


# Sexual health communication in COPD: The role, contents and design of patient information leaflets

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Sandra Esperanza Rubio-Rask<sup>1</sup> ,  
Ingeborg Farver-Vestergaard<sup>1</sup>, Ole Hilberg<sup>1</sup>  
and Anders Løkke<sup>1</sup>

## Abstract

Understanding need for support and information among people with COPD is important for the delivery of patient-centred care. Especially regarding intimacy matters, many people wish to remain sexually active but may be struggling to find out how, as information and communication regarding sexual health is scarce. This is especially true when it comes to people with chronic obstructive pulmonary disease (COPD). The present review seeks to provide an overview of the role, contents and design of patient information leaflets (PILs) and discuss their application in sexual health communication for COPD. Based on the literature, a number of key points in the design of high-quality PILs are suggested, and important areas for the improvement of patients-clinician communication are highlighted. While PILs is a commonly used format to provide information in healthcare, other formats, e.g. video and podcasts, could be explored. Prioritizing the development of material to support communication in the future is necessary to address the needs of both patients and caregivers and to support clinicians in initiating conversations about sexual health and intimacy matters.

## Keywords

chronic obstructive pulmonary disease, COPD, sexual health, leaflet, communication

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## Introduction

Chronic obstructive pulmonary disease (COPD) is a debilitating disease, in terms of functional limitations, morbidity and mortality, and a growing healthcare problem across the world.<sup>1,2</sup> Moreover, symptoms of anxiety and depression are common in COPD, which can put a strain on social and intimate relationships.<sup>2,3</sup> As COPD progresses, increased breathlessness can challenge participation in both physical and sexual activity.<sup>3</sup> Although the frequency and intensity of physical and sexual activity may naturally decrease with advancing age and disease progression, these activities are still possible and beneficial for health status and quality of life.<sup>1,3</sup> Education about COPD, sexual functioning and intimacy matters is important

to prevent deterioration of quality of life for people with COPD and their partners.<sup>4</sup> However, literature indicates that communication barriers are hindering patients and their partners to feel natural and relaxed concerning issues related to sexual activity.<sup>3,5</sup> Therefore, written health information about COPD-related sexual dysfunction is acknowledged as a priority, but clinically relevant approaches to meet the

<sup>1</sup> Department of Medicine, Vejle Hospital, Vejle, Denmark

### Corresponding author:

Sandra Esperanza Rubio-Rask, Department of Medicine, Vejle Hospital, Beriderbakken 4, 7100 Vejle, Denmark.  
Email: Sandra.esperanza.rubio-rask@rsyd.dk



informational needs of patients and their partners has not been elaborately described.<sup>1,3,5</sup>

Studies indicate that healthcare professionals in general feel insecure and embarrassed when talking about intimacy matters with patients.<sup>6–8</sup> Additionally, healthcare professionals lack sexual health education, which affects their abilities to discuss sexual challenges and limitations.<sup>8</sup> Nonetheless, proper communication as well as relevant health information remain crucial components in all steps of the healthcare process if patients are to be actively involved and to make sensible decisions about their health.<sup>5</sup> Evidence from both COPD-specific and other areas of healthcare suggest that written health information can enhance patient knowledge and awareness<sup>9</sup> and additionally to support communication between the healthcare professional and the patient.<sup>6,10</sup> However, written health information should be considered a supplement rather than an alternative to verbal communication.<sup>10</sup>

The most common form of written health information is patient information leaflets (PILs).<sup>5,10</sup> PILs seek to empower and motivate patients to promote and maintain health and serves as a supplement to verbal communication.<sup>5,7</sup> Yet, problems with information overload, incomprehensible medical terminology, misinterpretation of risk and benefits as well as language issues have been shown to compromise the effect and aims of PILs.<sup>7</sup> Hence, in order to be effective and serve their purpose, PILs must be readable, understandable, trustworthy and remembered, and they must allow flexibility in the timing and delivery of information.<sup>6,7</sup> All in all, well-designed PILs can increase the chances that patients will read, understand and use the written information and learn at their own pace,<sup>5,7</sup> but far from all existing PILs live up to these criteria. Hence, attention needs to be directed to relevant literature that can support the design of high-quality PILs in the future with the purpose of optimizing sexual health communication in COPD. COPD-related sexual concerns are vastly overlooked in the literature on written health information.<sup>11,12</sup> Therefore, we present studies of PILs in general as well as in other disease populations, e.g. cancer and heart disease, that can cause intimacy issues somewhat comparable to those of patients with COPD.<sup>13,14</sup>

On the basis of selected empirical and theoretical literature, the present review seeks to provide an overview of the role, contents and design of PILs and discuss their application in sexual health communication for COPD.

## Written health information

Generally, written health information appears to benefit patients, partners and healthcare professionals by supporting verbal communication and allowing patients to take an active part in their own care and well-being.<sup>15</sup> According to Griffin and colleagues' guidelines for contents and design of written health information,<sup>16</sup> PILs are more likely to support communication adequately if the content is readable, understandable and readily recalled by the recipient. Written information must be comprehensible to people across a range of literacy skills and therefore address according to the lowest reading level possible while still conveying the information accurately. Modifying the use of language and words can enhance readability and comprehensibility, while tailoring information can ease understanding (e.g. shorter sentences, shorter words, avoid or limit multiple phrases in sentences, avoid or limit medical jargon). Awareness towards the written tone is important and can enhance readability (e.g. avoid language that can be interpreted patronizing, blaming or judgmental).<sup>16</sup>

### Readability and literacy

In an observational study, Prothero et al.<sup>17</sup> explored the readability and literacy of 345 PILs from waiting rooms at 17 general practitioner (GP) practices in the UK. The PILs were categorized into six themes: health promotion, health protection, disease prevention, healthcare, management and systems navigation. They were assessed for readability and subject content using the Flesch Reading Ease scores and the Flesch-Kincaid Grade Levels.<sup>18–20</sup> The results demonstrated that 24.3% of PILs met the recommended reading level criteria of US grade 6 or below. However, 75% of PILs had a reading level too complex for 15% of the population in the UK.<sup>17</sup>

To our knowledge, no studies regarding readability and literacy level on PILs targeted towards patients with COPD currently exist, but as COPD is most often diagnosed relatively late in life, studies of written health information designed for older adults are relevant. Cronin et al.<sup>21</sup> evaluated the readability of 45 PILs designed adults above 50 years of age. PILs were collected from three different healthcare facilities across Ireland and categorized into eight themes: infection, cardiovascular, medications, stroke, general health, epilepsy, and welfare and health services. The Simplified Measure of Gobbledygook (SMOG) validation tool<sup>22–24</sup> was used to estimate the readability

level of included PILs of newspapers. The mean readability level of the PILs was 12.57, which was comparable to the included newspapers (mean = 12). However, 100% of PILs was written at an excessively high readability level (9th grade or higher) which is way above the literacy level of the older population.<sup>21</sup>

### *Format, document layout and illustrations*

The design format and layout of PILs are essential factors into an easy understandable leaflet.<sup>16</sup> Keeping features simple and clean can facilitate a more accessible, functional and trustworthy PIL that allows patients and/or relatives to assimilate knowledge and understanding. The use of paragraph, line breaks, spaces, punctuation marks as well as keeping sections well-spaced can help transform the pages into a final PIL or booklet that looks attractive and professional.<sup>16</sup> In a cross-sectional study of 191 pharmacy visitors, van Beusekom et al.<sup>25</sup> investigated the perception of organ illustrations (intestines from the digestive system, lungs, kidneys and ear) in PILs, to develop directions for the use of illustrations targeted towards a low-literate audience. Illustrations varied in details, backgrounds and type of frames and was designed and presented in 44 visuals. A survey was conducted to rate and evaluate the perception of illustrations. The results showed that low-level literate respondents preferred low-level detail on visuals. Respondents in general preferred visuals with a skeleton-background and, e.g. visuals of lungs depicted in the direct surrounding area of the body. The authors concluded that illustrations, if used correctly, could correct misunderstandings and compensate for high-level terminology of the written material and thereby serve to support understanding. Placement as well as recognizability of illustrations was suggested to further improve the function of the illustrations.<sup>25</sup> No studies have explore the role of PIL illustrations specifically in COPD. However, as the mean age of the population is relatively high, compared to the general population, and the educational level is relatively low, compared to other chronic illness groups, including visual illustrations with low level of details could be recommended for the design of PILs to support communication about sexual health.

### **Relational factors and communication**

In general, patients with COPD lack information on how to cope with and manage the multifaceted

consequences of their disease.<sup>3,26,27</sup> As COPD progresses, patients may become more care-dependent and rely increasingly on support from their partners, a troublesome reality, where relationship can become strained and difficult.<sup>3,26</sup>

### *Lack of information*

A mixed-methods systematic review by Noonan et al.<sup>28</sup> included a total of 54 studies with 26.453 caregivers (female 63, mean age 62) of adults living with COPD or heart disease. Results suggested that the complex role of caregivers requires coordination, information and education. Caregivers generally recognized a psychological change affecting relationship quality and intimate love. Caregivers to patients with COPD or heart failure experienced similar mental strains. They worried over the lack of knowledge, information and education and felt unprepared at their partners hospital discharge. Some received oral or written information at the hospital but did not receive any supportive interventions.<sup>28</sup> In a qualitative study by Lindqvist et al.,<sup>29</sup> caregiver narratives indicated that it became increasingly difficult to maintain an equal relationship between patient and partner as breathing difficulties progressed. Furthermore, caregivers felt gradually forced to take on the caregiver role in order to manage everyday tasks. They did not feel that they received sufficient support, information or education from healthcare professionals or municipalities. Caregivers felt restricted both personally, physically and intimately.<sup>29</sup> Another qualitative study of 22 caregivers by Bove et al.<sup>30</sup> found that caregivers felt ambivalent in their relationship as the unpredictability of the disease was exhausting and that they always had to be in a state of alertness. Caregivers sought information and education. They felt let down, overlooked, ignored and exploited.<sup>30</sup> Lastly, Kendall and colleagues' qualitative study of 14 patients with COPD<sup>31</sup> suggest that they, on the one hand, try to uphold their independence and autonomy by declining help offered by the hospital while they, on the other hand describe that their partners are longing for practical help, information and education. Further, healthcare professionals report substantial unmet needs and discrepancies in terms of the help and solutions offered and received, as well as patient and partner dissatisfaction on health provision.<sup>31</sup>

There seems to be a lack of research investigating the exact needs and demands of caregivers in relation to change in life rhythm, roles, intimacy and

sexuality, as well as a scarcity of PILs developed to support communication about relationship and intimacy issues. Differences between the experience of sexual health in COPD and heart disease have not been adequately explored, and it is therefore unknown whether communication needs and targets for PIL are comparable.

## Unmet needs in communication about sexual health

### *Patient and clinician communication behaviour*

Flynn et al.<sup>32</sup> investigated cancer patient experiences through a survey and a focus group study of sexual concerns before and after cancer treatment. Focus group respondents perceived lack of information as problematic as it deprived them of the opportunity to adjust and prepare for the side effects. Results of the survey showed that 78% of the included respondents thought it was essential to discuss sexual challenges and limitations with healthcare professionals, and 55% reported unmet information needs on potential effects of cancer treatment on sex life. Male respondents were more likely to receive information compared to women. Furthermore, 29% of survey respondents had self-initiated conversations on sexual side effects.<sup>32</sup> A survey performed by Faithful and White<sup>33</sup> included radiotherapy departments (n = 40), a convenience sample of specialist gynaecological nurses (n = 52) as well as available PILs (n = 32) from cancer units, cancer networks and vaginal dilator manufacturers, in which attitude behaviour among healthcare professionals were investigated. Although pelvic radiotherapy is used to treat women with bladder, rectal and anal malignancies, results showed that the included PILs primarily focused on the technical aspects of dilator use. Moreover, 72% of PILs provided general information on cancer supportive care but disease- and pelvic therapy-related impact on sexual health was only mentioned in 41%. Sixty percent of the included nurses stated that they provided verbal and written information, but only when teaching vaginal dilation. Moreover, those who reported initiation of sexual health inquiries also reported that they quickly moved on to other topics due to insecurity.<sup>33</sup> In a qualitative study conducted by Reese et al.,<sup>34</sup> the study aim was to explore patient-clinician communication post treatment of patients with breast cancer (n = 28), oncologist and nurse practitioners (n = 11). Results of the study showed that patients expected that their

healthcare professionals would provide information specific to their needs. Furthermore, the perceived lack of initiative by healthcare professionals to initiate conversations about sexual topics compelled patients to raise awareness on sexual concerns. Healthcare professionals evaluated their own conversations about sexual topics as rushed, insufficient and restrained. Therefore, these consultations had a low priority and patients were often referred elsewhere for sexual consultations. Generally, healthcare professionals expressed that specific concerns (e.g. vaginal dryness) were addressed, but that it did not lead to the inclusion of other sexual concerns in the conversation (e.g. loss of libido and intimacy) as they felt poorly equipped to educate and understand these matters. The few healthcare professionals who felt competent in assessing and handling sexual issues also felt time constrained, which compromised quality of care and patient satisfaction.<sup>34</sup>

While aspects of sexual health in cancer is most often directly related to effects of disease and treatment on hormone regulatory processes, reproductive organs and sexual function, e.g. breast-, colorectal-, and testicular cancer,<sup>35-37</sup> changes in sexual life for patients with COPD are thought to be more indirectly linked to disease symptoms through fear of breathlessness on exertion as well as reductions in functional level and exercise capacity.<sup>38</sup> Communication needs and PIL targets should therefore not be directly extrapolated from studies of cancer patients. In a review of 30 studies in chronic illness populations, exploring barriers and facilitators to communicate about sexual topics,<sup>39</sup> O'Connor et al. found, that fear of embarrassment, discomfort and causing offence were strong barriers to address sexual concerns among healthcare professionals in patient encounters. Personal boundaries- and- perception of sexuality also influenced whether sexual health topics were perceived as taboo. Moreover, healthcare professionals perceived female sexuality as complex and riskier to address, due to the perceived emotional character of female contrarily to male sexuality. Additionally, time constraints and lack of knowledge were considered strong barriers whereas training in communication skills as well as sexual care and health assessment models was perceived as good strategies to improve confidence among healthcare professionals.<sup>39</sup> High-quality PILs, as well as adequate communication training, may be relevant with the purpose of minimizing taboo and optimizing self-efficacy of the professional in the future.

## Approaches to ensure high-quality PILs

### Evaluation of PILs

Garner et al.<sup>40</sup> suggest that well-designed PIL goes beyond readability and a tripartite framework on communicative effectiveness was therefore proposed to enhance the quality of leaflets and increase comprehension. Patients goes through three overlapping, simultaneous but not coterminous processes: 1) reading the whole material, 2) obtaining a coherent meaning and 3) constructing a response to the wording of the leaflet. PILs should therefore be evaluated by complementary measures and methods of *readability*, *comprehensibility* and *communicative effectiveness*. As comprehensibility evaluation is an indispensable part of the overall evaluation of PIL, it is further suggested to: 1) divide PIL into five sentence chunks, 2) dissect each chunk of text by a group of readers, 3) complete a multiple-choice questionnaire related to lexical items and sentence structure, 4) perform semi-structured interviews to measure through *simulated behaviour* technique, in which respondents report what they intend to do, in reaction to a written scenario.<sup>40</sup> In line with this, a review by Luk et al.<sup>41</sup> aims to identify and review tools used to evaluate PILs from a comprehensive document and user perspective. They conclude, that many tools are available, but most are researcher focused and can therefore not be used directly for improvement of written materials in clinical practice. They argue that clinicians should include the target population in the development and testing of PILs before they are implemented for use in clinical practice.

In a randomized controlled trial (RCT), Chellayadhas et al.<sup>42</sup> investigated the effect of a sexual dysfunction information booklet on general concepts of sexual dysfunction following urological cancer (prostate, testicular, urinary bladder, kidney or penis). The content of the information booklet included common male sexual challenges and limitations such as: low libido, erectile dysfunction, premature ejaculation, dysorgasmia, delayed ejaculation, Peyroniés syndrome, and penile shrinkage. It also proposed ways of treating sexual dysfunction including mechanical, medical, surgical and psychological approaches. The results showed improvements in self-reported knowledge and understanding general concepts of sexual dysfunction. Moreover, patients found the booklet useful, adequate and easy-to-understand.<sup>42</sup> Scala et al.<sup>43</sup> developed an information PIL on basic COPD symptoms following best recommendations and

guidelines for producing well-designed written health information. They tested readability through the *Flesch-Vacca grade level 70* and *Kincaid grade level 8* (readability tests used to indicate how difficult the written material is to understand),<sup>23,24,44–46</sup> as well as retained knowledge level on a sample of patients through a short questionnaire. Patients were asked to read the PIL, complete the questionnaire and highlight ambiguous statements. The short-and-long-term effects on knowledge of the PIL were then evaluated in a pre-post intervention setup. Results showed that the PIL developed according to recommendations and guidelines had the potential for respondents to retain obtained knowledge level at least 1 year after exposure.<sup>43</sup>

Taken together, although testing for comprehensibility is time consuming, it might be well spend as it can reveal barriers to understanding and allow for changes to the written health information to improve content, format and design. This is especially relevant in the development of PILs to support communication about sexual health in COPD where written material and evidence of its quality is not publicly available.

### Future directions

The present review has sought to highlight relevant empirical and theoretical literature on the role, content and design of PILs, as well as to discuss its application in sexual health communication in COPD, which has been relatively overlooked in the area respiratory medicine.

In the future, high-quality PILs that can be used in sexual health communication with patients with COPD and their caregivers should be developed and made publicly available to optimize wider dissemination. In Table 1, we propose an overview of key points to consider when aiming to design high-quality PILs. This includes that 1) identification of aim, content, design and layout should follow best practice guidance (fx see Griffin et al.<sup>16</sup>), 2) caregiver needs should be addressed, 3) content should aim at answering previously reported unmet sexual health needs, 4) content, literacy, readability as well as comprehensibility must be tested through adequate instruments (for example, see Luk et al.<sup>41</sup>)

Although written information cannot substitute face-to-face education, it can have a significant impact on knowledge and understanding.<sup>17,40,42,43</sup> Written health information should be simple and easy-to-understand using a language and format

**Table 1.** Suggested key points for high-quality PILs.

Use adequate readability formulas to assess the reading level	Aim: to keep the content within the range for acceptable and readable content.
Follow guidelines for written health information	Aim: keeping features, layout and illustrations simple, clean and well arranged.
Evaluate the content aimed at the target group.	Aim: to include both patient and caregiver perspective. Patient perspective: Information on expected disease related changes on social and intimate level. Caregiver perspective: Information on expected disease related changes, expected relationship changes and coping strategies.
Cover unmet communication needs	Aim: To support clinical consultations. Patient needs: Specific information on relationship change, sexual health guidance. Clinician needs: Sexual health information.
Assess comprehensibility	Aim: to evaluate the written health information. Assess retained knowledge through questionnaires Comprehensibility test

appropriate for the target group.<sup>17,21</sup> To enhance patient comprehension and knowledge retention, design and development as well as targeted content of written information is key.<sup>40,42,43</sup> Obtaining patient involvement to clarify ambiguous content seems to be a valid and constructive way.<sup>43</sup>

### *Multiple formats of health information*

PILs represent one format of providing health information, and supporting both oral and written information with podcast and videos on health related matters might increase application and information uptake in clinical practice.<sup>47</sup> Podcast and videos could be a feasible tool for delivering health information, as it can promote broad listenership on information otherwise difficult and time consuming to transmit in face-to-face consultations and/or in written form,<sup>47,48</sup> Future research exploring different formats of providing health information are needed.

### *Systemic approaches to sexual health*

While the majority of the studies presented in this review has focused on the layout, structure and use of PILs in health communication, the optimal contents of PILs is less clear when it comes to communication about sexual health in COPD. Drawing on existing studies of sexual health in COPD, there is a clear overweight of studies focusing on erectile dysfunction (e.g.,<sup>11,49,50</sup>) Such studies are, quite naturally, gender-skewed, and represents a relatively mechanistic approach to sexual health, whereas results of existing qualitative studies<sup>51–53</sup> act as a

supplement by revealing that sexual activity is one systemic aspect of living a normal life and acting out or confirming an intimate relationship in times of physical limitation and psychological distress. Another consequence of taking this systemic perspective is that the partner cannot only be considered as “the caregiver,” but also as the receiver of intimate correspondence through the sexual relationship. This has been referred to as the concept of “sexual equilibrium,” which implies that any alteration in the emotional, interpersonal and sexual life in one partner will produce a change in the other – “there is no such thing as an uninvolved partner in a marriage where sexual dysfunction exists”.<sup>54</sup> Taking the systemic approach into consideration when designing the contents of PILs for sexual health communication in COPD can therefore be considered a corner stone of providing optimal care for the patient, the partner, and the two of them as a couple.

Taking a more general perspective on sexual health communication, sexual normativity impacts individuals’ perception of what bodily appearance and behaviour is sexually acceptable and attractive, which can lead to shame and stigmatization for those who fall outside the (gender; physical ability) norm – also referred to as “crip (cripple) theory”<sup>55,56</sup>—which can impact communication between patient and healthcare provider. Gender roles and physical ability in relation to sexual norms and behaviour has been lively debated on political and philosophical levels,<sup>57</sup> but is less investigated in relation to specific illnesses and how it can be targeted in healthcare systems with the purpose of increasing sexual well-being.

## Conclusions

With the purpose of designing PILs in COPD and sexual health in the future, the present review sought to highlight relevant literature regarding content and design of PILs and discuss its application in sexual health communication in COPD. Improvements in readability of leaflets and use of illustrations so it matches the literacy level of the target population is key. Caregivers often feel ignored and uninformed, and PILs could serve an important role in covering the information needs of both patients and caregivers. However, clinicians often feel that they do not possess adequate abilities to address such issues, and implementation of high-quality information material, as well as training in using them in communication, is therefore highly relevant. Lastly, when evaluating the use of PILs in clinical practice, there is a need for comprehensive evaluation models.

Due to the very limited magnitude of literature that specifically focus on PILs to support sexual health communication in COPD, we addressed additional literature concerning communication needs and barriers in other somatic (e.g. cancer) and/or demographic populations, which potentially compromises the translational value of the conclusions to COPD. Moreover, due to the scarcity of literature in the area, a systematic summary of study data made little sense. Hopefully, an increased number of studies in the future may result in a larger evidence base that can be subjected to a systematic quantitative and/or qualitative summary.


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## ORCID iD

Sandra Esperanza Rubio-Rask  <https://orcid.org/0000-0002-9181-5170>

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