstructive pulmonary disease (COPD)[1] . Human sexuality is a universal part of living that impacts the quality of life but it is often ignored when caring for people affected by COPD [2 3]. Despite the fact that intimacy and sexual activity can be markedly affected by breathlessness, fatigue, and anxiety [4 5] sexuality is rarely addressed by health care professionals (HCP) or patients. Stereotypes of older and chronically ill people often ignore the significance of intimacy and sexual fullfillment with respect to quality of life and emotional well being.

The English Longitudinal study of Aging (ELSA), a representative survey of a cohort aged 50 to >90 years captured information on sexual behaviors, attitudes, concerns, sexual function and quality of intimate relationships as people grow older. The data demonstrated that although sexual activities decline with increasing age and chronic conditions, older people judge sexual activity to be important for their well-being and do continue to have active sex lives. However, older people felt their concerns about sexual issues were not taken seriously and missed conversation and advice [6 7]. When sexual- function and intimacy are reduced by illness, treatment or anxiety, wellbeing and quality of life worsen in people affected by COPD [4 8] . Concerns about sexual activity are just as legitimate as concerns about any other physical activity in people with COPDand should be addressed in a respectful way.

Shyness and discomfort of HCP and patients as well as lack of the basic skills of HCP and low health literacy of people with COPD are reasons why sexuality is often ignored in the

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communication between HCP and patients [95 102 11]. Our aim was to develop a communication instrument intended as a "door opener" to promote conversation and counselling on sexual issues in the care of people living with COPD and to support HCP and patients to start the communication about sex. To our knowledge, this is the first COPD-specific instrument focusing on communication about sexuality and we are not aware of similar instruments for other chronic conditions.

Method:

We iteratively developed and validated the communication instrument in four steps (figure 1. diagram of the four-step development approach for COSY).

Step 1: Literature search

We performed a limited literature search in Pub Med applying a search strategy using the terms COPD and sexuality. We excluded publications with a focus on sexual dysfunction in the title (erectile dysfunction, incontinence, dyspareunia), pharmacological treatment of these disorders or associated psychological problems. We extracted information focusing on:

a) Problems reported by persons living with COPD in maintaining sexual activity

b) Needs from the patient perspective

c) Limitations and barriers on the part of HCP

d) Communication strategies, enablers, suggestions, counselling interventions

Step 2: Survey among HCP and COPD patients about their attitudes, experiences, barriers, and enablers when talking (or not) about sexuality

Based on the information in the literature and the experience of the participating experts, we developed one questionnaire for COPD patients and one for HCP (appendix).

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We piloted the questionnaires for comprehensibility and applicability with three general practitioners, one pulmonologist, three non-doctoral HCP and four COPD patients. Based on the feedback the questionnaires were adapted.

Within a 3-month period, 28 patients with COPD in primary care were asked to take part in a survey on sexuality in COPD patients. It was explained to them that the answers and data would be fully anonymized. Since the survey did not fall under the Human Law for Medical Research, because no identifiable medical data were collected, the ethics committee issued a waiver (BASEC Nr. Req-2019-01044) for the survey.

Twenty-five patients gave their written informed consent, filled in the questionnaires at home and returned them by pre-paid envelopes to the Epidemiology, Biostatistics und Prevention Institute at the University of Zurich (response rate of 89%). Fifty health professionals were contacted and informed by email and the questionnaire was attached with the option to complete the questionnaire and send it back via email or print it out and return it anonymously per post. Thirty-six completed the questionnaire (response rate of 72%).

Step 3: Workshop with an interdisciplinary project expert team

A project expert team with HCP from various disciplines and three patients with COPD was set up. We identified 24 national specialists active in research and/or practice, and persons living with COPD through professional networks, literature, publications, media, and national institutions. We contacted them by email and informed them about our intention to build up a multidisciplinary project team with expertise on sexuality and chronic disease. We asked whether they would be interested in collaborating on developing a practical, user-friendly communication aid that could serve as a "door opener" for initiating communication about sexual topics in patients with COPD. Nineteen experts (1 male, mean age 48.3 years) from health psychology and

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behavioural medicine (n= 2), clinical sexologists and sexual therapists (n=5), psychiatrists and psychotherapists (n=3), gynaecologists (n=2), psychosomatic and sexual medicine (n=1), psychologists (n=4) and physiotherapists (n=2) agreed, and we invited them to a half-day workshop. We, the initiators of the project consist of a pulmonologist and general practitioner, a respiratory physiotherapist and an epidemiologist with a special interest in COPD. Three COPD patients (59 years, 68 years and 76 years of age, one female) were also involved as experts. They agreed to an interview but did not want to participate in the workshop.

The workshop started with a detailed introduction round explaining the personal motivation to participate and giving personal examples and experiences when talking about sexuality in elderly and chronically ill people. It was followed by an introduction lecture about COPD and the disease-specific problems that can interfere with sexuality.

We discussed the literature review and the survey results as a basis for the contents, the when and how to address communication about sexuality and a possible design of the communication instrument. By the end of the day we had reached a consensus on the crucial issues in terms of the format, contents, and usability of the communication material.

Step 4: Development of the communication instrument.

The workshop resulted in a consensus that the communication instrument should be helpful for both professionals and patients and provide tools for both users.

Initially, a first draft of a paper-based communication leaflet for HCP was designed. The desk top helper series of the International Primary Care Respiratory group (IPCRG) https://www.ipcrg.org served as a template for the leaflet. In several review rounds among the members of the project team, feedback on the draft was collected and integrated into the final communication leaflet (Communication about Sexuality in COPD). During this process, a user manual was created as an

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aid in clinical practice with instructions on how to use the communication leaflet based on the principles of motivational interviewing. The third COSY tool is a pictorial representation of the spectrum of intimacy. To select the images, we considered four aspects: relationship status, sexual orientation, ethnicity and a broad representation of intimacy and sexuality. This was also the case for tool four, the picturized patient information booklet.

Beside the iterative development and testing of face validity described above we reached out to the European Lung Foundation (ELF) and the COPD foundation for further external validation. We introduced the instrument to representatives of ELF and the COPD foundation who expressed much interest and appreciation of addressing the topic of sexuality in COPD. Kristen Willard from the COPD Foundation sent the COSY materials to the patient and caregiver advisory board and met with them to discuss the material in detail. Jessica Denning from the ELF who is responsible for communication and education edited the English version of the COSY patient booklet.

Results:

Step 1. The Pub med search "COPD and sexuality" resulted in 158 hits (from 1982 to 2021). We screened and read the 158 abstracts but excluded the majority because the publications focused on sexual dysfunction in the title (erectile dysfunction, incontinence, dyspareunia) and or pharmacological treatment of these conditions or associated psychological problems. We examined the content of 18 publications in detail [2-5 8 9 12-23]. They showed that a substantial proportion of persons living with COPD perceive problems and miscommunication around sexual issues. The most frequent problems reported in maintaining sexual activity were fatigue, COPD symptoms, anxiety because of breathing problems, activity intolerance and loss of positive body image [8 12] . The needs formulated covered the issues of being more comfortable with breathing

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and sex, take the stress out of intercourse, energy management and the patient expectation that health professionals should ask them about any sexual concerns they might have and to obtain the support they require to talk about their sexual needs [14 23]. Barriers on the part of the health professional were mainly shame and lack of specific training on how to initiate communication [14 16]. Across publications it was consistently reported that this topic is still rarely addressed in clinical practice and research and that there is a need for better communication and disease-specific instruments that can help HCP to include such measures and assess sexual problems routinely in medical care for persons living with COPD [2 3 21].

Step 2. In the survey, 25 patients with COPD (mean age 63 years, 50 % female, mMRC 2.1±1.3, 61% in a relationship) from primary care and 36 HCP (mean age 46 years, 56% female, GPs 33%, lung specialists 19%, nurses/physiotherapists 47%) participated. Of the patients, 83% reported that they had never been asked about their sexuality since being diagnosed with COPD, although it was an important topic for one in two patients. Of the HCP, 86% considered sexuality important for quality of life, 69% wanted to address it but 49% never did. The main barriers for HCP in our survey were a lack of specific training on how to initiate communication and a misconception with respect to patients' barriers which were not shame or religion, but conversation barriers between them and their partners and wording (figures 2, 3, and 4). The results of the survey were presented as an abstract at the European Respiratory Society Meeting 2020 [24].

Step 3. From 19 experts, 14 (one male, mean age 48.4 years) took part in the half-day workshop led by a pulmonologist and a respiratory physiotherapist.

Based on the results of the literature review and survey, we discussed the content and form of the communication instrument and when and how to initiate communication about sexuality. There was a consensus that the COSY instrument should be helpful for HCP and patients and provide

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tools for both users. Finally, six of the experts (one male, mean age 46 years) collaborated with us further on the development of the instrument (figure 1).

Step 4. The COSY instrument we developed consists of four tools: a communication leaflet for HCP, an application guide, a pictorial representation of the spectrum of intimacy for HCP and an information booklet for patients. The communication leaflet (figure 5) covers four different domains that can limit sexual activity in people with COPD (limitations due to COPD symptoms, general physical condition, self-image or external stress factors). The application guide instructs HCP on how to best work with the communication leaflet following an active listening and motivational interviewing approach. It supports them with concrete instructions and example questions on sex and intimacy but also reminds the user to refer and collaborate with other providers and appropriate specialists. We finally complemented the COSY instrument with a pictorial representation of the spectrum of intimacy for HCP (figure 6) and a patient information booklet combining a pictorial approach and six helpful tips and instructions that could help COPD patients to enhance their sexual experience (figure 7: extract from the original COSY patient booklet) The entire patient booklet is available in the supplementary material.

We were able to test the instrument externally thanks to the COPD foundation. The members of the patient and caregiver advisory board felt the topic is often overlooked but essential to overall health and well-being. They very much appreciated the topics addressed, the illustrations, that the materials addressed intimacy and sensuality rather than sex alone. They also welcomed that the instrument highlights the importance of communication between persons with COPD and their partners as well as between the HCP and patient. Despite their very positive response to the COSY materials, they felt that the U.S. health care system was not structured to be conducive to such discussions, with patient seeing their doctors for only short consultations at a time. They also thought that HCPs were ill equipped to have these conversations.

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All four COSY tools can be viewed and downloaded for free.

https://www.lungenliga.ch/de/meta/fachpersonen/fachpublikationen/copd.html

Discussion

Based on information in the literature, the results of a survey with patients and HCP and the expertise of specialists, we developed, to our knowledge, the first COPD-specific instrument (COSY) to facilitate communication about sexuality and address the needs of both patients and caregivers. Despite the high prevalence of sexual dissatisfaction of patients with COPD, communication about sexuality very often remains taboo and is rarely addressed in practice nor incorporated in quality of life measures for COPD patients [2 3]

Our survey results are in line with Zysman et al and others [5 24 25] reporting that 80-90 % of patients with COPD confirmed that the topic was never raised by doctors or patients themselves, but that the majority would like to talk about sexual matters. Explanations as to why this did not happen are similar in our data [24] compared to others [11 25]. Reported reasons are shyness and embarrassment of HCP and the lack of basic skills.

In addition there are mutual misconceptions and that talking about the issue will make the other person uncomfortable [12 14 24] as well as the lack of support tools to address sexuality with greater confidence [3].

The COSY instrument is such a supportive tool addressing the needs of both caregivers and patients. COSY includes approaches to solutions and provides concrete assistance for communication and counselling. An important message provided by the COSY instrument for HCP who care for people living with COPD is that one must not be a sexologist to be able to start

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communication about sexuality. Professionals who understand that intimacy and sexual relationships are important parts of life and offer counselling to troubled persons might improve the well-being of persons living with COPD. Evidence from chronic cancer disease suggests that discussion on sexuality can be helpful and sexual activity beneficial for health status and quality of life [26 27]

Our survey also showed that for persons with COPD, communication about sexuality requires a trusted relationship with the HCP and that for every other person, communication with the partner was a problem. The COSY instrument highlights the importance of communication between the partner and the person with COPD as well as the HCP and patient. Hahn [12] described a support group program that helped persons with COPD become more knowledgeable and comfortable discussing sexual matters with HCP and partners. Proper communication, health information and improved health literacy are needed for people living with COPD to get them involved and empowered [10]. An important part of the COSY instrument is the patient information booklet. It allows patients and or partners to better understand and use the health information by providing concrete advice. Eleven illustrations that speak for themselves cover the broad spectrum with possible expressions and manifestations of caring and intimacy. The COSY patient booklet allows flexibility in the timing and delivery of information and is easy to read. It fulfils the key points highlighted for quality and effectiveness in a recent review article on the role, contents and design of patient information leaflets (PILs) in COPD in terms of sexual health communication [13].

The COSY instrument is available in English, German, French and Italian for wider dissemination and could be used in the patient-physician consultation and within pulmonary rehabilitation and self-management programs. Thoughts from the COPD foundation patient and caregiver advisory board on an effective approach in the U.S. included making sexuality and

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intimacy a component of a larger series/educational program, for example as part of pulmonary rehabilitation and of a larger self-care educational campaign (e.g., pamphlet or flyer).

To approach sexual activity as any other physical activity and correlate it with the energy requirements, such as walking or household tasks, to determine an individual's activity and sexual activity tolerance, could change practice. We and others have proven with the "Living Well with COPD" (LWWCOPD) intervention that it is possible for persons living with COPD to live a healthier and more fulfilling life [28 29]. To develop a partnership with patients is central in LWWCOPD and might therefore serve as an ideal framework to consider sexuality, identify the sexual needs and to promote and facilitate the communication and counselling about sexuality. The next steps planned are to include the topic intimacy and sexuality in the LWWCOPD that is implemented in clinical practice in Switzerland. HCP who apply the LWWCOPD program must pass training modules. The topic sexuality and communication about sexuality in COPD will be an extra module integrated in the training and thereby more HCP will be empowered to apply and work with the COSY instrument and to test the use in clinical settings.

The main limitation of our work is that the evaluation of the COSY tools are limited so far. However, we cannot see any harm either for patients or for HCP to work with COSY, which is based on respect, free will and autonomy. Working with COSY can serve as a ressource for HCP and patients. Future work needs to include implementation studies that examine the acceptance of the instrument in larger and diverse populations during the clinical encounter and should evaluate what speaks for and against the use of COSY for patients and HCP. Ideally, a randomized controlled trial would test whether communication and counselling about sexual activity using the COSY tools versus not using them increases well-being, improves the experience of sexuality and serves as motivation to increase or maintain long-term physical activity.

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Conclusion:

The COSY instrument creates opportunities to overcome taboos and clichés, start communication and being more sensitive to the sexual concerns of COPD affected people in daily practice, thereby supporting a more holistic consideration of QoL.

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Contributorship: Claudia Steurer-Stey and Kaba Dalla Lana were the project initiators, project leaders and main authors of the communication instrument. They performed the literature review and survey.
A. Strassmann and A. Frei contributed to the development and analyses of the questionnaires for the survey.
Stefanie Gonin-Spahni, Michelle Borgmann, Ursina Brun del Re, Sebastian Haas, Eliane Sarasin and Andrea Burri were members of the project expert team. The expert team, C. Steurer-Stey, K. Dalla Lana and Milo Puhan discussed the results of the literature review and the survey as a basis for the contents, the “when and how” to address communication about sexuality and the design of the communication instrument.

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All authors contributed to the development and final version of the COSY instrument (Communication about SexualitY in COPD). All authors read and contributed to the manuscript.

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Fig 1. Diagram Development of the COSY instrument four-step approach

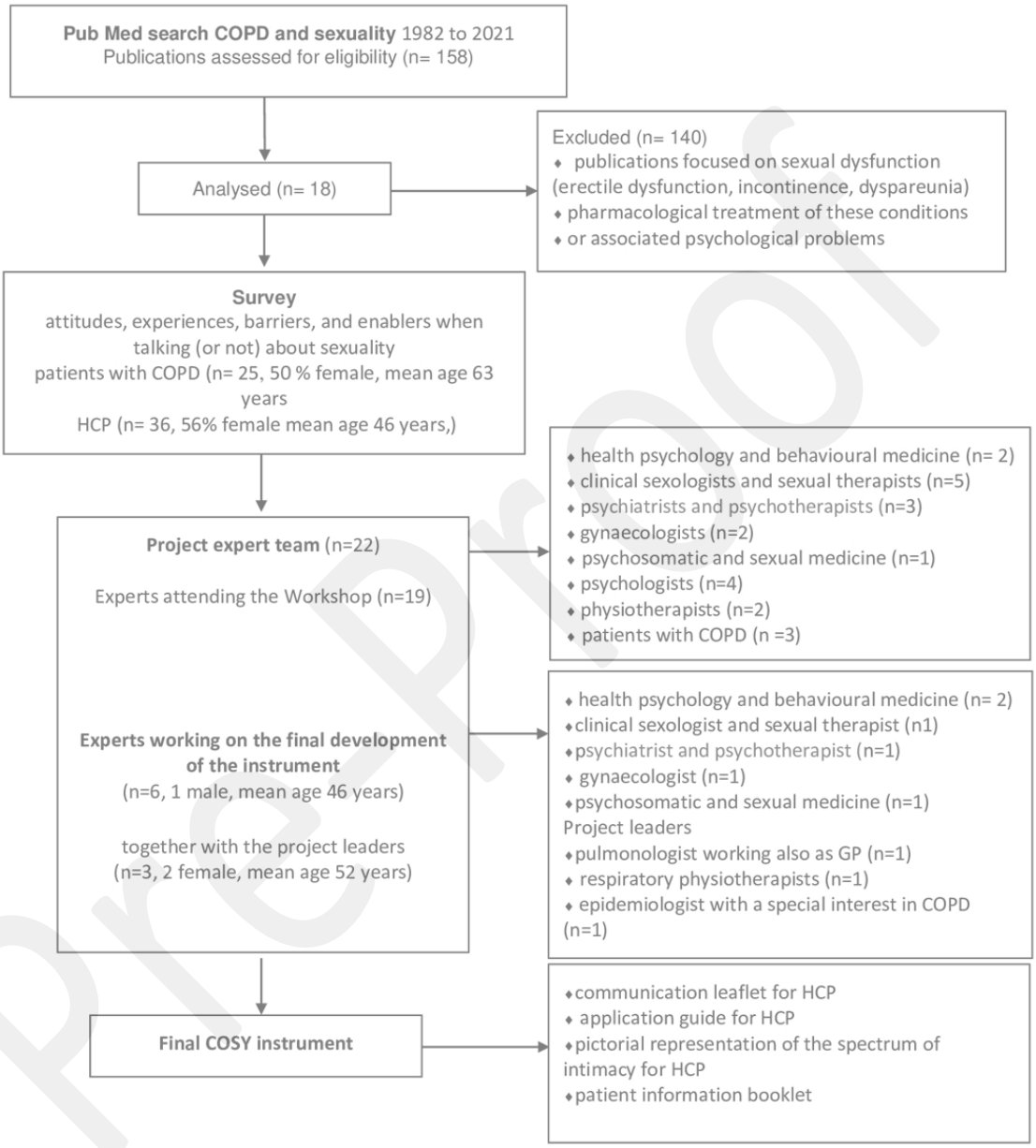

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Figure 2: Health professionals` barriers to start the conversation about sexuality

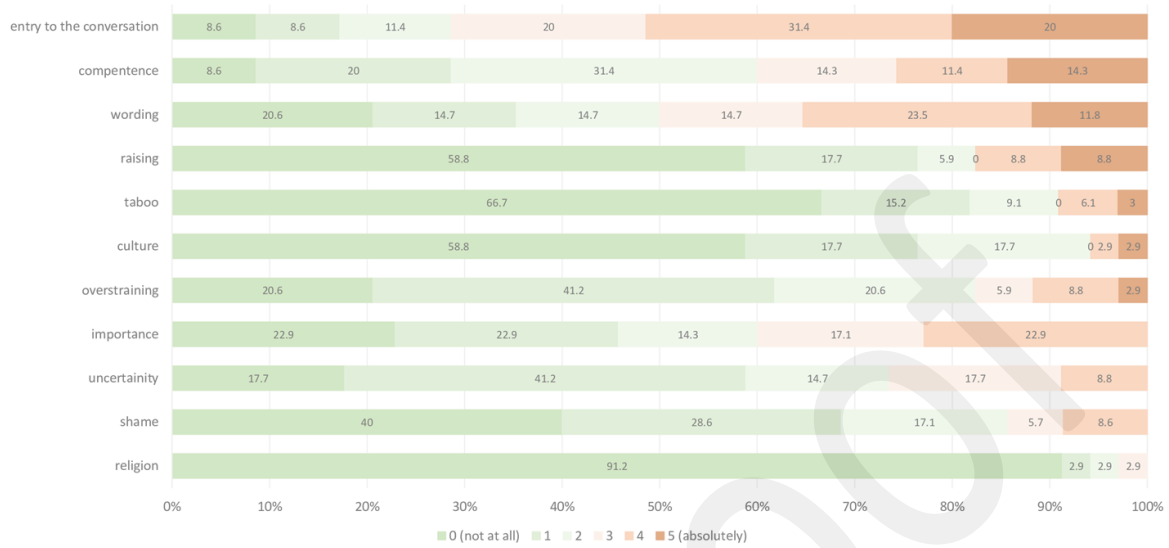

Figure 3: Barriers that professionals assume from patients`side

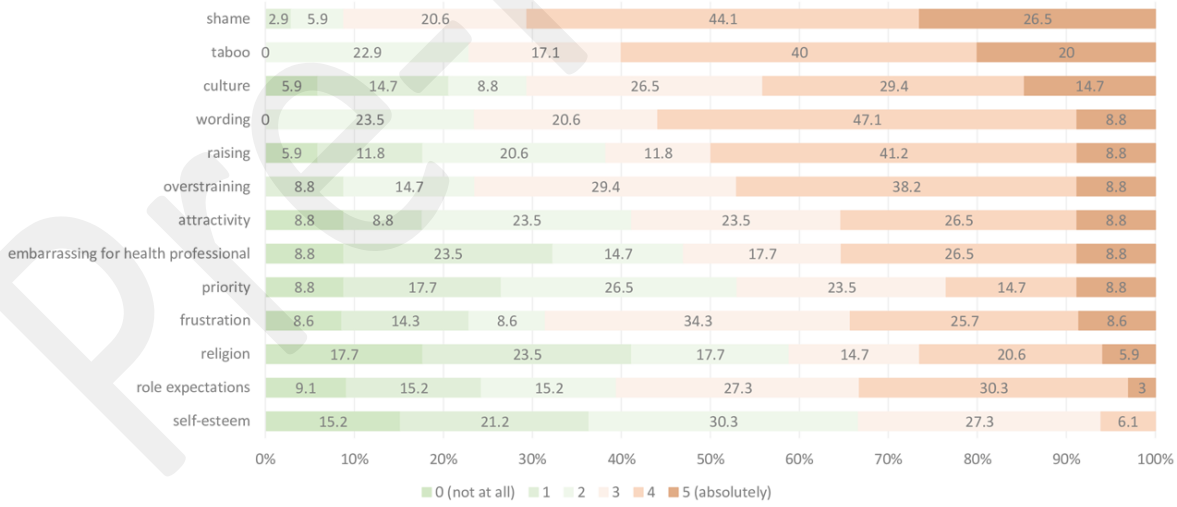

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Figure 4: Barriers from the patient's point of view

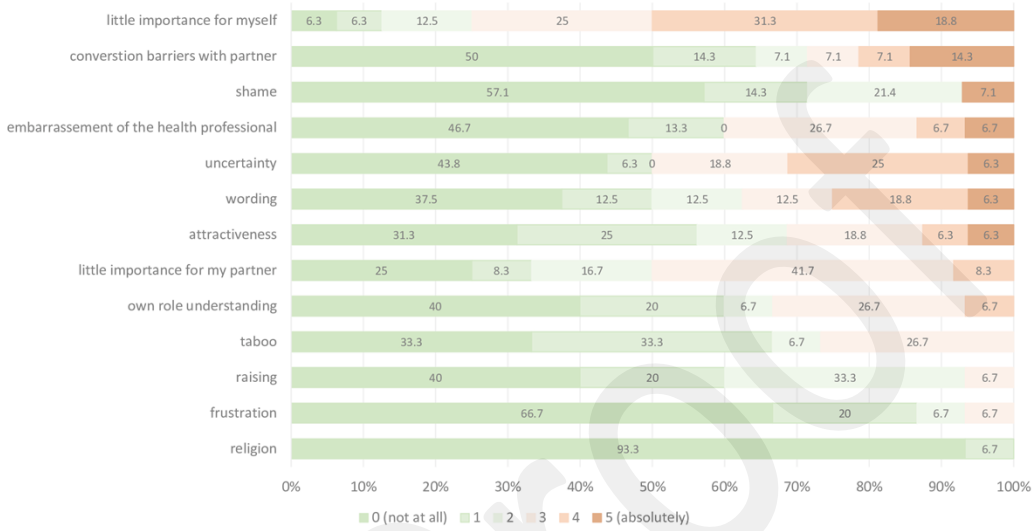

Figure 5

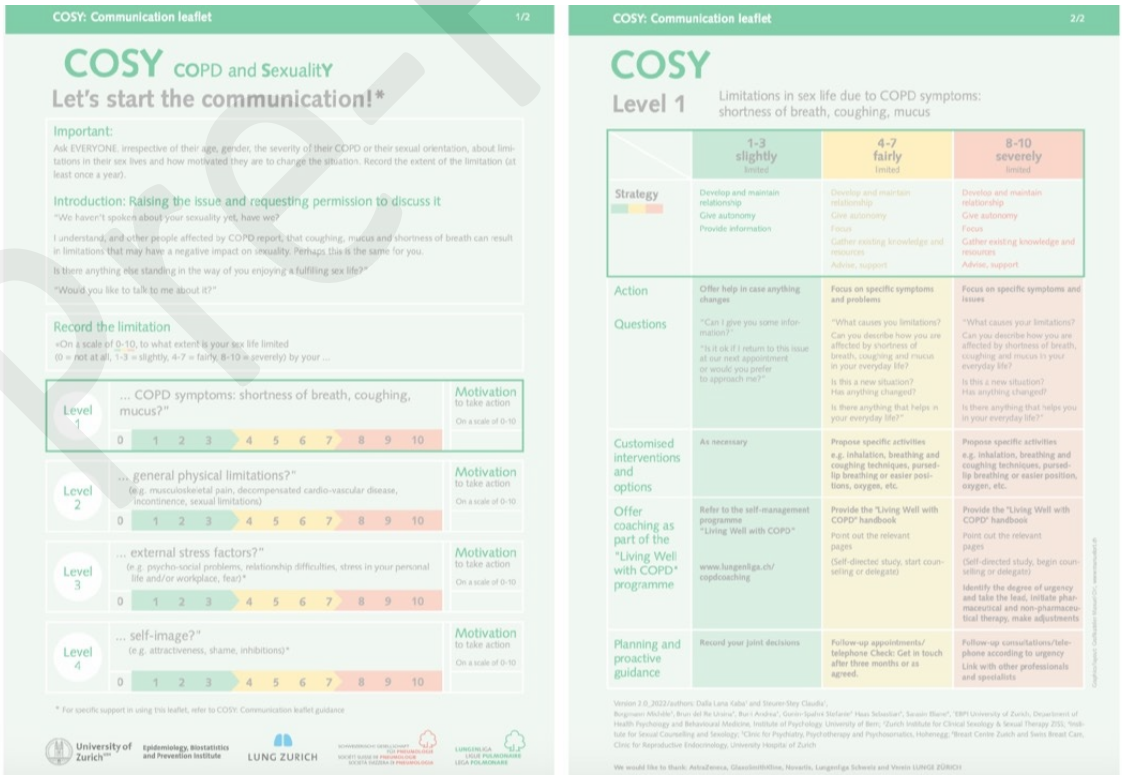

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Figure 6

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Figure 7

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Online Supplement

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0.1	Date	I__I__I.I__I__I.I__I__I__I__I
1.1	Gender	☐(1) male ☐(2) female
1.2	Birthday	I__I__I__I__I
1.3	Employment status	☐(1) Working ☐(2) partial retirement ☐(3) pension ☐(4) unemployed
1.4	Years of education	☐(1) ≤9 ☐(2) 10-12 ☐(3) ≥13
1.5	Living situation	☐(1) living with a partner ☐(2) living alone ☐(3) assisted living at home ☐(4) community living in a home
2.1	Year of COPD Diagnosis	J I__I__I__I__I
2.2.	Severity of your breathlessness	☐(1) never ☐(2) only during heavy exertion ☐(3) walking fast or walking on a slight incline ☐(4) When walking on level ground, I have to walk slowly (at my own pace) ☐(5) When walking on level ground, I need a break after about 100 meters ☐(6) I have too much shortness of breath to leave the house or have shortness of breath even when dressing
2.3	Breathlessness during sexual activity Sexual activity understood as: kissing, cuddling, sexual intercourse, masturbation	☐(1) I have shortness of breath during sexual activity If yes since when ca..... ☐(2) I have no shortness of breath during sexual activity ☐(3) I avoid sexual activity because of breathing difficulties

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		If yes, since when ca.....
3.1	**Before Diagnosis** of COPD How often were you asked about the topic of sexuality and sexual life in the practice or in hospital	☐ never (**if never continue with question 3.3**) ☐ once ☐ more than 1 time, how often ca? .....
3.2	**Before Diagnosis** of COPD Who approached you about the topic	☐ doctor/ GP, ☐ lung specialist ☐ non-physician professional ☐ other.....
3.3	**Before Diagnosis** of COPD How often did you raise the issue of sexuality and your sexual life in practice or in hospital	☐ never ☐ once ☐ more than 1 time, how often ca?.....
3.4	**Before Diagnosis** of COPD With whom did you raise the issue of sexuality and sexual life	☐ doctor/ GP, ☐ lung specialist, ☐ non-physician professional ☐ other.....
3.5	**Since Diagnosis** of COPD How often were you asked about the topic of sexuality and sexual life in the practice or in hospital	☐ never (**if never continue with 3.7**) ☐ once ☐ more than 1 time, how often ca?.....
3.6	**Since Diagnosis** of COPD Who approached you on the issue sexuality and your sexual life	☐ doctor/ GP, ☐ lung specialist, ☐ non-physician professional ☐ other.....
3.7	**Since Diagnosis** of COPD	☐ never (**if never continue with 3.7**)

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	How often have you raised the issue of sexuality and sexual life in the practice or hospital?	☐ once ☐ more than 1 time, how often ca?.....
3.8	**Since Diagnosis** of COPD With whom did you raise the issue of sexuality and sexual life	☐ doctor/ GP, ☐ lung specialist, ☐ non-physician professional ☐ other.....

3.9	As a patient, would you like to be addressed on the subject of sexuality and your sexual life	☐ Yes ☐ No **(continue with 3.93)** ☐ Want to address it myself
3.91		**If Yes** **How would you like to be addressed?** ☐ directly in an individual conversation ☐ indirectly, e.g. questionnaire
3.92		**How regularly would you like to be addressed** ☐ regularly, e.g. 1x /year ☐ more frequently than 1x /year ☐ less frequently than1x /Jayear ☐ Other interval.....
3.93	In which life situation do you **not want to be addressed**	☐ if I do not have a partner ☐ when I feel too ill ☐ when I feel lonely ☐ when I feel sad ☐ Other..... .....

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4.0	Is the gender of the interlocutor relevant for a relaxed conversation about sexuality and your sexual life?	☐ Yes ☐ No **If yes, do you prefer a** **same-sex** interlocutor ☐ **opposite-sex** interlocutor ☐
4.1	Is the age of the interlocutor relevant	☐ Yes ☐ No **If yes, do YOU prefer (compare to your age)** A younger conversation partner ☐ about the same age ☐ an older interlocutor ☐ .....
4.2	Do you prefer to be addressed on the topic of sexuality and your sexual life	With partner ☐ without partner ☐
4.3	In addition to gender and age of the interlocutor, what factors do you think promote a trusting, relaxed and helpful conversation? (Multiple answers possible)	Enough time ☐ Professional competence ☐ Experience of the interlocutor ☐ Sympathy ☐ Trusting relationship ☐ Empathy ☐ Please name the 2 most important factors from your point of view..... ..... Other factors that are important for you ....
4.4	**What are YOUR barriers to addressing sexuality?** please rate the factors on a scale from 0 to 5 Not at all true = 0 completely true = 5 **Multiple answers possible**	Too low a priority for me 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ Too low a priority for my partner 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐

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	What are YOUR barriers to addressing sexuality? please rate the factors on a scale from 0 to 5 Not at all true = 0 completely true = 5 **Multiple answers possible**	My self-esteem 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ My attractivity 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ I can't talk about it with my partner 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ Wording 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ Shame 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ Religion 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ Upbringing 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ Role expectations 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ Embarrassment of doctor / health professional 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐

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5.	**What are YOUR barriers to addressing sexuality?** please rate the factors on a scale from 0 to 5 Not at all true = 0 completely true = 5 **Multiple answers possible** General comments from you on this survey	Other barriers ....

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	Date	I__I__I.I__I__I.I__I__I__I__I

1. Basisangaben

1.1	Gender	☐(1) male ☐(2) female
1.2	Year of birth	I__I__I__I__I
1.3	Ethnicity	☐(1) Kaukasier ☐(2) Nicht-Kaukasier
1.4	Professional Activity	☐ GP ☐ Lung specialist ☐ Non-medical professional
1.5		since (year) I__I__I__I__I

2. Thema Sexualität bei COPD (alle Fragen beziehen sich auf COPD)

2.1	Is sexuality an issue in your professional work or in consultations with people with COPD?	☐ never ☐ rarely ☐ often ☐ routinely/always
2.1.1	I do not address the issue of sexuality with patients with COPD in my professional practice	☐ Completely true ☐ Partly true ☐ Does not apply
2.2	What are the problems for you personally in addressing the topic of sexuality and sexual life? **Multiple answers possible** **On a scale from 0 to 5** **Does not apply = 0** **Completely true = 5**	**Personal overload with the topic** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ **own shame** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐

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	What are the problems for you personally in addressing the topic of sexuality and sexual life? **Multiple answers possible** **On a scale from 0 to 5** **Does not apply = 0** **Completely true = 5**	**Own uncertainty** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ **Insufficient priority** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ **Insufficient professional competence** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ **Difficulty in finding the entry point to converstation** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ **Difficulty in choosing the right words** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ **My upbringing** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ **My cultural background** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ **Religion** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ **Other**.....
2.3	As a caregiver, do you consider the topic of sexuality and sexual life important for chronically ill people?	☐ Yes ☐ No

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2.4	As a caregiver, would you like to address the topic of sexuality and sexual life	☐ Yes ☐ No **If yes: How would you like to address it** Directly in individual conversation ☐ Indirectly e.g. by a questionnaire ☐
2.5	in an individual conversation Is the gender of the interlocutor relevant for a relaxed conversation about sexuality and sexual life?	☐ Yes ☐ No **If yes** do you prefer Interlocutor of the same sex ☐ Interlocutor of the opposite sex ☐
2.6	Is the age of the interlocutor relevant?	☐ Yes ☐ No **If yes,** do you prefer a A younger interlocutor ☐ An interlocutor of about the same age ☐ An older interlocutor ☐
2.7	Other factors besides gender and age of the interlocutor that promote a trusting, relaxed and helpful conversation about sexuality to your opinion (multiple answers possible)	Sufficient time ☐ Professional competence ☐ Own experience of conversation ☐ Sympathy ☐ Trusting relationship ☐ Communication aid ☐ (e.g. introductory questions, choice of words) Name the 2 most important factors for you .... Other ....
2.8	In your opinion, what are the problems in addressing sexuality and sexual life from the patient's point of view?	**Overchallenge** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐

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	In your opinion, what are the problems in addressing sexuality and sexual life from the patient's point of view? please rate the factors on a scale from 0 to 5 Not at all true = 0 to completely true = 5 0 1 2 3 4 5 **(Multiple answers possible)**	**Shame** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ **Insecurity** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ **Lack of self-esteem** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ **Dissatisfaction with physical attractiveness** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ **Low priority of the topic** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ **Uncertainty in the choice of words** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ **Generational (taboo subject)** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ **Culture-related (taboo subject)** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ **Religious reasons** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐

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		Upbringing 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ **Role expectations** 0 1 2 3 4 5 ☐ ☐ ☐ ☐ ☐ ☐ **Other**.....
2.9	Why do you think the topic of sexuality and sexual life should be included in the consultation and the consultation interview? **Multiple answers possible**	☐ Relevance for quality of life ☐ Relevance for self-esteem ☐ Relevance for self-image ☐ Reducing stress and anxiety about the issue ☐ Neutral conversation opportunity **Other**..... ....
2.10	Why do you think the topic of sexuality and sexual life should NOT be proactively included in the consultation and the consultation conversation? **Multiple answers possible**	☐ Violation of privacy ☐ Risk of symptom exacerbation ☐ Could be life threatening ☐ presence of comorbidities e.g..... .... ☐ Insufficient evidence for benefit

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2.11		☐ insufficient emphasis in guidelines and curriculum Other..... .....
2.12	When do you think the topic of sexuality and sexual life should **NOT** be proactively included in the consultation and the consultation interview	☐ from a certain age, e.g.....years ☐ Very severe COPD with oxygen therapy ☐ Not living in a partnership
3.0	General comments on your part regarding this survey	....

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Sex & COPD

The expression of love, affection, and sexuality is a part of being human.

The diagnosis of COPD does not mean the end of sexual activity.

The spectrum of sexuality is wide, the desires and possi- bilities are individual. Expressing intimacy with atten- tion, affection, cuddling, bathing together, massages and touching, also with yourself can be just as important as sexual intercourse.

To discover how intimacy can be lived on a different level when sexual activity / arousal is limited, can be an exciting, beautiful task.

It can also be fun to be creative. Both as single person as well as a couple, you may find that you can discover yourself on a whole new level alone or together.

Take the time to think about what you desire and what you want to try for your sensual, intimate experience.

A fulfilling sex life is possible regardless of your age, marital status or stage of illness. It is an important element for the best possible quality of life, which you have the right to if you are ill (European Charter of Patients' Rights).

Fears from the perspective of those affected

For people with COPD, the thought of having sex can be frightening. Perhaps it is the fear of getting short of breath during sex or disappointing their partner. Or the fear of being too tired and unattractive for sex. These are just some of the fears that can cause people with COPD to avoid intimacy and sexual activity in general.

Fears from the partners' perspective

Partners of people with COPD may be concerned that sexual activity may lead to a worsening of symptoms or could even be dangerous.

There is no need to withdraw from intimacy, emotionally detach from their partner or give up sexual activity. There are positive ways to work around COPD.

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Following these six helpful tips can help you to experience sex and

Perceive needs and talk about them

No one can hear your thoughts and know what makes you feel good or uncomfortable. Good communication is very important for improving your sex life. Do not wait too long to talk about it if you are not satisfied with your sex life.

Both you and your partner should be able to honestly express your feelings, desires and fears and find cre- ative solutions to mutual satisfaction.

For example, the following statement can make it easier for you to address this issue: «It is not easy for me, but I would like to talk to you about our sex life.»

Do not be afraid to talk to your doctor or a trusted professional about sex and intimacy.

Get fit, stay fit

Regular physical activity taking part in a training program, e.g., as part of an outpatient rehabilitation program, will help you to reduce your fears about respiratory distress and increase your performance. During physical activity, a certain amount of shortness of breath is normal. Learn what is normal for you and your condition. With regular training, your condition will improve and yu will be less breathless.

During sexual activity with moderate effort (such as cuddling on the sofa) is estimated to use up 2,0 METs*. This is equivalent, for example, to watering a lawn or being a dedicated spectator at a sporting event. An orgasm, which consumes considerably more sexual energy, is equated with >3 METs which is equivalent to climbing a flight of stairs, for example.

Remember! Physical activity is important and of great benefit to slowing the progression of your COPD. If you

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improve your physical activity and increase your fitness, your sexual activity will also benefit. Increased fitness means being able to experience fulfilling sexual activity with less breathlessness.

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intimacy in a fulfilling way.

Listen to your body

Fatigue can be a result of COPD and can put a damper on intimate life. Pay attention to your body's signals to find out what time of day you feel the most energy. It can make a big difference if sex takes place at a time of day when your energy level is higher. Don't assume that you have to wait until bedtime to have sex.

If you feel rested and take breaks as needed during sex- ual activity, sex can be easier and more enjoyable.

Conserve energy

Managing your energy is fundamentally important, especially if you are affected by COPD. Avoid excessive alcohol consumption and heavy meals before sex.

The choice of sexual positions can also affect energy consumption. The partner, who does not have COPD, should take the more active role, if possible.

Inhale your bronchodilator and feel less shortness of breath

Regular inhaling is part of the basic treatment. Addi- tional inhalation prior to sex with a bronchodilator medication can, like inhaling before before exercise, reduce your shortness of breath during exertion.

Oxygen reduces shortness of breath

If you use oxygen for daily activities, you should also use it during sex. This can make breathing easier. Ask the oxygen provider for extended oxygen tubing so there is more breathing room between you and the tank.

* MET is a «metabolic equivalent», or the ratio of work energy turnover to rest energy turnover. 1 MET is equal to the amount of energy used by an adult person sitting quietly.

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It is not always easy to find words for the broad spectrum of intimacy and sexuality – and for one's own needs.

On the following pages, we would like to inspire you with a selection of pictures to tune in to your individual sensuality and support you in feeling your needs and desires regarding intimacy and sexuality and to com- municate them if necessary.

We sincerely wish that you find the kind of intimacy and sexuality that suits you best.

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Me with myself...
Me and...

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Me with myself...

smile at myself

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Me with myself...

nurture myself

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Me with myself...

spoil myself

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Me with myself...

be with myself

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Me with myself...

touch myself

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Me and...

be connected

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Me and...

cuddle – be tender

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Me and...

kiss

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Me and...

having sex – making love

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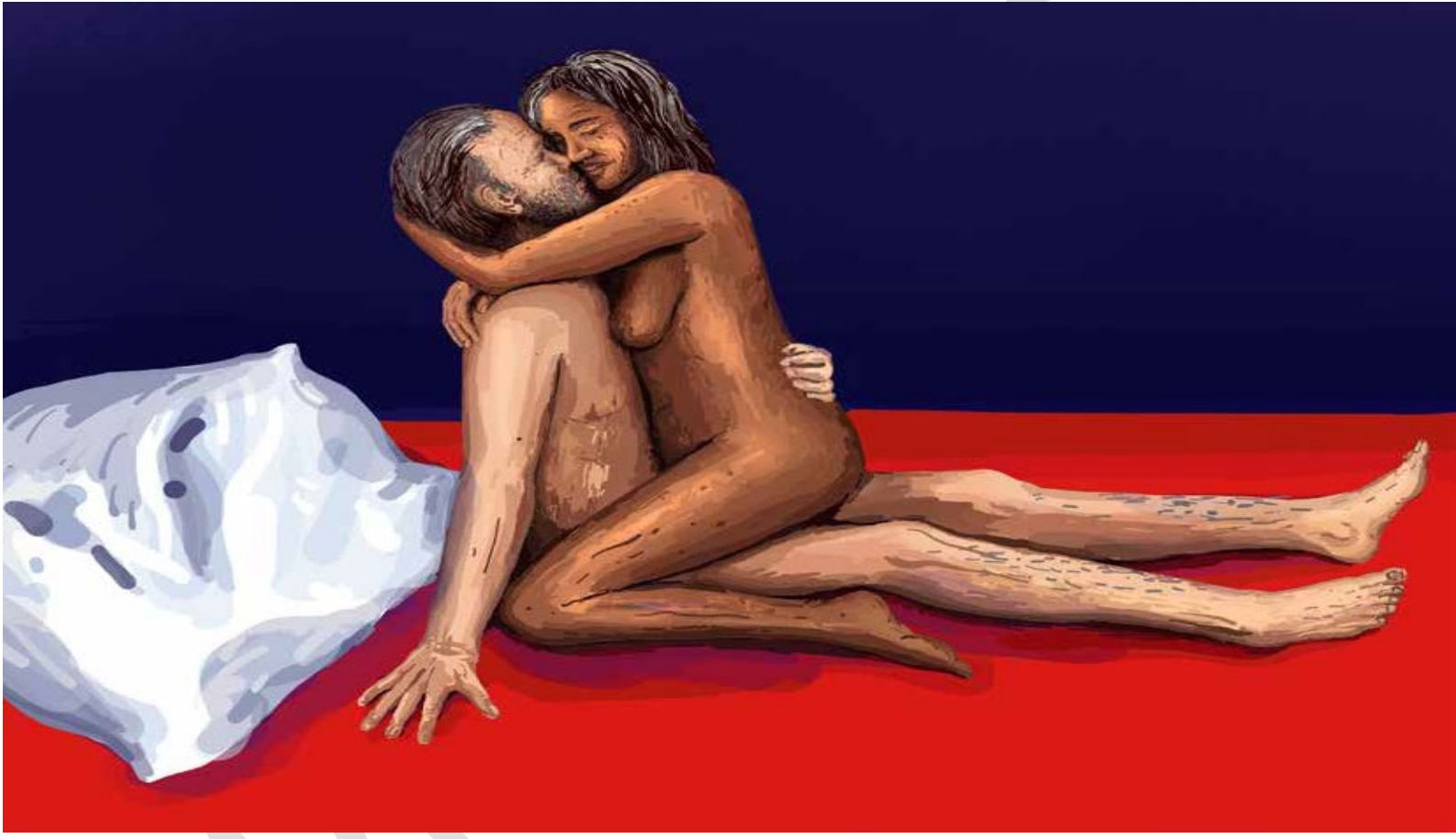

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Me and...

having sex – making love

energy saving position

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Me and...

having sex – making love

oxygen can help

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Words of Love

I enjoy being near you.

I want to caress you

Thank you for being close to me.

A little cuddle would be nice!

May I hold you in my arms?

You make me feel good.

I enjoy touching you.

Do you have 10 minutes just for the two of us?

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I like the way you touch me.

I'm glad you're here.

It`s nice to look into your eyes.

I love you.

May I give you pleasure

You are warm and soft.

University of Zurich[UZH] Epidemiology, Biostatistics and Prevention Institute

LUNG ZURICH

SCHWEIZERISCHE GESELLSCHAFT FÜR PNEUMOLOGIE
SOCIÉTÉ SUISSE DE PNEUMOLOGIE
SOCIETÀ SVIZZERA DI PNEUMOLOGIA

LUNGENLIGA
LIGUE PULMONAIRE
LEGA POLMONARE

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