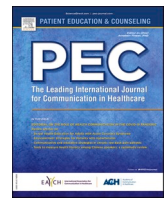


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Exercising power in the self-management of COPD: A narrative inquiry. Patient and user perspectives

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ABSTRACT

Objective: To develop an in-depth understanding of how people with COPD exercise power in the self-management of their illness.

Methods: This was a narrative inquiry using Foucault's concepts of power, knowledge and agency as a conceptual framework. Up to three unstructured interviews were conducted with 31 people with COPD in the Republic of Ireland. Thematic template analysis was used to analyse the data. The COREQ checklist was used to report this qualitative study.

Results: The findings of the study show that participants exercised power through mobilising agency in two main ways. They resisted the imposition of power by leveraging different types of knowledge. They also engaged in practices designed to operate on the self and the body in order to achieve happiness and health. However, this agency was constrained by the imposition of power by health care professionals.

Conclusion: The findings expand the understanding of self-management as a complex and multi-dimensional concept that is negotiated and constructed by people with COPD, using their own knowledge and agency.

Practice implications: Honouring the considerable skills and resources that people with COPD mobilise to self-manage should form the heart of person-centred self-management support.

1. Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a common but underdiagnosed illness of the lungs and airways, usually caused by significant exposure to "noxious particles or gases" [1], including tobacco smoke. It is characterised by breathlessness, chronic airway obstruction, and chronic cough with sputum production [2]. These everyday symptoms can be punctuated by exacerbations of respiratory symptoms. It is estimated that the global prevalence of COPD is 10.3%, and this is expected to rise [3]. A central element of COPD treatment is the requirement for individuals to follow complex treatment and self-management regimens [4].

Self-management refers to activities, triggered by illness, undertaken to manage the experience of living with COPD every day [5]. The concept of self-management originally emerged from the development of the self-help movements in the 1960s and 1970s and the rise of consumerist approaches to health care [6] and emphasised the power of patients to direct the management of their illness. However, in the 1980s and 1990s increasing attention was paid in "rich world" nations to the

potential of self-management to reduce the impact of chronic illness on health service utilisation and associated costs [7].

The literature review that underpins this study found that self-management is predominantly conceptualised as medical in focus, with an emphasis on compliance with the prescriptions of health professionals, and with much less attention paid to the experiences of people living with COPD in self-management [8]. Despite literature that highlights the experience of people with chronic illness as a source of power [9–14] there is little or no literature that investigates how individuals with COPD exercise power in the self-management of their illness. The exercise of power in COPD self-management is defined as the ability to create change [15,16]. It encompasses both the exercise of power *on* individuals by dominant others, and the exercise of power *by* individuals to effect change (agency). The study of the exercise of power by people with COPD in their self-management adds valuable information for policy makers and health care professionals to facilitate and improve the design and delivery of interventions to support COPD self-management practice. Based on these considerations, the aim of the study was to develop an in-depth understanding of how people with

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COPD exercise power in the self-management of their illness.

2. Methods

2.1. Theoretical framework and methodology

The qualitative methodology of narrative inquiry was selected for this study, using Foucault's [17,18] concepts of power, knowledge and agency as a conceptual framework (see Fig. 1). Narrative inquiry refers to a family of methods for analysing and interpreting texts that follow the form of a story: oral; written; or visual [19]. In Foucauldian approaches to narrative inquiry, the power relations at play in the emergence and sustaining of particular narratives become the focus of study [20–22].

2.2. Study participants

2.2.1. Population and sample

The population for this study were adults aged over 18 with a diagnosis of COPD. The sample was drawn from members of local COPD support groups (n = 390), under the umbrella of a non-governmental organisation (NGO), COPD Support Ireland. Purposeful criterion sampling was used as it ensured access to people who had experience of living with and managing COPD over time [23]. The principle of data saturation was not used to determine the sample size. Narrative inquiry does not rely on data saturation, treating each person's narrative as unique in its own right [24].

2.2.2. Recruitment

Participants were recruited to the study through COPD Support Ireland, who acted as gatekeeper. Recruitment packs were sent to the Chairpersons of the ten local support groups active in the Republic of Ireland at the time (January 2017) for distribution to individual members. Recruitment packs included a reply slip which could be returned to the first author (SD) using a pre-paid addressed envelope. Those who responded were contacted by telephone to explain the study in more detail. If they wished to take part, a time and date was arranged to conduct the initial interview. 31 eligible people with COPD were recruited to the study by this method. A detailed description of participants is presented in Table 1.

2.3. Ethical considerations

Formal ethical approval was granted by the Trinity College Dublin, School of Nursing and Midwifery Research Ethics Committee in June 2016. Written informed consent was obtained from all participants at each interview. In addition to formal ethical approval for this study, steps were taken to manage any participant distress during fieldwork. If an individual became distressed, they were offered two options of suspending or terminating the interview, and/or referral back to COPD

Support Ireland for follow-up.

2.4. Data collection

Up to three unstructured in-depth face-to-face audio recorded interviews were conducted by the first author (SD) with the 31 participants from 2017 to 2018, with approximately six months between each interview. The interviews were based on Jovchelovitch and Bauer's [25] phases of the narrative interview (see supplementary files 1 and 2 for more detail).

An attempt was made to interview every participant at least twice and this was achieved for 26 people. Five participants were interviewed once only and were lost to follow up (due to family illness (n = 1), personal illness (n = 2), and being uncontactable at the time of scheduling second interviews (n = 2)). The audio files and the transcripts of the first and second interviews were examined to determine if there were any questions arising that would necessitate a third interview [26]. On this basis a list of 13 participants was drawn up who were interviewed a third time.

Participants could choose to include a family member in one or more of the interviews, and ten family members joined in participant interviews. Participants were interviewed mainly in their own homes. Three people chose to take part in interviews in hotels (n = 2) or a café (n = 1). Interviews were recorded using a digital audio recorder, and lasted between 16 min and one hour 24 min. Reflexive field notes were written as soon as possible after each interview. Participants were offered the opportunity to read the transcripts of their interviews.

2.5. Data analysis

Thematic narrative analysis using King's [27] template approach was employed to analyse the data (see Table 2). This approach combines *a priori* deductive analysis with inductive analysis arising from close reading of the interview transcripts.

Interviews were transcribed in full and imported along with accompanying field notes to NVivo 12. Initial thematic coding to *a priori* codes (based on the Foucauldian conceptual framework set out in Fig. 1), inductive codes and sub-codes was undertaken by the first author (SD). This resulted in an initial coding template based on the interviews with the first ten participants. This was applied to the following cases, with modifications and adjustments where necessary to allow for analysis of data relevant to the research question which the initial coding template did not adequately cover. This resulted in the production of a final coding template (see supplementary file 3). Post-coding analysis was then undertaken. Key narratives were highlighted, and annotations and analytic memos were written to link the coded data with the conceptual framework. The themes and sub-themes were drawn together to generate a higher order conceptual narrative of participants' exercise of power in the self-management of their illness.

2.6. Research team and reflexivity

All members of the research team are women. The second (SHM) and third (PC) authors supervised this PhD study. No prior relationship existed between the research team and the participants in this study. The first author (SD) has a background in Social Anthropology and Applied Social Research (MSc) and 15 years' experience of conducting qualitative research interviews. As a full-time, doctoral student the first author (SD) conducted the interviews. The second (SHM) and third (PC) authors have considerable experience in teaching, conducting and supervising qualitative research projects. The first author (SD) engaged in critical self-reflection and journaling throughout the study to ensure the final narratives were co-constructed with the participants, taking account of the assumptions and positioning of herself and the participants.

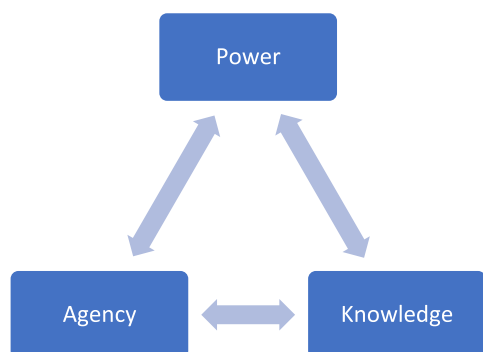


Fig. 1. Foucauldian conceptual framework for this study.

Table 1
Participant characteristics.

ID/ Pseudonym	Gender	Age	Living alone Y (yes)/ N (no)	Self-reported severity of COPD (GOLD criteria)	Self-reported comorbidities	Help with personal/ practical care Y (yes)/ N (no)	Treatment for COPD
1/ Eoin	Male	66	N	Very severe	Gastro-oesophageal reflux disease (GORD), hiatus hernia, pharyngeal pouch, arterial narrowing	Y Spouse/partner	Antibiotics, steroids, inhalers, nebuliser, oxygen, pulmonary rehabilitation, BIPAP
2/ Aidan	Male	60	N	Moderate	Cancer in remission	Y Spouse/partner	Inhalers, nebulisers, oxygen, exercise class
3/ Eileen	Female	75	N	Mild	High blood pressure, thyroid, osteoarthritis, kidney infections, macular degeneration	N	Antibiotics, inhalers, oral bronchodilators
4/ Declan	Male	64	N	Mild	Asthma, respiratory failure, atrial fibrillation, sleep apnoea, immune deficiency, osteoarthritis, osteoporosis, fibromyalgia, depression, adrenal gland deficiency, prostate problems, hernia navel, avascular necrosis, right ankle fractures, rib fractures	Y Spouse/partner Other family/ friends Paid carers	Antibiotics, steroids, inhalers, nebuliser, oxygen
5/ Cathal	Male	74	N	Moderate		N	Inhalers, pulmonary rehabilitation, exercise class
6/ Caitriona	Female	76	Y	Severe	High cholesterol, pain in back and legs post-car accident, diverticulitis, anaemia	Y Other family/ friends	Antibiotics, inhalers, nebuliser
7/ Betty	Female	54	Y	Moderate	Bronchiolitis Obliterans organising pneumonia (BOOP), lymphoedema, steroid-induced type 2 diabetes, hiatus hernia, reflux, depression	Y Paid carers	Antibiotics, steroids, inhalers, oxygen, pulmonary rehabilitation, exercise class
8/ Helen	Female	67	Y	Moderate	Osteoarthritis, 1 episode of fibrillation	Y Other family/ friends	Antibiotics, steroids, inhalers, nebuliser, pulmonary rehabilitation
9/ George	Male	83	Y	Mild	High blood pressure, high cholesterol, hearing loss	Y Paid carers	Inhalers, pulmonary rehabilitation
10/ Kevin	Male	68	N	Very severe	Blood clotting problem, cancer	N	Antibiotics, inhalers, nebuliser, oxygen, pulmonary rehabilitation
11/ Eamon	Male	74	N	Moderate	Shoulder prosthesis, cancer in remission	N	Antibiotics, steroids, inhalers, pulmonary rehabilitation, inspiratory muscle training (IMT) device
12/ Grainne	Female	75	Y	Mild	Vertigo, high blood pressure	N	Antibiotics, steroids, pulmonary rehabilitation, exercise class
13/ Jane	Female	82	N	Severe	Atrial fibrillation	Y Other family/ friends	Antibiotics, steroids, inhalers, pulmonary rehabilitation, exercise and dance classes
14/ Aileen	Female	61	N	Moderate	Osteoarthritis	Y Other family/ friends	Antibiotics, steroids, inhalers, nebuliser, pulmonary rehabilitation
15/ Liam	Male	63	N	Severe	Type 2 diabetes, high blood pressure	N	Antibiotics, steroids, inhalers, nebuliser, oxygen, pulmonary rehabilitation
16/ Finbar	Male	72	Y	Mild	GORD	N	Antibiotics, steroids, inhalers, pulmonary rehabilitation, exercise class and physiotherapy-led fitness
17/ Jack	Male	71	N	Severe	Diabetes	N	Antibiotics, steroids, inhalers, pulmonary rehabilitation
18/ Niamh	Female	73	N	Moderate	Coronary bypass, surgery on back - 2 disks removed, varicose veins	N	Antibiotics, steroids, inhalers
19/ Niall	Male	69	N	Moderate	Cancer in remission, osteoarthritis, depression, anxiety	Y Spouse/partner	Antibiotics, steroids, inhalers, nebuliser, oxygen, pulmonary rehabilitation, CPAP
20/ Oisín	Male	62	Y	Moderate	Ischaemic heart disease, borderline kidney failure, cancer, Barrett's oesophagus, hiatus hernia	N	Antibiotics, steroids, inhalers, pulmonary rehabilitation
22/ Lisa	Female	72	N	Severe	High blood pressure	Y Paid carers	Antibiotics, steroids, inhalers, nebuliser, oxygen, pulmonary rehabilitation
23/ Sally	Female	72	N	Mild	Heart disease (past mild heart attack), high blood pressure	Y Spouse/partner	Antibiotics, steroids, inhalers, oxygen, pulmonary rehabilitation
24/ Pdraig	Male	63	N	Severe		N	Antibiotics, steroids, inhalers, nebuliser, oxygen, pulmonary rehabilitation, analgesia
25/ Rory	Male	67	N	Moderate	High blood pressure	N	Antibiotics, inhalers, pulmonary rehabilitation
26/ Steven	Male	48	N	Moderate	Thrombosis	Y Spouse/partner Other family/ friends	Steroids, inhalers, oxygen, pulmonary rehabilitation

(continued on next page)

Table 1 (continued)

ID/ Pseudonym	Gender	Age	Living alone Y (yes)/ N (no)	Self-reported severity of COPD (GOLD criteria)	Self-reported comorbidities	Help with personal/ practical care Y (yes)/ N (no)	Treatment for COPD
27/ Terry	Male	72	N	Severe		N	Steroids, inhalers, oxygen, pulmonary rehabilitation
28/ Ultan	Male	85	Y	Mild	Cancer now in remission, stable kidney disease, low blood pressure, eye disease	Y Other family/ friends Paid carers	Inhalers, pulmonary rehabilitation
29/ Sinead	Female	61	N	Severe	Reflux, psoriasis, asthma, eczema, anxiety, dizziness	Y Other family/ friends	Antibiotics, steroids, inhalers, nebuliser, pulmonary rehabilitation, oral bronchodilator
30/ Alva	Female	66	N	Mild		N	Antibiotics, steroids, inhalers, nebuliser, oxygen, pulmonary rehabilitation
31/ Bronagh	Female	66	N	Mild		Y Spouse/partner	Antibiotics, steroids, inhalers, nebuliser
32/ Kate	Female	68	N	Moderate	Osteoporosis	N	Inhalers

Table 2

Step-by-step approach to template analysis adapted from King [24].

1. Transcribe interviews
2. Identify *a priori* themes
3. Listen to audio files and read through interview transcripts to familiarise oneself with the data. Attach field notes as memos to interviews
4. Carry out an initial thematic coding of the data. Code for *a priori* themes, adapt *a priori* themes, and generate new themes. Within these broad themes, code more specific themes and group according to both *a priori* themes and inductive themes arising from the data
5. On the basis of this initial thematic coding, produce an initial coding template
6. Develop the final template by applying the initial template to all interviews and reviewing and refining the template in an iterative coding process
7. Interpretation of findings – “after coding”

2.7. Quality and rigour

Lincoln and Guba's [28] trustworthiness criteria were adapted for this narrative inquiry to ensure its quality (see Table 3).

The COREQ checklist for reporting qualitative research was used to guide reporting of this study (see supplementary file 4).

3. Results

For participants in this study, the exercise of power is expressed through the mobilisation of agency. They resisted the imposition of power by leveraging and mobilising different types of knowledge. They also engaged in practices designed to operate on the self and the body in order to achieve happiness and health. However, this agency was constrained by the imposition of power by health care professionals and sometimes family members. The following sections present these findings in more detail.

3.1. Power

Power exercised on participants in this study was represented as 1) the extension of surveillance and discipline into their private lives: a process termed by Foucault as “pastoral power” [32] and 2) the transfer of responsibility for managing COPD from health care professionals to participants in a process known as “responsibilisation” [33]. Fig. 2 presents these key themes.

3.1.1. Pastoral power

Many participants gave accounts in which key aspects of their lifestyles, such as weight and diet, fell under scrutiny and discipline. Eileen gave an account of the scrutiny and interrogation of her weight by her

specialist.

That's the first thing that the specialist I go to, he said, “How are you?” and then, “Well, did you lose any weight?”

[ID 3: Eileen interview 2]

Some participants described how family members scrutinised their behaviour and activities. This scrutiny – born out of love, care and anxiety – could still be a source of tension. Sinéad's daughter Tracey used language that constructed her mother as child-like and in need of encouragement and discipline in order to stay engaged with support activities.

She's like a child at times, you literally have to dress her and put her out the door.

[ID 29 (family member): Tracey interview 1]

A few participants reacted to the scrutiny of their lifestyle with guilt and anxiety. These people described an ongoing struggle of self-discipline. Niamh held herself as culpable regarding what she saw as her less-than-optimal diet and weight.

I do eat rubbish, but I eat good food too. But I'm trying to give it up now for the dieting. Because everybody told me if I lost weight it would ease the pressure on my lungs...I should lose it too, should I not be better?

[ID 18: Niamh interview 1]

3.1.2. Responsibilisation

Many participants' accounts of self-management contained examples of health care professionals' expectations that their patients should take responsibility for the management of their illness. Gráinne spoke of doctors increasingly handing responsibility to patients, while at the same time resisting being challenged or confronted by their patients.

Doctors have handed it back to the person, to their client, to look after themselves. I know some of them don't like being confronted... or challenged...like the priest.

[ID 12: Gráinne interview 3]

The conflicting expectations of taking responsibility for self-management while at the same time being compliant with the expectations of health care professionals gave rise to uncertainty on the part of some participants about deciding whether or not to attend health care professionals. In Betty's case, this contradiction led to conflict with her respiratory consultant.

Table 3
Trustworthiness criteria adapted from Lincoln and Guba [28].

Trustworthiness criteria	Purpose	Techniques to achieve criteria	Strategies applied in our study
Credibility	Confirms the extent to which the research presents the socially constructed experiences and perceptions of the participants	Prolonged engagement Referential adequacy	We interviewed each participant up to three times over the course of 12 months in order to trace the unfolding of narratives over time. We retained copies of audio files, transcripts, field notes, as well as a diary recording key decisions made throughout the study and reflexive diary entries.
Transferability	Ensures that the findings of a qualitative study can be transferred to similar situations or participants	Thick description	We used Ponterotto's [29] approach to thick description adapted for interview studies. We engaged in thick description of the sample, the data collection and data analysis processes, our presentation of the findings and our interpretation and discussion of the findings.
Dependability	Evaluates the extent to which a study is consistent and accurate	Audit trail Reflexivity	We developed an audit trail to help readers follow how we achieved our conclusions based on Rodgers and Cowles' [30] framework of four types of documentation: 1. Contextual 2. Methodological 3. Analytic 4. Personal response (reflexivity) We used a number of key strategies in our reflexive practice: 1. Repeated interviews with each participant over 12 months (recommended by Berger [31]) 2. Regular peer debriefing with research team 3. Allowing time to pass between initial and subsequent review of coded transcripts 4. Reflexive journaling and decision diary
Confirmability		Audit trail Thick description Reflexivity Referential adequacy	The strategies we used to achieve confirmability have been described earlier in this table

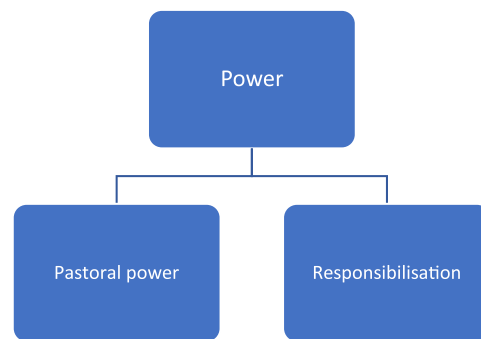


Fig. 2. The two manifestations of power identified in participants' accounts.

when he just went for me, and he was with three or four different people. So talk about feeling vulnerable!

[ID 7: Betty interview 1]

Some participants gave accounts in which they projected responsibilisation on to other people with COPD, expressing annoyance when they perceived other people with COPD as not self-managing in line with their own expectations of responsibility. Oisín was critical of someone with COPD who would not stop drinking or smoking.

There's this guy, and I said, "You need to quit them [cigarettes]". "I'm not giving them up", he says. But it's an awful ignorant choice, because smoking has an impact on others. I remember remarking to myself, "That's a bit selfish".

[ID 20: Oisín interview 1]

3.2. Knowledge

Knowledge in participants' accounts took two main forms. Firstly, dominant, hegemonic knowledge that is legitimated as being in some way "true" [17]. This took the form of medicocentric knowledge. Medicocentric knowledge describes knowledge of the medical aspects of illness, as opposed to health and illness in sociocultural, political, and economic context [8,34].

However, in this study, dominant medicocentric knowledge was appropriated by individuals to serve their own interests. They also had recourse to local, popular knowledge (often disqualified by health care professionals as inadequate), termed by Foucault as "subjugated knowledge" [17]. This took two forms: knowledge of the body's reactions to COPD and its treatment (embodied knowledge); and knowledge of complementary and alternative treatments and therapies for COPD (alternative knowledge) Fig. 3.

3.2.1. Medicocentric knowledge

All participants' narratives included accounts of receiving medicocentric knowledge from pulmonary rehabilitation (PR), individual health care professionals, or family members who worked as health care professionals. The aim was to educate participants in the "correct" way to self-manage their illness. Eoin, for example, spoke of how PR encompassed advice on the correct way to manage medication.

Every aspect of life, you're told about your medication, the reason you're taking them, and the importance of taking them.

[ID 1: Eoin interview 1]

However, many of the participants in this study were not simply passive recipients of medicocentric knowledge. They actively used it to adapt their own self-management practice. Eamon, for example, had stopped using his nebuliser after attending the information meeting which cautioned against its use.

I was in and out of the [hospital] quite a bit. I had been told to err on the side of caution. But my consultant felt that I was going into hospital just for the good of my health, that there were much sicker people in hospital than me. But any time I'd ever had a chest infection, I always went to my GP first. I was actually in a public ward

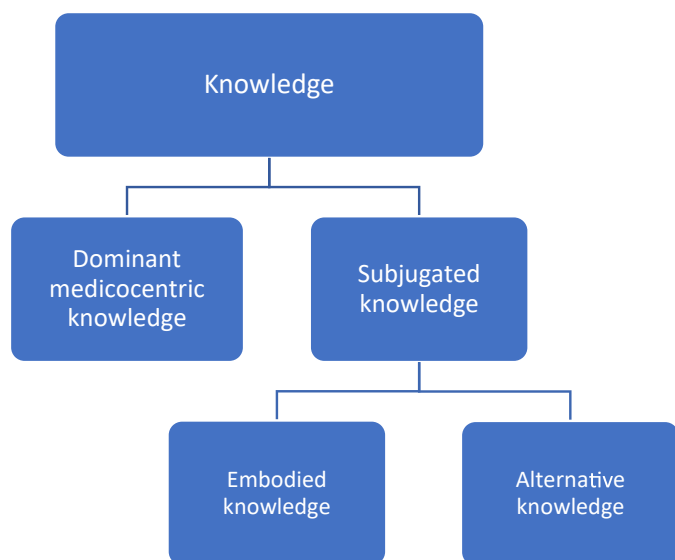


Fig. 3. Types of self-management knowledge identified in participants' accounts.

So even though I did find it [nebuliser] good, I haven't used it since that evening when there was a [consultant] from [hospital], and the other from the nursing side and they spoke against it.

[ID 11: Eamon interview 1]

3.2.2. Subjugated knowledge

3.2.2.1. *Embodied knowledge.* Many participants' accounts revealed embodied knowledge to come from within, as a result of their experience of living with COPD over time. Eoin spoke of the importance of knowing one's body and letting this knowledge guide one in self-management.

The way I look at it is, you know your own body and you have to go by that...You tune into that, you do what suits you.

[ID 1: Eoin interview 3]

Embodied knowledge was mobilised to prompt participants to take action when necessary. Bronagh described coming to know specific warning signs of incipient episodes of exacerbation, prompting her to use her nebuliser.

If I'm bad and I can't breathe, I get this pain in my head...like little men with hammers, and I know straightaway when I can hear them, "I have to go on the nebuliser".

[ID 31: Bronagh interview 1]

Some participants were ambivalent about their prescribed COPD medication, based on their knowledge of their bodies' reactions to the medication and related side effects.

I find the powder inhalers very hard...it's like as if you burned your tongue. I'm supposed to take them at night but actually I forget about them most of the time. But you see it's this thing with the tongue that gets me down.

[ID 18: Niamh interview 1].

3.2.2.2. *Alternative knowledge.* Alternative knowledge was described in some participants' accounts as transmitted between people at local level and operating in parallel to medicocentric knowledge. Finbar described receiving knowledge about a salt therapy device and sharing it with others.

I was speaking to a man, and he said to me that I should try a salt pump, so I got one. And I can't believe the difference. So, there's another man in the exercises and I said it to him, I said about the salt pump.

[ID 16: Finbar interview 1]

Participants who discussed alternative knowledge integrated it with medicocentric knowledge. Jack combined medicocentric knowledge of exercise and medication with alternative knowledge of salt therapy and poitín (a traditional Irish distilled beverage often produced illegally) in his self-management practice.

These fellas [inhalers] and the [salt therapy device] there. It'll be plugged in tonight. And that poitín now, if you did feel a cold coming on, you'd take a right shot of that in the hot water.

[ID 17: Jack interview 1]

3.3. Agency: care of the self and technologies of the self

For the participants in this study, agency was represented in Foucauldian terms as "care of the self", achieved via a complex array of practices known as "technologies of the self" [35,36], which involve transformation, correction, and purification of the self in order to find salvation and redemption [37]. However, as the findings illustrate, these practices are also shaped and constrained by dominant relations of power Fig. 4.

These practices were intimately tied to their understanding of self-management. These included introspection, nurturing well-being and happiness, abstinence and restriction, exercise and routine. For a few participants, introspection and self-reflection were inherently moral technologies of the self in which they confronted themselves honestly, in order to transform and perfect themselves as good self-managers.

You have to look in the mirror and be honest with yourself and say what you did wrong and what you didn't do wrong. I found it great to be blessed to be able to see my wrongs. You have to address everything.

[ID 20: Oisín interview 2]

Nurturing mental wellbeing was another practice used by some people to transform the self into one that is transcendent from the confines of COPD. Jane found art an important way of doing this.

When I paint I forget everything. I think it's the most relaxing thing doing any kind of artwork.

[ID 13: Jane interview 1]

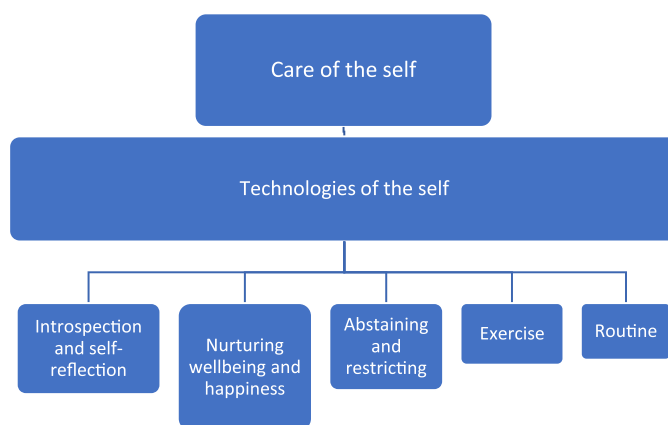


Fig. 4. Care of the self and technologies of the self identified in participants' accounts.

Other practices such as abstinence and restriction and exercise were performed upon the body to manage physical health by many participants. Abstinence could be an agentic process, providing the possibility of transformation.

I'm three months without sugar. It's really about opening your mind to new possibilities and new changes.

[ID 20: Oisín interview 2]

However, these practices were at the same time sites for the exercise of power on participants. Abstinence and restriction involved scrutiny of and discipline over participants' diet and weight by "experts". Alva spoke of her struggle to meet the expectations of the weight loss organisation she attended.

If I lost weight, it'd be a help, but I am trying, but it's not easy.

[ID 30: Alva interview 2]

Some participants also described anxiety about failing to live up to their responsibility to be "good" self-managers.

I could be better; I certainly could do more. My plan was to be really good and do the exercises, but then I just stopped.

[ID 7: Betty interview 1]

4. Discussion and conclusion

4.1. Discussion

Power, knowledge and agency in participants' narratives of COPD self-management are fundamentally interrelated and interdependent in an enduring dialectic relationship. This section examines these findings in the context of the literature on power, knowledge and agency in chronic illness self-management, encompassing COPD and other chronic illnesses.

4.1.1. Power

The accounts of participants in the current study presented how power is exercised on them by key stakeholders in their lives as they navigate the complexities of self-management. A number of studies have examined the relations of power underpinning chronic illness self-management [6,11,12,14,38]. They identified a tendency to cast the person with chronic illness in a subjugated role compared to health professionals and other "experts", reinforcing expectations of compliance with what is judged by "experts" to be ideal self-management. Ellis et al. [14] argued that this positions individuals as either "good" or "bad" self-managers. This idea of "good" self-management was identified in the findings of the current study, as participants strove to perfect themselves according to the norms and standards set by experts.

The process of responsabilisation found in participants' accounts in this study has been examined by other authors who highlighted its central paradox – where responsibility for the management of chronic illness is shifted to the individual, while at the same time the power to determine "good" self-management rests in the hands of professionals [6,12–14,39,40]. In this study, participants had to negotiate the expectations of responsibility and autonomy placed upon them to reduce their dependency on health services, against the expectation that they should attend health professionals promptly.

4.1.2. Knowledge

Knowledge was identified in participants' accounts as fundamental to self-management. It acted both as a vehicle for the imposition of power by experts on participants, and as a route for agency exercised by participants in their approach to self-management. Ellis et al. [14], Fletcher et al. [41] and Brand and Timmons [42] also found that medicocentric knowledge about chronic illness was seen by health care

professionals as a legitimated body of knowledge that should be utilised to enact behaviour expected of a "good" self-manager. However, even when participants in the current study received medicocentric knowledge, they exercised agency by appropriating and taking ownership of it. Participants also accessed a rich body of knowledge that developed as a result of the experience of living with COPD over time. They spoke of such knowledge as essentially rooted in the body. Other work in the field of chronic illness [43–47] has found that individuals regarded their own bodies as the most valuable source of knowledge for self-management.

Participants also drew on knowledge of non-medical complementary and alternative therapies that were not necessarily endorsed by health care professionals. Alternative knowledge was integrated with both medicocentric and embodied knowledge to construct participants' individualised self-management practice. This finding is supported by Thorne et al. [48] who found that individuals in their study recognised complementary and alternative medicine as offering different possibilities for achieving the best level of health possible.

4.1.3. Agency

In addition to the mobilisation and appropriation of knowledge, participants in this study exercised agency by engaging in a range of reflexive practices, constituting a set of "technologies of the self" [36].

Participants gave accounts which illustrated the agentic aspect of these technologies of the self. However, their accounts also revealed the imposition of power that bound and constrained them. This tension between the agency of participants and the power imposed upon them is reflected in the small body of literature on technologies of the self in chronic illness. Some authors emphasise the interrelationship between agency and power in technologies of the self [49,50], whereas others focus on technologies of the self solely practices of power [51,52]. Participants in this study did provide examples of technologies as sites of power, for example in the cases of practices of abstinence and restriction, and exercise. However, power was neither final nor totalising in participants' accounts. Technologies of the self encompassed a more holistic view of self-management as nurturing and caring for the self in creative ways, and undergoing a transformation of the self beyond the confines of biomedicine. Reflecting this, Naue [50] and Powell and Biggs [49] argued that agency and power in technologies of the self should be viewed as intertwined and interacting.

Participants in this study constantly negotiated the balance between the exercise of power *on* them, and the exercise of power *by* them as agency, quietly constructing their own unique and individualised self-management practice. This finding is supported by Ellis et al. [14], who found that living with chronic illness involved balancing medicocentric expectations of compliance against making self-management decisions influenced by lifestyle and social well-being and sometimes prioritised these over complying with medical advice. This negotiation is at the core of Foucault's [53] recommendation that the nexus between agency and power, the point at which the two meet and interact, should be the focus of scholarly inquiry.

4.2. Conclusion

This study found a dialectic and iterative relationship between power and agency in participants' accounts of self-management. The negotiation of agency and power identified in the current study resulted in individuals actively integrating medicocentric and experiential practices into an individualised and unique approach to self-management. This is the first published study that has examined how people with COPD exercise power in the self-management of their illness. The findings offer insight into and contribute knowledge to this topic by showing how a Foucauldian theoretical framing of individuals' agency in their COPD self-management practice can assist in promoting a model of self-management that is holistic, complex and multi-dimensional, based on the recognition of the value of COPD patients' knowledge and agency.

4.2.1. Practice implications

These findings demonstrate the need for an acknowledgement in COPD self-management policy, practice and research of the complex interweaving of medicocentric and experiential aspects of self-management by people with COPD, as well as an acknowledgement of the skilled work that people put into their everyday self-management practice. The process of honouring and leveraging the considerable resources of people with COPD to self-manage should form the heart of person-centred self-management support. The important role that professionals play in recognising individuals' own knowledge and agency in practicing self-management must be highlighted.

CRedit authorship contribution statement

Sarah Delaney: Conceptualisation, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Visualisation, Writing – original draft, Writing – review & editing. **Sylvia Huntley-Moore:** Writing – review & editing, Supervision. **Patricia Cronin:** Conceptualisation, Data curation, Formal analysis, Funding acquisition, Methodology, Project administration, Supervision, Visualisation, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Anonymity statement

We confirm all personal identifiers have been removed or disguised so that persons described are not identifiable and cannot be identified through the details of the story.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.pec.2023.107990](https://doi.org/10.1016/j.pec.2023.107990).

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