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Imaging and imagining chronic obstructive pulmonary disease (COPD): Uruguayans draw their lungs

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ABSTRACT

Purpose: This anthropological study investigated what people imagined chronic obstructive pulmonary disease to look like in their lungs, what may be influencing these images and how this imagery shapes embodiment.

Method: Employing graphic elicitation, in one of multiple ethnographic interviews, participants were asked to draw their lungs: "If we could look inside your chest now, what would we see?" Lung drawings and accompanying narratives and fieldnotes from 14 participants were analyzed for themes and patterns.

Results: The theme of "imaging/imagining" emerged and three distinct patterns within this theme were identified: the microscope perspective, the X-ray perspective and the reduced pulmonary capacity perspective. These patterns demonstrate how embodiment can be shaped by an integration and reinterpretation of the medical images that form part of everyday clinic visits and pulmonary rehabilitation.

Conclusions: Medical technology and images impact patients' embodiment. Understanding this is important for rehabilitation practitioners who work in a challenging space created by potentially conflicting medical narratives: on the one hand, chronic obstructive pulmonary disease is incurable permanent damage, and on the other, improvement is possible through rehabilitation. Drawing could be integrated into pulmonary rehabilitation and may help identify perceptions of the body that could hinder the rehabilitation process.

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KEYWORDS

Chronic bronchitis; chronic obstructive pulmonary disease; drawing; emphysema; medical imagery; phenomenology; Uruguay

► IMPLICATIONS FOR REHABILITATION

- Drawings, when combined with interviews, can lead to a deeper and more complex understanding of patients' perspectives and embodiment.
- Rehabilitation practitioners should be concerned with how patients embody the medical technology and imagery they are exposed to as part of the educational component of pulmonary rehabilitation and healthcare generally.
- Asking patients to visualize their illness through drawing may help pulmonary rehabilitation practitioners identify perceptions of the body which could hinder the patient's ability to reap the full benefit of their treatment.

Introduction

In the qualitative literature on the experience of chronic obstructive pulmonary disease (COPD), phenomenological approaches have helped researchers and health professionals gain a better understanding of illness experience, particularly the complex interplay of emotional and bodily symptoms [1–8]. Embodiment is a key concept of phenomenology and refers to an existential condition of "being in the world" or "... a process in which meaning is taken into or upon the body" [9, p0.20]. To date, there has been little exploration however, of how people with COPD imagine the illness in their bodies, and how this in turn shapes their experiences of their own embodiment.

Participant-generated drawings (also called graphic elicitation) fall within the domain of visual methods or visual anthropology [10–13] and have proven to be a useful method for research with children [14] and adults. With adults, graphic elicitation has been used to understand whether certain patterns in drawings

correspond to functional, clinical or emotional states [15], the individual experience of a particular event, state or experience socially, emotionally and physically [16–19], and to gain insight into participants' knowledge of the physiology of a condition, or their interpretation of the disease process [20,21].

Understanding this is important because beliefs about what is going on inside the body influence the perception and presentation of illness, and how medical treatment is responded to [22]. "Images encourage embodied knowledge" [23, p0.46] and encourage the sharing of that knowledge between the expert and the researcher (or practitioner in a clinical setting). Drawing, when combined with interviews and other data gathering approaches, can yield deeper and more complex data than would otherwise surface using interviews alone [24].

For Guillemin [25]:

The drawing as a visual product is a visual record of how the drawer understands his or her condition at that particular place and time. In

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this way, drawings, like other representations, can be used as ways of understanding how people see their world [25, p.275].

The aim of this anthropological study was to investigate what people imagined COPD to look like in their lungs, what might be influencing these images and how this imagery shapes embodiment. The study represents an engagement of the anthropology of chronic illness with occupational and rehabilitation sciences [26], and responds to an increased interest in how the tools and insights generated through anthropological approaches can be applied to rehabilitation [27]. Furthermore, this study contributes to filling the enormous gap in research on COPD in the Global South [28,29] where the vast majority of COPD deaths occur [30].

Methodology

Ethnographic study design

This study reports an analysis of participant-produced lung drawings and ethnographic interview and participant observation data. These methods were some of many research tools that made up the ethnographic approach which guided a 12-month social medical anthropology study of living with and caring for COPD in Uruguay (2010–2011). Social anthropology is “a telling about society” [31, p.412], that is grounded in fieldwork which “bring us into direct dialogue *with* others” [32, p.0.8]. Fieldwork is the basis of the ethnographic approach. This study took a quintessential ethnographic approach where the author conducted fieldwork for a full calendar year and integrated herself in society, in particular by living with different Uruguayan families for the entire course of fieldwork. Participant observation consisted of interacting and conversing with health professionals and patients in consultation rooms, at bedsides and in home settings. Detailed fieldnotes of observations and conversations were written throughout and at the end of each day. The research was conducted in Spanish, the author’s 3rd language, which she spoke fluently. One participant was bilingual so the interview occurred in a mix of Spanish and English. In this study, the author, the researcher, the interviewer, the analyzer and the translator are one and the same. Ethical approval for the study was granted by the Department of Anthropology’s Research Ethics Committee at Durham University.

Theoretical foundations

The study drew theoretically on phenomenology [33] and phenomenological and sensorial anthropology [9,32,34,35]. The author subscribed to the notion that a chronic disease can be understood as a chronic condition of fluid states [36] which inspired the emphasis on multiple encounters with the same participants over an extended period of fieldwork.

Setting

At the time of fieldwork, Uruguay was a middle-income country of 3.3 million inhabitants with a life expectancy of 73 for males and 80 for females. While now known for leading in tobacco control, Uruguay has historically had some of the highest smoking rates in the world. In total, 60% of men over the age of 55 are or have been smokers, and a third of women have smoked in their lifetime [37]. Uruguay had some of the highest rates of COPD in the population, and misdiagnosis and underdiagnosis were prevalent [38,39].

The study was multi-sited, involving seven months of fieldwork in the capital city Montevideo (1.5 million inhabitants), and five months in the town of Tacuarembó (55,000 inhabitants). Participant observation [27] was carried out in pulmonology

outpatient clinics in two private and one public hospital in Montevideo, and one private and one public hospital in Tacuarembó. Access to pulmonary rehabilitation was very limited across the country. Of the five institutions accessed, only one public hospital in Montevideo offered it and the ethnography included participant observation of this three-month program. At the time of fieldwork, COPD was a largely unknown disease among the general population. There were no widespread health campaigns or public information displayed about COPD and so it was unlikely that participants had been exposed to information about COPD outside their consultations, rehabilitation or own internet activity after diagnosis.

Study participants

Fourteen participants with COPD drew their lungs (Table 1). Eight participants were male and six were female, ranging between 36 and 72 years old. All but one had quit smoking, and four were oxygen-dependent. All participants were met in secondary and tertiary level outpatient or inpatient care where the author was conducting participant observation. The author introduced the study and asked whether she could observe their appointment and contact them for a home-based interview. Sampling was purposive – the emphasis being on maximizing the range of perspectives on COPD in terms of severity, age and gender. Three were from Tacuarembó, 11 from Montevideo, six from state-funded hospitals and eight from private hospitals. All had undergone spirometry confirming COPD and X-ray, but not all had undergone computational tomography (CT) or magnetic resonance imaging (MRI) (either because it was not needed, not available or they were waiting for such a test). Five of the participants who drew their lungs had completed a pulmonary rehabilitation program (four in the program observed by the author).

Data collection and analysis

The steps taken in employing graphic elicitation are presented here following Guillemin and Drew’s [40] processual framework for contextualizing participant-produced drawings and associated narratives. The ethnographic design of this study meant that there were multiple encounters and conversations with participants through the method of participant observation – usually beginning with meeting them in clinics and observing their appointments, followed by multiple home-based ethnographic interviews. Ethnographic interviews are defined here as “contextualized conversations” [41] that were guided by predefined and emergent research questions but in a loose, largely unstructured format. The drawing exercise fell within at least the third ethnographic interview with each participant and the purpose of this interview was to pick up on, and explore in greater depth, some of the topics covered in previous interviews, and further explore embodiment using drawing and pile sorting (for the analysis of pile sorting data, see [42]).

Participants were asked were asked to draw draw what they thought COPD looked like in their lungs. The more descriptive prompt was “If we could look inside your chest now, what would we see?” The exact timing of the prompt in the interview was not considered important as interviews were conversational and tailored to each participant. Attention was paid to not overly formalize the activity and to present it as a fun exercise rather than a test of their drawing ability or knowledge. Some of the participants were more nervous of drawing than others and all needed a little encouragement and reassurance. Pictures were drawn directly into a fieldnote book and participants were aware these

Table 1. Participants' demographic and clinical characteristics.

Drawing # (Figure 1)	Participants	Age	Sex	Healthcare	Location	Smoking status	Pack years	Home oxygen therapy	PR	Year	Spirometry						
											FVC Liters	FVC %	FEV1 Liters	FEV1 %	FVC/FEV1 %	Post-BD FEV1 Liters	Post-BD FEV1 %
1	Joaquín	72	M	Private	TAC	F-S	52	No	No	b	b	b	b	b	b	b	
2	Tomás	60	M	Private	MVD	F-S	80	No	No	2000	2.56	51	1.78	45	70	2.14	+9
3	Bruno	71	M	Private	TAC	F-S	21	No	No	2011	3.07	122	1.32	67	54	1.41	+7
4	Sebastián	36	M	Public	MVD	F-S	14 ^a	Yes	Yes	2010	2.07	42	0.70	17	34	0.88	+24
5	Marco	55	M	Private	MVD	F-S	30	No	No	2010	3.13	80	1.77	56	57	1.84	+4
6	Macarena	59	F	Public	MVD	F-S	17	No	Yes	2010	2.39	82	1.34	56	56	1.34	0
7	Gustavo	54	M	Public	MVD	F-S	31	No	Yes	2010	2.19	57	0.73	23	41	c	c
8	Soledad	72	F	Private	MVD	F-S	125	No	No	2009	1.31	51	0.92	44	70	0.95	+3
9	Vivian	62	F	Private	MVD	F-S	21	No	No	2010	3.08	104	2.19	92	71	2.31	+5
10	Martín	60	M	Public	MVD	F-S	38	Yes	Yes	2010	1.31	29	0.81	22	62	0.95	+17
11	Claudia	50	F	Private	TAC	F-S	26	Yes	No	2010	1.44	48	0.35	14	30	0.52	+21
12	José	53	M	Private	MVD	F-S	120	Yes	No	2007	4.03	97	2.38	73	59	2.75	-18
13	Daniela	61	F	Public	MVD	S	28	No	No	2009	2.18	85	1.84	78	74	1.62	-12
14	Patricia	45	F	Public	MVD	F-S	28	No	Yes	2009	1.88	65	0.55	22	29	0.53	-3

M: male; F: female; MVD: Montevideo; TAC: Tacuarembó; F-S: former smoker; S: smoker; PR: pulmonary rehabilitation; FVC: forced vital capacity; FEV1: forced expiratory volume exhaled in one second; BD: bronchodilator.
^aSmokes hand-rolled tobacco. Pack years based on an equivalence estimate of 60 cigarettes per pack of loose tobacco. ^bParticipant's doctor confirmed with the researcher that the patient had received spirometry in 2006 that confirmed COPD, but data are not available as spirometry report was not seen by the researcher. ^cData are not available at the time of data collection but doctor's written report confirms very severe obstructive disease and cor pulmonale.

became part of the data set. When they finished drawing, they were asked to describe and explain their image.

Images and the recorded interviews were analyzed simultaneously [40,43]. Following Guillemin and Drew [40], the first layer of interpretation of the image comes from the participant who explains and talks through the image. The second "overall analysis" [40, p.184] comes from the researcher who, with access to the whole data set and other contextual knowledge, and also enough distance, can identify patterns. Researcher distance in this case came from extended fieldwork across multiple settings and the fact that the explicit analysis of these drawings came after the entire year of fieldnotes had been coded (months after leaving Uruguay). Drawings were digitally scanned and imported to the NVivo 9 [44] project alongside fieldnotes and interview recordings which facilitated immersion in the data by being able to move between seeing the image, listening to the descriptions, memoing and transcribing. Analysis was interpretive and inductive [27,45] focusing on the identification of patterns of similarity and difference, and developing an interpretation of these patterns. The findings presented here are these interpreted patterns.

These images can only be taken as a snapshot – an understanding of participants' "... condition at that particular place and time" [25, p.275] – of what is a probably ever-changing conceptualization of COPD in the body. The fact that these images were prompted by the author also means that, like interview data, these are social constructions and it is impossible to say specifically and with certainty how the researcher, the context, the exact timing or recent events shaped the images. However, it is worth noting that none of the participants were experiencing an acute exacerbation at the time of drawing. Also, the author never used visuals of COPD in interviews, and so it is firmly believed that these images represent co-constructions occurring in clinical spaces, rather than through participation in the research.

The credibility [27] of the interpretation presented here is strengthened by the fact that there was prolonged engagement with participants and the data, that images were triangulated against ethnographic interviews and extensive participant observation and that the interpretations were discussed with peers (PhD supervisors, examiners and at a conference). However, member checking was not conducted and only the author had access to raw data. The interpretations presented are therefore uniquely the author's. Others, if they had done the fieldwork and accessed the full data set, may have come to different interpretations and conclusions. Sanjek [31] proposes "validity" as the ethnographic equivalent of "reliability." This study meets Sanjek's [31] criteria for validity by making explicit the theoretical foundations, the context in which the participants were met and the fieldnote data.

Findings

The most clear and compelling theme¹ identified by the author in the 14 images (Figure 1) and narratives was that of the influence of medical imagery and technology on how COPD is visualized – termed "imaging/imagining COPD." Within this theme, three patterns of "imaging/imagining COPD" were identified: "the microscope perspective," "the X-ray perspective" and "the reduced pulmonary capacity perspective."

The microscope perspective

Macarena represented her understanding of what was going on inside her body by comparing it to a normal lung. She said that her lungs are obstructed. On the right, she has represented a normal lung by drawing a bronchial tube (the circle) and alveoli

(the cauliflower shape) (Figure 2). On the left is how she imagines her lung. She said you can see that her bronchial tube is obstructed so that “there is not much capacity for air to enter and leave.” Then she explained that the things “that look like little bags or a vine of grapes, which are called alveoli, transport blood and are where the oxygen gets in.” These are also obstructed, she said, “it lets the air in but not out so that you can’t oxygenate properly.”

Martín had a distinct understanding of his lungs which was related to his dual experience of being asthmatic since childhood and having COPD at the age of 60. His picture represents the lungs (above) and the bronchial tubes (below) (Figure 3). He said that the way he understands it is that the bronchial tubes are not in the lungs, “they are outside.” “My lungs are damaged because they have COPD and cigarette smoking has dried them out.” However, for him, his breathlessness comes from his bronchial tubes being small because of asthma and therefore he takes the inhalers to open his bronchial tubes and treat asthma, not treat his COPD. He explained that the oxygen, which he uses permanently, is what he uses for the COPD.

The striking feature common across both Macarena’s and Martín’s drawings is the way in which bronchial tubes and alveoli are represented as distinct drawings within or even outside the lungs. Also, in both their drawings, the bronchial tubes appear as a cross-section. Both had completed a three-month program in pulmonary rehabilitation at which it was observed that the healthcare professional used pharmaceutical industry posters showing the pathology of COPD in the alveoli and bronchi in the lungs. Below is a similar image from the “Living Well with COPD” program (Figure 4) [46], alongside Macarena and Martín’s drawings.

Considering these images side by side, it is therefore entirely understandable how Martín had come to understand the bronchial tubes as being outside the lungs. The magnification of a small section of the body, implicit in these kinds of medical images, can be easily misinterpreted. In both cases, the participants clearly understood that their lung problems included two elements of the respiratory system: the bronchial tubes and the alveoli. However, where they were placed and their relative size or

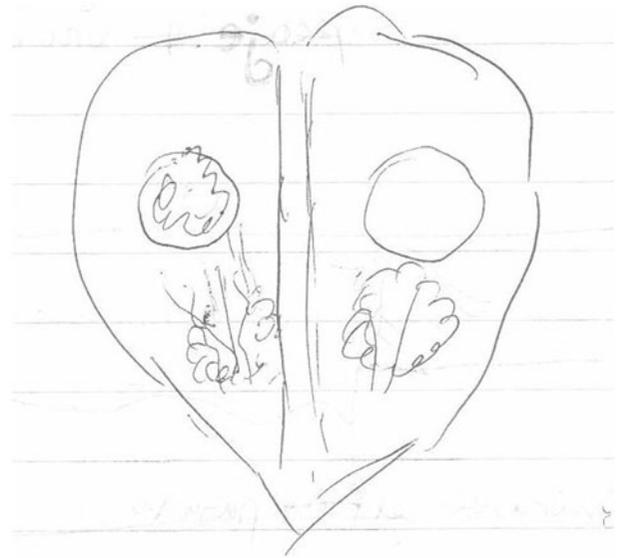


Figure 2. Macarena’s lungs.

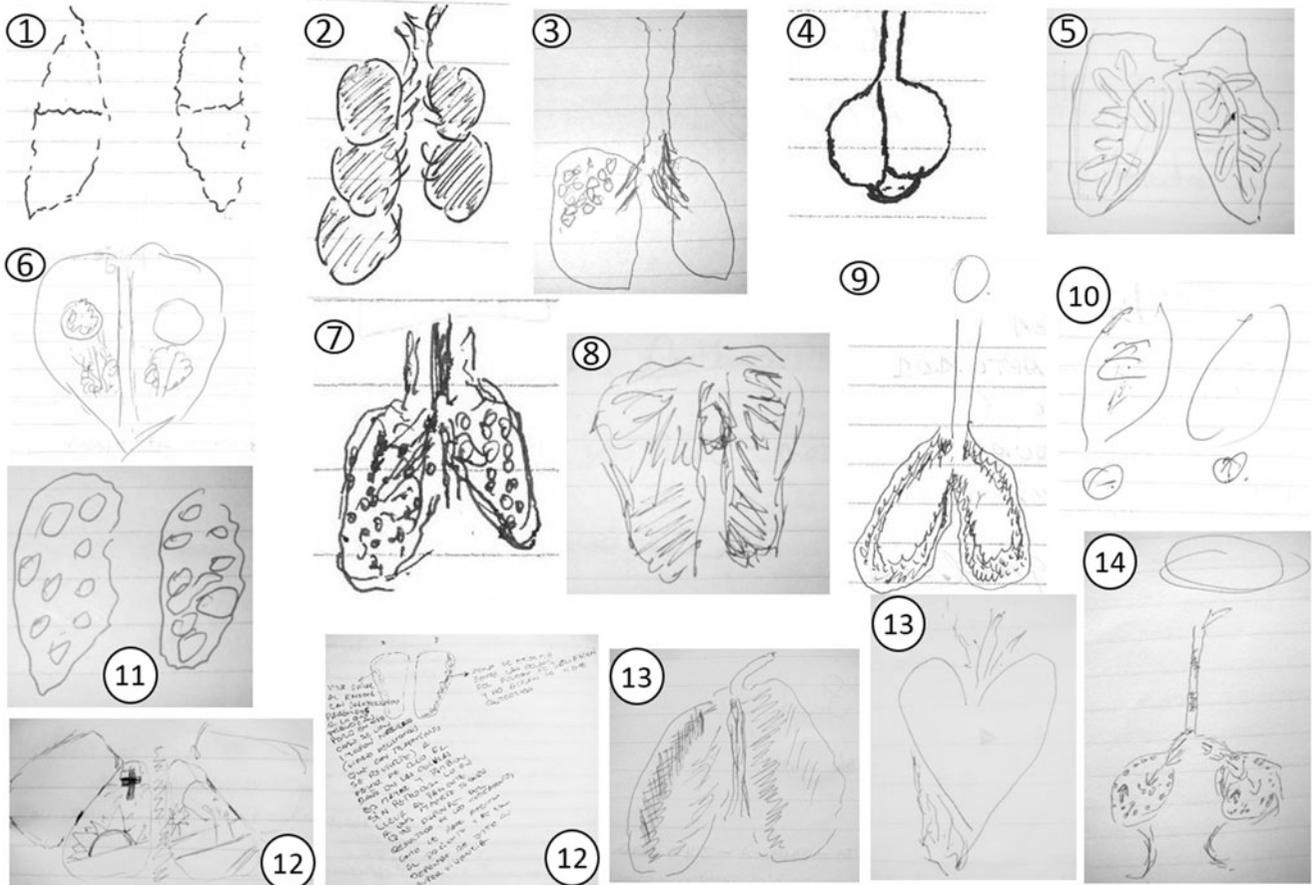


Figure 1. All drawings.

number remained less clear. Their visual and imaginative lens was that of magnification via microscope. Martín's image of the bronchial tubes outside the lungs supports his theory that asthma affects the tubes and COPD affects the lungs which in turn require different treatment.

The X-ray perspective

The co-construction of visual perspectives is also evident in the way in which some participants referred to X-rays. The co-construction in this case is a dynamic process taking place between the patient, the health professional and the image. Consider the following examples:

Tomás, 60, was the epitome of the "expert patient." During one of his observed appointments, he was invited by the doctor to walk around behind his desk and look at his X-rays as features were being pointed out. In his home, Tomás explained that he had learned to read X-rays, just as he had learned when he should start antibiotics and corticosteroids. He frequently used the internet to look up information on COPD and medications. Interestingly, when asked to draw his lungs, not only was he the only participant who drew them as a sum of five lobes (as indeed

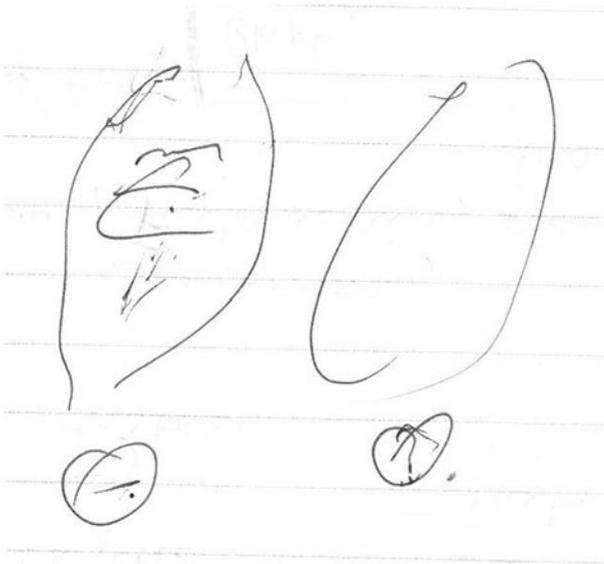


Figure 3. Martín's lungs.

they are), he also colored them in black (Figure 5). This was not, however, in reference to dirty lungs, as implied in other occasions by participants talking about black lungs. Rather, he said that in the X-ray, the area with emphysema "looks totally black."

Gustavo, 54, explained that he deliberately made the lobe on the right incomplete (Figure 6). He said that on his X-ray, he can see that one lung is whole, whereas on the other side, part of the lung is missing. He searched for the word for alveoli but could not remember it so said "those little dots, those little 'bags', they don't have any elasticity, they have nothing." He then started inhaling and exhaling deeply with his hands on his rib cage to show that his chest did not expand because of this loss of elasticity. He asked to see from the outside, what he feels and imagines on the inside – i.e., this loss of lung and internal elasticity.

When Tomás and Gustavo drew their lungs, they were seeing their lungs through the lens of an X-ray or CT. They expressed this in the following ways: that certain parts of their lungs are "black," and that certain parts of the lung seem as though they are "missing." In Figure 7, Tomás' and Gustavo's drawings have been placed next to images of emphysema produced by X-ray and CT scans used in Midgley's [47] edited book *Chronic Obstructive Pulmonary Disease: A Forgotten Killer* (2008). The caption under the image from Midgley [47] explains that the arrows in Figure 6.1a (Figure 7) point to darkened areas of the lung which represent trapped air called bullae caused by emphysema. Figure 6.1b (Figure 7), a CT scan, shows how the areas where there are bullae are transparent (i.e., as though there are parts

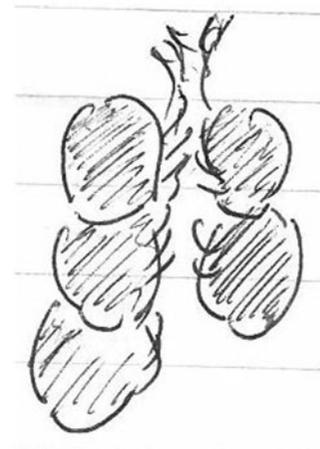


Figure 5. Tomás' lungs.

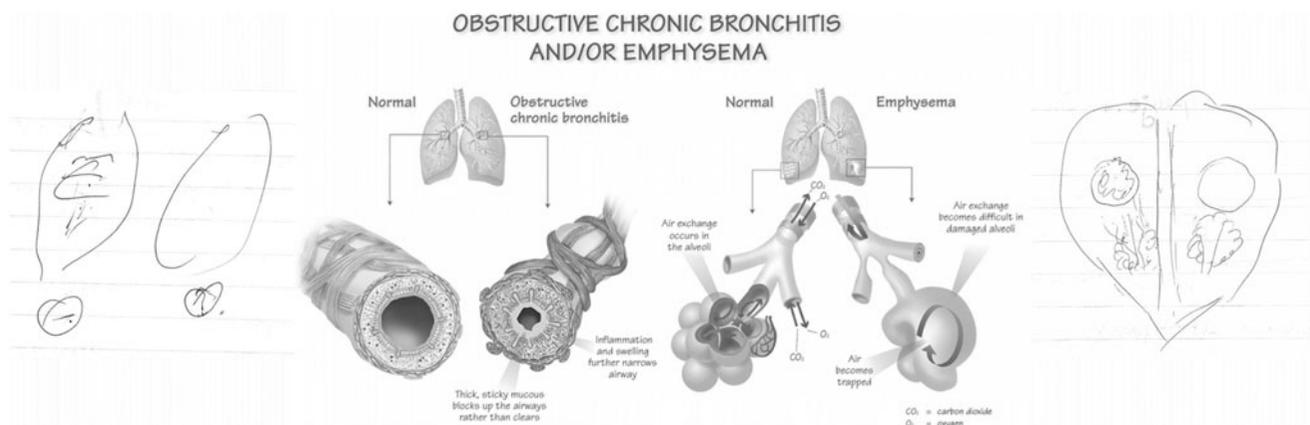


Figure 4. Comparison of participant and medical drawings. Medical illustrations from "Living Well with COPD" reprinted with permission from RESPIPLUS™ [56].

missing) and arguably could be interpreted as looking black and not transparent. The comparison illustrates the way in which perspective, in this case a biotechnological perspective, might be taken up by some patients, which in turn shapes their understandings and imaginings of COPD in an embodied sense. In this case, Gustavo and Tomás are both speaking, seeing and thinking from an X-ray perspective. In so doing, they make the non-reversibility of their COPD, in relation to the damaged structure of the lung, very clear to themselves. Gustavo in particular could feel that part of his lung “was missing” when he inhaled and exhaled and felt a difference in the expansion of the rib cage on the right and left.

The reduced pulmonary capacity perspective

In contrast to the previous two patterns which highlight how images have been embodied, the third highlights how measurements of reduced pulmonary capacity are visualized in a physical sense. Participants largely agreed that COPD was a disease of the bronchial tubes and the alveoli, and they understood that they lost or were losing pulmonary capacity or respiratory capacity. While X-rays or CT scans let you see emphysema, these technologies cannot directly visualize a person’s pulmonary capacity. For this, pulmonary function tests (spirometry) are used which

produce numerical and graphical representations of how much lung function one has in relation to what would be expected of a healthy person of the same age, gender, height and weight. Participants often knew their percentages of pulmonary capacity.

Each of the images and narratives below convey the idea that there is a whole lung but only part of it is available for respiration and receiving air. Therefore, even though pulmonary function is measured by quantifying breath through a machine, these images suggest that some participants visualized reduced pulmonary capacity as having less space for air in the lungs, in a literal sense.

Sebastián, after saying he did not know how to draw lungs, produced the drawing in Figure 8. He explained that the vertical line that seems to run between the lungs represents one lung being blocked off. He said this is the sensation he experiences when “*me falta el aire* (when I lack or am out of air/short of breath), as though there is one lung that is working more than the other,” he said. In response to being asked what it is like when he is not breathless, he said that when he is sitting or not doing anything strenuous, it is open and he can feel the air in both lungs.

Joaquín, 72, who no longer considered himself ill with COPD, said he barely noticed his COPD ever since he was diagnosed and had received treatment. He no longer experienced exacerbations like he used to – ones that required a home visit from a doctor, nurse or ambulance. He understood his COPD in terms of a



Figure 6. Gustavo’s lungs.

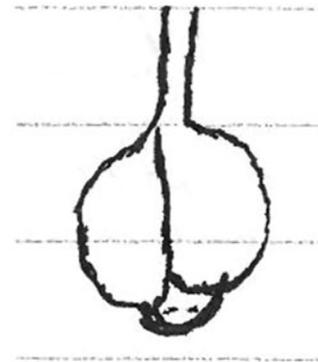


Figure 8. Sebastián’s lungs.



Figure 6.1 Images of the lungs of two people with severe emphysema. (a) An X-ray image of a lung with large areas of trapped air, called bullae (indicated by arrows). (Source: GJLP/CNRI/Science Photo Library). (b) A CT scan showing bullae as more transparent areas compared with the rest of the lung. (Source: Du Cane Medical Imaging Ltd/Science Photo Library)

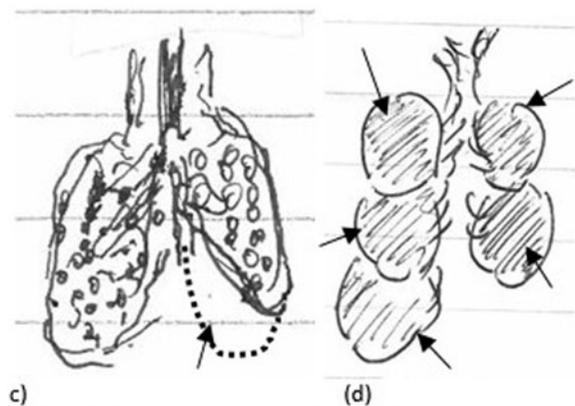


Figure 7. The X-ray perspective: comparison of (a) X-ray of the lungs with emphysema [M150/0338] and (b) a CT scan of lungs with emphysema [M150/0223] (As appears in Midgley [47], reprinted with permission from Photo Science Library) with (c) Gustavo’s and (d) Tomás’ lung drawings.

Gustavo’s drawing emphasised that there was a section “missing” on his left lung (c). Tomás coloured-in the five lobes to demonstrate that they are black. Both are speaking, seeing and thinking from an x-ray perspective.

reduced pulmonary capacity. He was apprehensive about drawing but in the end produced this picture of two lungs with a line dividing each of them (Figure 9). He explained that the line represents having only a portion of one's original pulmonary capacity left. Interestingly, this underlying state has not implied ill health since the control of his symptoms was achieved.

Vivian drew her lungs and then colored in a dark circumference (Figure 10). She explained that the white space represented the pulmonary capacity or the space for air she had left. She said that from what she understands, she does not have very much pulmonary capacity and that "it's a bit squeezed because of other stuff occupying the dark part." She did not know what was in the dark circumference, i.e., what exactly was taking up space where air should be. When asked she said, "Maybe it's COPD or something from the cigarettes, but there is less space for the air." Interestingly in this case, it mattered not that Sebastián had very severe COPD and Vivian only very mild COPD, they both marked large areas of the lung as "blocked off," "squeezed off" or reduced. Unlike Vivian and Joaquin however, Sebastián's blockage seemed to come and go depending on how much exertion he was doing.

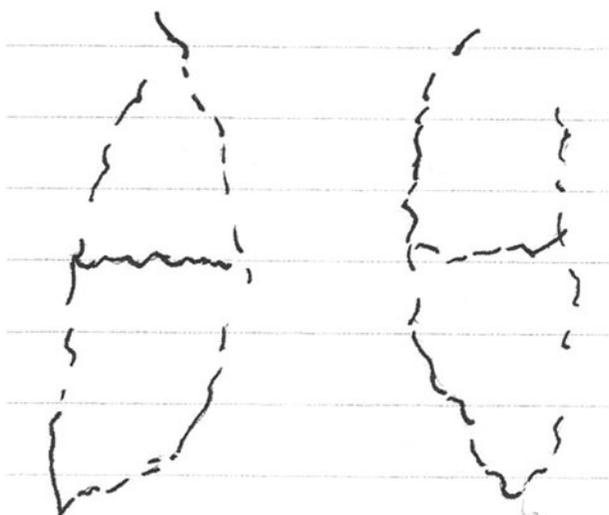


Figure 9. Joaquín's lungs.

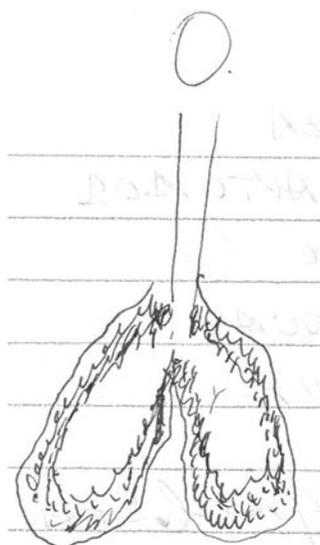


Figure 10. Vivian's lungs.

Discussion

In this study, participants were asked to draw what they thought their lungs looked like, and what emerged was evidence of the impact of medical technology and imagery on embodiment – imagery which either magnified COPD, visualized damaged lungs or measured pulmonary capacity. This was noted regardless of where participants were from or whether they had private or public healthcare. Participants' drawings shed light onto how medical imagery can be taken into one's embodiment of the illness, a similar point made by Reventlow et al.'s [48] study of healthy women who underwent a bone scan for the prevention of osteoporosis. They found that women, who saw their bone images and who conflated "risk of" with "having" osteoporosis, saw their bodies as "weak" and "fragile," and interpreted sensations in the body (such as pain) as indications of the disease.

In the case of COPD, the influence of medical technology and imagery on embodiment could have important implications for pulmonary rehabilitation. In this discussion, it is argued firstly that the image of permanent, irreversible damage represented in many of these drawings could conflict with the message of pulmonary rehabilitation – that improvement in function and quality of life is possible. Secondly, it is suggested that pulmonary rehabilitation practitioners (members of the healthcare team of any profession) could incorporate drawing methods into their assessments with patients in order to explore the embodiment of medical imagery and help identify perceptions of the body that could hinder patients' ability to reap the full benefit of treatment.

Embodied irreversibility: implications for pulmonary rehabilitation

In Halting and Heggdal [49], participants arriving into pulmonary rehabilitation mainly recalled that the initial information received from their general practitioner was that COPD was an incurable illness. However, attending pulmonary rehabilitation reminded patients of their remaining health. This points to the fact that pulmonary rehabilitation is placed in an awkward position vis-à-vis patients diagnosed with chronic illnesses such as COPD. On the one hand, the diagnosis emphasizes the incurability of the illness, especially to incentivize patients to quit smoking. On the other hand, the message of rehabilitation is that one can improve in function, quality of life and emotional health, despite an underlying chronic and incurable disease [49]. Indeed, Stromberg et al.'s [50] study of people with COPD's attitudes toward exercise found that participants were ambivalent and unsure of the benefit of exercise, as "... to their knowledge there was nothing to improve or to be gained" [50, p0.1426]. There was, in their participant group a strong sense of helplessness. In Harrison et al.'s [8] study of people with COPD who refused pulmonary rehabilitation after hospitalization, they found that participants demonstrated low feelings of self-worth and normalized their condition in order to maintain emotional equilibrium.

In this study, the image of "black," "missing parts," "having sections blocked off," "having less room in them for air" and being "all obstructed" solidified the message that damage was permanent and irreversible. Such notions may also contribute to the vulnerability, anxiety, panic and fear that we know from previous research is part of the experience of chronic and acute breathlessness caused by COPD [4,50–53].

Lewis et al. [54] suggest that more needs to be done to determine whether framing COPD as a cyclical disease rather than a chronic deteriorating process could reduce uncertainty and panic. At the time of this study, coming to terms with the irreversibility

of COPD was a part of patient care and the process of acceptance of the diagnosis. However, elaborating on Lewis et al.'s [54] point, research has not amply studied how the idea of incurability conflicts with the notion of improvement and whether a reframing as Lewis et al. [54] suggests could be beneficial.

Drawing: a tool for rehabilitation

In the clinic, pulmonary rehabilitation practitioners may be best placed to explore and address these issues in embodiment. In Winance's [55] phenomenological study of rehabilitation and reeducation for people living with chronic pain, she makes the case that reeducation is "not only functional, it also helps one to 'learn to feel one's body'" [55, p0.1115]. As a body is transformed by pain [55], a body is also transformed by COPD. The inside of the body is out of view, but is still perceived. Medical technologies such as scans and spirometry make the body's invisible parts visible [48]. When perceptions of the body meet images externalizing the inside body, hybrid interpretations may emerge alongside changes in embodiment, new symptom interpretation and new actions [48]. Lewis et al. [54, p0.176] refer to the process of embodying medical information and the expression of it through a mix of lay and medical terminology as "pathophysiological perceptions." Medical information is considered key to addressing patients' insufficient knowledge and education about their condition [54,56,57]. Rehabilitation programs perform a key role in education around the disease and patients appreciate receiving additional knowledge about the disease and how it is treated [58]. However, it is equally important that the impact of medical information on patients be evaluated and pulmonary rehabilitation practitioners are well placed to do this.

The results of this study suggest that pulmonary rehabilitation practitioners (and possibly other members of the healthcare team) could gain important insight into how COPD is imagined by the patient, and how medical imagery finds its way into patients' conceptualizations by simply asking patients to draw. This could be made part of a patient's needs assessment [57] or incorporated into a family-based approach to pulmonary rehabilitation [59]. The method requires careful thought and reflexivity but is also simple and flexible enough to be incorporated into diverse pulmonary rehabilitation settings. The point is less about identifying if patients have got it "right" or "wrong," and more about offering health professionals an opportunity to investigate whether a patient's interpretation is positively or negatively affecting their chances of reaping the full benefits of treatment. In Martín's case, his image could be taken up by a rehabilitation practitioner to enquire as to whether he takes his medications in an appropriate way for COPD.

Future research

Despite the common reference to COPD as an invisible illness both in social terms (the disability can be hard to see) and biological terms (the disease is hidden inside the lungs), there exists many technologies that visualize the illness such as X-rays, CTs, MRIs, oximeters and spirometers and the impact of these on patient conception and experience of illness is an important area of future research. How does embodied experience of improvement reconcile itself with images of permanently altered lungs such as those represented in the drawings presented here? Is Joaquín's experience of visualizing his lungs as having half the capacity, yet feeling like he is not at all ill, common or exceptional? And how might these visualizations of the physicality of COPD shape perspectives on the possibility of improvement and

the benefit of pulmonary rehabilitation? While this study raises some of these questions, more research is needed to answer them.

Reflecting on images and context

Medical anthropology theory and literature remind us that neither illness categories, biomedicine nor the human body should be taken as single entities around the world [60]. The vast majority of research on COPD comes from the Global North and while this is a rare example from the Global South, it is unclear whether there is anything particularly Uruguayan about the way in which medical images shape how COPD is imagined by these participants and so no such claims are made. Some contextual factors may be important though. Uruguayans with COPD may spend more time viewing their spirometry results and their X-ray results because it is common place for patients to keep their own medical records. Also, one participant's comment that he knew what lungs looked like because he had butchered a lot of animals raises the possibility that the culture of Uruguayan *asado* (barbecue) involving the self-slaughter (in rural areas) of animals, and the consumption of meat on the bone and some internal organs, could mean the Uruguayans have a better sense of the shape and features of internal organs than other nationalities. However, further cross-cultural research is needed if claims to cultural specificity are to be made.

Study limitations

In this study, participants were prompted to draw what they thought COPD looked like in their lungs. Seeing that COPD is increasingly understood as a systemic disease affecting multiple bodily systems, the prompt's emphasis on lungs was, in retrospect, a limitation. Future studies employing such a method should consider not binding the question to the lungs only. Also, in response to the prompt, one participant asked: "What does it look like to me, or what does it look like?" He was asked to draw both and in one he produced a symbolic representation (setting and rising suns, flowers and graves), and in the other what he thought his lungs looked like with detailed medical description (Figure 1, drawings #12). The study could have expanded the drawing method by encouraging all participants to produce different images from different perspectives. While the author was fluent in Spanish, a mother tongue Spanish speaker for future studies in this context may offer an advantage in terms of mastery of the subtler aspects of language.

Conclusion

Research in pulmonary rehabilitation for COPD patients has argued that by exercising, patients learn through their bodies the limits of the disease's disabling effects [49]. While COPD's disabling effects are felt and experienced subjectively by individuals, these same individuals are exposed to medical visualizations of COPD pathology through X-rays, CT scans, spirometry, oximetry and other technologies. We infrequently consider what these external readings of the body mean to patients. This study's use of the drawing method showed how medical information is embodied, reimagined and reinterpreted by people with COPD and what the implications for rehabilitation might be. Incorporating drawing exercises into pulmonary rehabilitation may offer another opportunity for taking stock of how patients imagine their disease and visualize its incurability. Further studies are needed to determine whether this embodiment of imagery

across settings is common, whether drawing could be a useful assessment exercise for rehabilitation practitioners and whether drawing could serve as a catalyst to helping patients reframe their conceptualization, and in turn, their experience of, their bodies and breath.

Note

1. Two additional themes, not the focus of this article, were as follows: adopting medical metaphor and seeing COPD in relation to another illness. The latter has been discussed briefly elsewhere [42, p.163].

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