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# **How do People with COPD Value Different Activities? An Adapted Meta-Ethnography of Qualitative Research**

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## **Abstract**

Chronic Obstructive Pulmonary Disease (COPD) is a long-term condition where activities of daily living (ADLs) may be very restricted; people with COPD need to prioritize what is important to them. We conducted a meta-ethnography to understand which ADLs are valued and why, systematically searching for articles including experiences of ADLs and organizing themes from the articles into five linked concepts: 1) Caring for the Body; 2) Caring for the personal environment; 3) Moving between spaces; 4) Interacting with others and 5) Selfhood across time. Additionally, we identified three key aspects of personal integrity: Effectiveness, Connectedness and Control. We found that ADLs were valued if they increased integrity; however this process was also informed by gendered roles and social values. People whose sense of control depended on effectiveness often found accepting help very difficult to bear; therefore redefining control as situational and relational may help enjoyment of activities that are possible.

Keywords: Illness and disease, chronic; Illness and disease, experiences; meta-ethnography; respiratory disorders

## Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a long-term condition characterized by persistent airflow limitation. As treatment of COPD is improving, people with COPD can survive for a long time in spite of severe respiratory impairment and disability (Peruzza et al., 2003). It is therefore important to understand how they experience everyday life with their condition and how their quality of life might be improved. A qualitative approach is ideally suited for this as it makes visible the struggle with a formerly taken for granted, 'habitual' body; the difficulty of small everyday acts that people without illness would not think about (such as getting into restrooms or fetching a glass of water) can shape the lives of people with chronic illness (Ironside et al., 2003). Ironside and colleagues argue that a focus on particular conditions can overlook the common experiences and shared meanings that emerge across chronic illnesses. However, it is worthwhile to focus on COPD on its own even though there may be many parallels with other conditions. Firstly, it will be useful for clinicians who want to understand their patients' experience; secondly, breathlessness is a particularly distressing phenomenon which can cause an existential fear as a constant reminder of death (Donaghue, 2012). The possibility that anything a person does can lead to breathlessness places a particular value and meaning on activities which are nevertheless carried out.

Within a clinical context, these small, crucially important activities are known as Activities of Daily Living (ADLs); and in order to know how COPD impacts on everyday life or how well a treatment works, it is important to elicit from patients what they can or cannot do. There is however a tension between the medical profession's focus on function e.g. the distance people can walk and individuals' experience of what is important e.g. being able to look after children (Ironside et al., 2003). In their review of commonly used questionnaires designed for patients with COPD, Janaudis-Ferreira et al. (2014) found that while some

included activities needed for independent living (shopping, transport), most focused on simple activities that a person could do themselves while in a hospital or care home (washing, dressing) which is problematic as most people with COPD live in the community. The two questionnaires most commonly used in the United Kingdom are the St George's Respiratory Questionnaire (Jones, Quirk, Baveystock, & Littlejohns, 1992) and the Chronic Respiratory Disease Questionnaire (J. E. Williams, Singh, Sewell, Guyatt, & Morgan, 2001). In addition to set questions, both ask patients to give examples of activities that are they would like to do but that they find difficult or impossible because of COPD. Examples given by patients could be studied to understand which ADLs are prioritized by people with COPD; however the question as to why these are important and why some give a sense of 'satisfaction' over and above their practical value (Leidy & Haase, 1996) still remains open. Qualitative studies have begun to tackle these questions; however, there is as yet no synthesized review of ADLs in the lives of people with COPD.

### **Aims of the review**

This synthesis has two main aims. The first is to describe which ADLs may be particularly valuable to people with COPD in a way that is useful for clinicians working with or developing interventions for people with COPD. The second is to better understand the essence of everyday life with COPD and how ADLs contribute to this life being meaningful.

### **Methods**

In order to reach these aims, we chose a meta-ethnography method as this allowed us both to explore the included studies' descriptions and interpretations of the importance of ADLs in the lives of people with COPD and to build up a picture that offers greater understanding in depth and breadth than the findings from individual studies (Bondas & Hall, 2007). We followed the worked example presented by Britten (2002) in the steps outlined below:

*Step 1.* AL began by retrieving qualitative literature on COPD, using a Medline search (search terms were COPD and related terms, and ‘qualitative research’ as MeSH term/ ‘qualitative’ as keyword). This was followed up by extracting references from articles already identified including a comprehensive overview of the qualitative literature (Giacomini, DeJean, Simeonov, & Smith, 2012) and searching the contents of journals with a qualitative focus via their web pages (Sociology of Health and Illness, Social Science and Medicine, Qualitative Health Research, Chronic Illness). Initially, we considered any qualitative study on living with COPD. Of the 68 articles originally retrieved, 61 fulfilled our inclusion criteria of: 1) qualitative method; 2) patients with COPD and 3) any aspect of everyday life with COPD (excluding articles solely focused on experience of breathlessness, hospitalization or interaction with carers or health care professionals). On discussing the findings from these studies as a team, we identified four main thematic domains (Understanding, Emotion, Activity and Restriction); however, studies were too numerous and too heterogeneous for a meta-ethnography approach to be possible. However, we found that there was a subset of studies focusing on ADLs which would be most relevant to development of interventions to improve the health and quality of life of people with COPD (such as pulmonary rehabilitation programs). Therefore we decided to focus the review on these studies (see Figure 1).

[INSERT FIGURE 1 ABOUT HERE]

*Step 2.* From the 61 articles described above, we selected 19 articles reporting on 17 studies. We were looking for descriptions of ADLs and explanations why they were both important and sometimes difficult. No articles were excluded because of their descriptive nature; however, some were useful mainly because of detailed quotations from the participants. Articles with a high level of theoretical interpretation were characterized as ‘key’ as they would contribute more strongly to the development of the meta-ethnography (see Malpass et al., 2009).

*Step 3.* AL and CG appraised the quality of the articles using the Critical Appraisal Skills Programme (CASP) tool consisting of 10 questions to discern appropriateness, quality and bias of qualitative studies (CASP, 2014). While none were identified as poor by the appraisal, some authors claimed to have used a highly theoretical approach when the reported analysis did not bear out these claims. Otherwise, we would have liked more information about the interactions between interviewers and interviewees, especially where the interviewer was a health professional, and more reflection on whether patients who volunteered to be interviewed might be different to those who declined.

*Step 4.* We mapped the clinical and theoretical backgrounds of articles and the main conceptual areas where daily activities appear. The majority were written from a nursing perspective with a phenomenological or grounded theory approach. They spanned a continuum between a patient focused approach exploring the experience of COPD and a more researcher-led focus on clinical practice (e.g. pulmonary rehabilitation); some were very descriptive while others were more exploratory, developing theories explaining the importance of particular ADLs. While it might be expected that these two tendencies are linked, there also existed some experience based articles which were quite descriptive and more exploratory articles with a clinical focus (see Figure 2).

[INSERT FIGURE 2 ABOUT HERE]

There is a wide consensus that a true meta-ethnography consists of a re-interpretation of the authors' interpretation of the data and therefore should not aim to interpret raw data found within the reviewed articles (Thorne, Jensen, Kearney, Noblit, & Sandelowski, 2004). However, as several articles were very descriptive while still containing very important detail on ADLs, we adapted the method by allowing a 'secondary analysis' element: in addition to identifying and synthesizing first order (descriptive) and second order (explanatory) concepts as specified by Britten (2002), we collated discussions of different activities directly from

participants' accounts in quotations or summaries of these given by the authors. Activities were organized into five linked concepts.

*Step 5.* In order to arrive at an integrated whole from the data and interpretations given in the articles, we chose a 'line of argument' approach (Noblit & Hare, 1988) by developing a set of logically linked statements from the interpretive 'second order' conclusions made by study authors centering around three constructs developed by study authors, but mostly not used to their full interpretive potential (Effectiveness, Connectedness and Control). It is being debated whether a meta-ethnography should culminate with entirely new 'third order' concepts developed by the reviewers as part of the synthesis or whether it would be acceptable to work with concepts developed by study authors (Dixon-Woods et al., 2006). In our case, using these three constructs helped to build a holistic, dynamic picture of the experience of COPD.

## **Results**

As part of the synthesis, we identified different types of ADLs ranging from basic to very complex; they all contributed in varying ways to a sense of selfhood over time which provides a concept in its own right. While sorting activities by radiating out from the participant's body to their engagement with the wider world, we found that they mapped onto four of the five linked dimensions of the Lifeworld framework developed by Todres, Galvin and Dahlberg (2007): embodiment, spatiality, intersubjectivity and temporality (mood, the fifth, being addressed only indirectly due to our focus on activity). We begin with the most basic needs of caring for the body (embodiment); then move on to the bounded environment such as the house or garden (spatiality); following that, we look at leaving the bounded environment and interacting with others (intersubjectivity), and finally we address ADLs as a way of maintaining integrity of the self over time (temporality). Table 1 provides the main

characteristics of the included studies as well as mapping how the concepts are represented in the studies.

[INSERT TABLE 1 ABOUT HERE]

### *Concept 1: Caring for the Body*

Caring for the body through washing, dressing, cooking and eating provide the bare minimum for survival and social acceptability, and loss or decline of any of these activities can be very traumatic. This concept is prominent in articles by Barnett (2005), Ek and Ternestedt (2008), Nield (2000) , O'Neill (2002) and Odencrants, Ehnfors, and Grobe (2005), but backgrounded in other studies. Participants described difficulties with washing and dressing, especially if it involved steam, standing up for a length of time, or bending over (showering, washing hair, tying shoelaces). Strategies to overcome these included taking rest breaks, using inhalers, drying off in a terrycloth robe or sitting down. For many, getting ready in the morning took a very long time. People with COPD also described having to be helped by spouses or other family members which was difficult for some: "I get very upset when my husband helps me [to wash her back and feet]. I realize there is nothing wrong with that, I just find it very hard to accept." (Barnett, 2005, p. 809) One participant in the same study accepted help from his wife but avoided showering when other family members were in the house rather than let it be known that he could not manage by himself. However, the situation of people without recourse to care by family members may be even more problematic as people living alone with advanced COPD may need to entrust their body to ever-changing carers helping them to wash or dress (Ek, Sahlberg-Blom, Andershed, & Ternestedt, 2011). Odencrants describes how COPD affects the relationship with food; outlining coping strategies such as asking a spouse to help carry the shopping, eating cold or liquid food, or small portions. Being alone meant that participants lacked motivation to cook (as standing in



a steamy kitchen was exhausting) or eat (due to lack of appetite or enjoyment of food). One participant said “if I were alone, I would starve to death.” (2005, p. 235) Sexual activity, although a very important part of life for many middle aged and older people (Lochlainn & Kenny, 2013), was rarely mentioned; where it was raised (Barnett; O’Neill), it was said to be impossible.

Study authors interpreted the importance e.g. of getting dressed even if it took a lot of time and energy as a sign of ‘not giving in’ to the illness and trying to live a normal life; conversely, staying in bed or in a bathrobe was a sign of a bad day with COPD (Barnett, 2005). Just being able to live a ‘normal’ day could involve a lot of effort: “I have to control everything I do from the time I get up in the morning until I go to bed at night. I push myself so I don’t stay in bed all day.” (O’Neill, 2002, p. 299-300) While caring for the body can be very intimate, these studies show that it is also social. Giving/ accepting help was important and sometimes difficult, with many participants feeling that they should be able to do these things for themselves. Odencrants describes eating as a social activity: eating with other people was more enjoyable while some participants felt ashamed that they could eat only small portions or had to cough while eating. Closeness between spouses could increase through care: one participant described his wife as his ‘best friend’ (Wilson et al., 2008, p. 352). However, Gullick and Stainton (2012) and O’Neill (2002) note that frustration about dependency could also lead to anger and conflict.

### *Concept 2: Caring for the Personal Environment*

Caring for the personal environment could take many forms but was often depicted (both by participants and study authors) as gendered and divided into housework (cleaning, hoovering, tidying, making beds, washing dishes) and gardening / maintenance (mowing the lawn, DIY, decorating, repairing). Being able to continue these tasks contributed to feeling useful and

keeping active; at a low intensity level they could be a pleasurable ‘potter[ing] about’(Ek & Ternstedt, 2008, p. 475) or ‘tinker[ing]’ (V. Williams, Bruton, Ellis-Hill, & McPherson, 2007, p. 80). However, many recounted a need for others to take over: “Decorating and all that sort of thing, mostly the wife has to do that now because I can’t keep getting up on ladders ... or we have somebody in to decorate.” (Harris, Hayter, & Allender, 2008, p. 705); “I hate housework now. I’ve got to get somebody, it’s driving me crazy; I swear to God I never had such a messy house.” (Wilson et al., 2008, p. 352) Many participants found strategies to complete tasks; e.g. cleaning floors while sitting down (O'Neill, 2002). People with COPD “not only forced themselves to attempt a task, but would consciously push themselves to their absolute physical limit to try and complete it [in ways that] people with ‘normal’ breathing would never entertain merely for the completion of a household chore.” (J. Gullick & Stainton, 2008, p. 610) Women with COPD often wanted to make sure that tasks were “done right”; however, some described how they relaxed their standards: "If something is dirty and I can't get to it, I'll get to it the next day. I don't worry like I used to. Not that I was fanatical, but I would get right on a lot of things.” (Leidy & Haase, 1996, p. 82); “I hope they come to see me, not to look at my mess ... I don’t bother now, not so much.” (Harris et al., 2008, p. 707) Being able to do housework or maintenance was also linked with a sense of usefulness and not being idle or a burden on others: “I do most things, cook and clean and that ... I do all the washing and do the ironing ... I don’t know what I’ll do if I just had to sit here, I couldn’t stand that.” (V. Williams et al., 2007, p. 80) Control over the household could be retained in different ways, e.g. by one of Leidy’s participants keeping her immediate surroundings and household paperwork as her responsibility while her daughter did most of the housework.

Similar to the ADLs needed in ‘caring for the body’ these activities had a strong social aspect, both for the dynamics within families and social acceptability for outside

visitors. Williams et al. (2010) describe an unwanted gender role reversal for men as carers had to take over; wanting to be able to do their usual tasks again was a motivator to take up pulmonary rehabilitation. Some male participants implied that they resented people outside the family taking over (especially if they had to be paid) or compared their former ease—e.g. with gardening—with the difficulty the same activities posed now. However, Gullick and Stainton (2012) argue that female participants with COPD in their study were more wedded to their gendered role and household tasks than were men; women who had a male partner with COPD were also more likely to take over completely (in keeping with the female role as caring for others) and then become overburdened. Other authors also described a struggle against ‘giving in’ to the illness which led to continuing e.g. housework at enormous cost of time and energy. However, household activities were very important to some participants but not others; some of the studies also described a process of ‘letting go’ of less important activity to preserve the more important social contacts. This was seen as different to ‘giving up’ which was linked to a sense of resignation and loss (Leidy & Haase, 1996).

### *Concept 3: Moving Between Spaces*

Loss of freedom to move is one of the defining features of COPD. It has been understood as a shrinking of the lifeworld (Gullick & Stainton, 2008) and was raised by most of the included articles. Many participants could rarely leave the home and described themselves as ‘housebound’. Others described the limit of their radius of movement (e.g. the garden gate, the car, the shops, or the local town center): “When the weather is fine, I get out ... I got my 2 sticks ... if I can get up to the top of that garden and back again, I’ll be quite happy about that.” (V. Williams et al., 2007, p. 79) Often this was aided by holding on to a walking frame or shopping trolley and punctuated by known sitting/ resting places. This limit could expand on good days and shrink on bad days, but overall it tended to reduce over time. Williams et

al. (2007) distinguish between functional and recreational walking, with recreational activity still possible even after walking has ceased to be functional. Several studies discuss ways in which participants could remain active while not extending spatial boundaries e.g. by using a treadmill or exercise bike. A later study by Williams et al. (2011) focuses on the importance of fresh air as a symbol for the ‘flowing stream’ of life, reminiscent of the seaside or countryside and good times in the past; having to stay indoors was seen as part of the ‘stagnant pond’ of restricted life that people with COPD often have to lead. Some compromised by using the garden as an outdoor, yet protected area where they could breathe freely:

Since I’ve had COPD I love the feel of a breeze, like today. Oh, it’s lovely. I can stand in the garden. Oh come on wind, ‘cause it really does help you breathe. I feel more comfortable, whereas over a period of time with stale air ... and you’re fighting all the time to get air into your lungs. (V. Williams, Bruton, Ellis-Hill, & McPherson, 2011, p. 1243)

For those who could not use walking functionally, the car often was the remaining mode of transport. Those who could still drive saw this as crucial to their freedom of movement; those who could not relied on their families for transport. This was unproblematic for some (Nield, 2000) but a major shift in family dynamics for others, with a feeling of dependence and a diminishing of the social role of husband and father as driver (Williams, 2007). Leaving the home was even more difficult for people with acute breathing difficulties. While some found it difficult to travel, especially while dependent on oxygen therapy, others described taking their equipment with them without major problems: “On a good day me and my wife we go for walks in South Bank, we walk around the markets, we go down for a meal, we take the Ventolin and the breathing spacer. Mandy [wife] puts it in her purse.” (Milne, Moyle, & Cooke, 2009, p. 302) While COPD restricted the horizon of movement, many people

endeavored to extend it by remaining active within their boundaries, by enlisting the help of others or by enrolling in pulmonary rehabilitation classes. The ability or inability to do outdoor activities was seen to impact on mood. Some derived satisfaction from increasing the number of steps walked or the regularity of their exercise: “I’m trying to get this weight off, walking in the park ... I’m trying to help myself. I’ve built it up now and I stride out, I love it.” (Harris et al., 2008, p. 707) Others felt despondent because of their loss of movement and the social roles and activities that accompanied it. For those worst affected, a lack of energy and motivation contributed to “a fatigue that affected both body and mind ... [a feeling] that life had lost its meaning”. (Ek & Ternestedt, 2008, p. 475)

#### *Concept 4: Interacting with others*

This concept is linked with the preceding one as study participants talked about a range of social activities that took place outside the home: visiting friends and family, going to the pub, meeting others with the same hobby, or doing gentle exercise (swimming, yoga, golf and rehabilitation classes). For those not retired, work also included an important social aspect. All these were important as they were enjoyable; a ‘good day’ was often seen as a day where activities with family and friends were possible:

Walking was so difficult and we were supposed to bring our swimming gear and bottles [referring to oxygen tanks], so I got a wheelchair and the children pushed me and then parked me somewhere ... I sat there and drank coffee and read ... and occasionally they came over to touch base ... but we had an outing anyhow, and that was the main thing. (Ek & Ternestedt, 2008, p. 475)

The couples interviewed by Jonsdottir (2007) also found it vital to get away from the house for activities together (e.g. swimming) whenever possible. Social activity could foster a sense of belonging and feeling useful: Leidy stresses that altruistic activities (volunteering/ helping)

could be more satisfying than mere pastimes as they countered the sense of being a burden. However, the overarching impression in this area was a sense of loss; for many people with COPD, social activity reduced to their spouse and immediate family. The main barrier was the loss of the ability to plan in advance (as the body was becoming increasingly unpredictable) or conversely the opportunity to act spontaneously (as current energy levels, transport, oxygen, inhalers and medications all had to be considered). Those relying on family members for transport were dependent on their schedules. As social activities involve getting out and about, the difficulties in moving between spaces described above also apply, including fatigue and lack of motivation to leave the home. “If someone rang and said ‘are you coming for a pint’ and you say ‘no’, they think you’re skint [broke] and say ‘I’ll buy you a beer’. I’m not spending very much; I’m probably richer now than I were!” (Nicolson & Anderson, 2003, p. 265) Some managed to stay in touch with their social groups by talking about activities shared in the past: “When my friends are going out hunting and want me to join in, I have no business there. I can’t do everything anyhow. I’d rather listen to them afterwards.” (Ek et al., 2011, p. 1483)

#### *Concept 5: Selfhood across time*

This last concept was mainly drawn from study authors’ explanations as to how particular ADLs helped to preserve personal integrity across time; and how the loss of activities might damage a person’s sense of self.; they often employed widely understood conceptualizations of chronic illness as a biographical disruption (Bury, 1982) and a threat to the taken-for-granted continuity of past, present and future (Charmaz, 1991). In most studies, participants felt a deep sense of loss and frustration at the inability to do activities once enjoyed, especially if they contributed to defining the person (linked to family relationships or social/gendered roles). Similar to people with other chronic illnesses, e.g. severe back pain (Osborn

& Smith, 2006), some participants described a split between the ill body and the self: “Daily life can be hard and frustrating. You want to do so many things but your body is just not able to.” (Barnett, 2005, p. 810) There was also a link to perceptions of ageing; some felt that while the body had aged due to COPD, the mind was ‘still young’ (V. Williams et al., 2011, p. 1242). When activities that were expected for the current stage of life (e.g. being able to work, having a sex life) had to be abandoned, the split between what the body ‘ought’ to be doing to maintain the current sense of self and the current state became especially acute. For older participants, doing more gentle activities (‘pottering about’) or hobbies were expected, and the sense of dissonance was not so great.

Authors also described ways in which participants could build bridges to the past that made it possible to maintain a more continuous sense of self, for example by doing activities that were enjoyed in the past whenever possible, especially when they were associated with past ‘good times’ (country walks, holidays). Finding new capabilities and developing substitute activities was seen as preferable to giving up activities; for example, skills acquired at work could be used in a volunteer role. Other people could also contribute to developing continuity by doing activities together with the person with COPD. Both Ek and Ternestedt (2008) and Gullick and Stainton (2008) stress that it is crucial for people with COPD to be known by others as essentially the same person in spite of the illness, while Leidy argues that this can be done by others listening to stories of past achievements and suggests that a continuous sense of self may be strongly bound up with a history of work: “I worked hard all my life . . . When I was in high school I used to work in a [vegetable] truck all day for a dollar a day.” (Leidy & Haase, 1999, p. 72) Those not currently working appreciated feeling useful and being a person with ‘so much to give’ (Ek & Ternestedt, 2008, p. 475); this was enhanced by altruistic activities like helping neighbors or volunteering. For those who were

very restricted in the activities they could do, reminiscing with friends could improve a sense of personal integrity.

For those with chronic illness, the imagined future plays an important role for the integrity of self over time. However, horizons of expected futurity can expand and contract depending on the current state of illness and disappear entirely in phases where illness takes over the self (Charmaz, 1991). As the trajectory of COPD is characterized by a slow physical decline, punctuated by potentially serious but unpredictable exacerbations, patients will experience phases of relative normality where imagining a future is possible but may expect imminent death during a crisis (Pinnock et al., 2011). However, Milne et al. (2009) argue that relative normality can be overshadowed by being diagnosed with an illness for which there is no cure, while participants in the article by Ek and Ternestedt (2008) found it often hard to think of the future when life did not seem to be worth living. For people with advanced COPD, hope was often not focused on the future, but on finding reward in small things and living in the moment.

### **Line of Argument Synthesis**

In order to develop more overarching concepts explaining why particular activities were particularly important and their absence so acutely felt, we compared interpretive themes developed by study authors. Leidy and Haase (1999) argue that daily activities express a central sense of personal integrity which they define as a sense of one's individuality and wholeness as a human being, encompassing physical appearance and functioning, skills, roles, knowledge, memories, environment, family, and friends. They identify the two central components of personal integrity as Effectiveness or 'being-able'; and connectedness or 'being-with'. In the studies we reviewed, ADLs were described as meaningful as they contributed to participants' sense of self and continuity (being able to live a normal life,



enjoyment/ satisfaction, feeling useful, taking part in social life). Additionally, a third concept emerged which was connected to the other two: that of control or mastery over the body and self. A dynamic relationship between the three concepts meant that any changes in one area could affect the others, e.g. a loss of effectiveness could lead to being helped by family members, increasing connectedness for some, or to a loss of connectedness and social withdrawal for others. (see Figure 3).

INSERT FIGURE 3 ABOUT HERE

We then developed a ‘line of argument’ to further explore dynamic relationships between these three concepts (Finfgeld-Connett, 2014). George Noblit (in Thorne et al., 2004, p. 1349) describes a ‘line of argument’ synthesis as offering “a fuller account of the phenomenon by arranging the studies’ metaphors [i.e. interpretations of data] in some order that [allows] us to construct an argument about what the set of [studies] say”. We developed a line of argument synthesis to express the dynamic links between these three concepts. This is summarized in the following statements:

- Effectiveness, connectedness and control or mastery are needed for leading a full life with COPD as they enable personal integrity over time
- Activities of daily living are valued if they contribute to effectiveness, connectedness or a sense of control or mastery
- This contribution is embedded in a more general understanding of selfhood mediated by gendered roles and social values including the value of physical labor
- A loss of connectedness can result in social isolation and (temporarily) losing the sense of meaning in life
- A loss of effectiveness (especially in caring for the body and self) is distressing but can be mitigated by help from a spouse, family member or friend, enabled by and increasing connectedness

- However, becoming more dependent on others may lead to a loss of the feeling of control or mastery (over body, self or life)
- People whose sense of control or mastery depends on effectiveness may find accepting help very difficult to bear
- Redefining control as situational and relational may help enjoyment of activities that are possible at the moment.

## **Discussion**

In synthesizing the qualitative literature on ADLs we aimed to increase understanding of activities that are important for people with COPD and why. We identified a set of reasons (linked to effectiveness, connectedness and control); further research is needed to ascertain how they can be applied in practice. The studies we reviewed encompassed a wide range of participants with a broad range of experiences (and varying degrees of COPD); however, their participants were mostly white UK, US, Canadian, Australian and Scandinavian patients. Nield (2000) entirely focused on African-Americans whose self management strategies were said to be not substantially different to those of other patient groups while two very short exploratory articles with Chinese and Taiwanese patients suggest that importance of ADLs may be culturally diverse (Chan, 2004; Chen, Chen, Lee, Cho, & Weng, 2008). The availability of resources (personal wealth, state funded care services) made a difference for many; however, outright poverty (e.g. life in a rough housing estate on a steep hill) was discussed only in one article also not included here as its focus was specifically on leaving hospital (Gruffydd-Jones, Langley-Johnson, Dyer, Badlan, & Ward, 2007).

Discussing their experience of conducting a meta-ethnography of qualitative research around an ‘applied’ health topic (adherence to treatment), Atkins and colleagues argue that this may be quite difficult as the literature they retrieved tended to be more concerned with solutions to problems, evaluation, and policy relevant questions than with the ‘thick

description’ of the ethnographic studies that initially gave rise to the method (Atkins et al., 2008). We similarly found that studies which used rich detail on their participants also tended to use more theoretical approaches for understanding their experience (phenomenology, personal integrity, development of gender roles) and therefore impacted more strongly on the synthesis. However, sorting quotes from research participants into the different aspects of the Lifeworld framework acted as a ‘proxy’ and allowed us to integrate them with the more interpretive articles even though we did not have access to the entire data.

Our analysis resonates with the work of other researchers studying the importance of ADLs for people with chronic illness; for example, Hammell (2004) describes how people with chronic illness might find meaning in the occupations of daily life by Doing (work, activity); Being (reflection, time for self); Belonging (friendship, support) and Becoming (envisioning a meaningful future with illness). However, the Lifeworld framework (Todres et al., 2007) helped to understand the particular essence of daily life with COPD as a person’s struggle to sustain the body, maintain a personal space that reflects social values, extend the horizons to the outside world, remain connected to others, and develop a sense of self identity across time. All this has to be carried out in the face of the constant threat of breathlessness and the knowledge that COPD is incurable so that loss of any one ADL may be seen as part of a long decline. Fear of further episodes of breathlessness may discourage activity and lead to a negative spiral (Willgoss, Yohannes, Goldbart, & Fatoye, 2012). There are also other well-known approaches that would be fruitful for an understanding of aspects of the experience of COPD. Bury’s theory of illness as biographical disruption and Charmaz’ discussion of temporality in chronic illness were already included to support the importance of ADLs in constructing a continuous sense of self; additionally, Corbin and Strauss’ (1991) illness trajectory model might be useful to study the impact of sudden crises and exacerbations in between stable phases. The ‘shifting perspectives model’ of chronic illness

as a fluid process in which either illness or wellness can be 'foregrounded' (Paterson, 2003) could explain why some study participants prioritized activities that they could do while others perceived only loss and decline. The conceptualization of chronic illness as biographical disruption has been disputed by Faircloth (2004) who finds that aspects of chronic illness can be integrated with expectations of decline in older age, resulting in a feeling of biographical flow. Some of the studies reviewed here also found that if activities people with COPD could do were in synch with what was expected for older age there was less of a sense of disruption, while younger people suffered a much greater sense of loss and grieving for the former self.

An understanding of the diverse range of activities people with COPD value is vital for clinicians working with them. As discussed above, tools such as the St George's Respiratory Questionnaire (Jones et al., 1992) and the Chronic Respiratory Disease Questionnaire (J. E. Williams et al., 2001) address ADLs both in standardized and open questions which ask patients to provide examples of activities that are difficult. These questions allow health care professionals to gauge how severely disease impacts on daily life e.g. whether breathlessness already makes it difficult to walk around the house or becomes only apparent when playing sports. However, a dialogue is needed to find out about 1) dynamic changes in what is important and/or possible and 2) how valued particular activities are. Clinicians could use a questionnaire in consultations with patients and carers to ascertain which activities are difficult and then use qualitative questions to discuss their importance, set goals (e.g. 'what would you most like to be able to do' or 'what would make you feel most confident') or coping with loss of ADLs ('is there something else that you would find enjoyable'). Consultations should also include discussion of psychological issues and coping strategies to improve quality of life.

Further qualitative research could explore values and priorities around ADLs; for example, they could develop a list of activities together with the researcher and then explore which ones are more or less important, and whether a ‘good day’ or a ‘bad day’ makes a difference. The dimensions of the lifeworld approach could be used to guide these discussions. Alternatively, a ‘photovoice’ method could invite participants to contextualize ADL by taking pictures of social and geographical spaces and settings in which these activities take place (Harrison, 2002). Further qualitative research could explore the influence of socio-demographics as patient priorities may vary by gender, ethnicity, and the availability of support networks. These activities could also contribute to the development of more practical applications such as patient reported outcome measures (PROMS). As pulmonary rehabilitation or self-management programs are increasingly being developed for people with COPD, an understanding of what is important to the individual is key. For example, patients are more likely to take part in one of these programs if the invitation they receive addresses issues of value to them.

From the articles reviewed here, we identified a strong narrative of increasing dependency and decline throughout the experience of COPD where jobs, practical capabilities, social relationships, intimate relations and even the sense of a meaningful life may all be lost. However, ADLs could also provide a sense of personal integrity by contributing to feeling effective, connected and in control. Needing to decide how to use dwindling resources placed particular value on activities that were still possible. However, redefining control as not absolute but situational and embedded in relationships might reduce frustration and enable enjoyment of everyday activities that give meaning to life. Jonsdottir captures this challenge when stating that people with COPD and those close to them “*all at once* wanted to make the most out of life, keep the disease and its ramifications at minimum,

and take things as they came. ... It seems as if the wisdom of the families was preserved by being able to treasure these aspects *all at once*, albeit knowing what was of most significance each time.” (2007, p. 456)

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Figure 1: Search Strategy

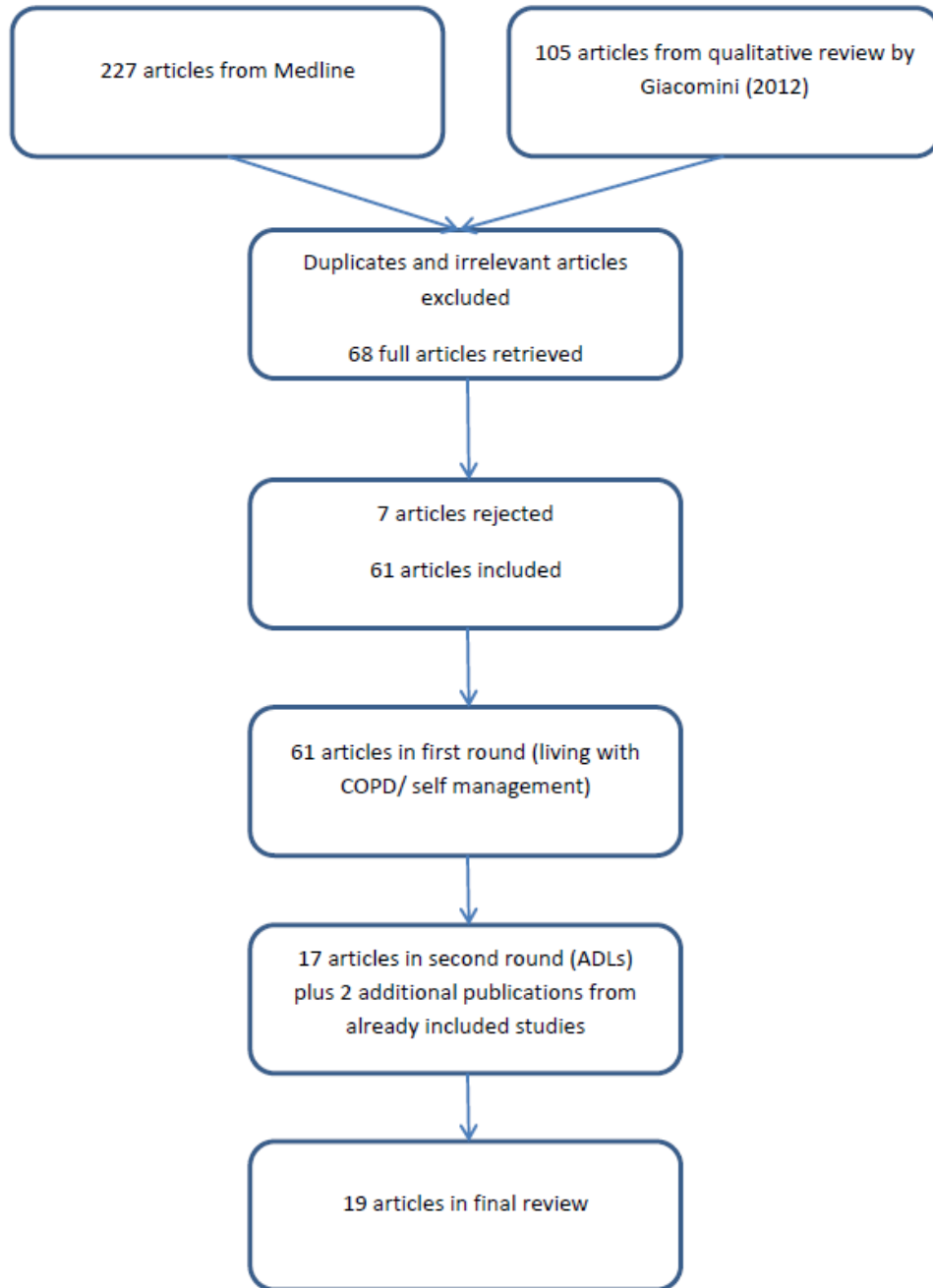
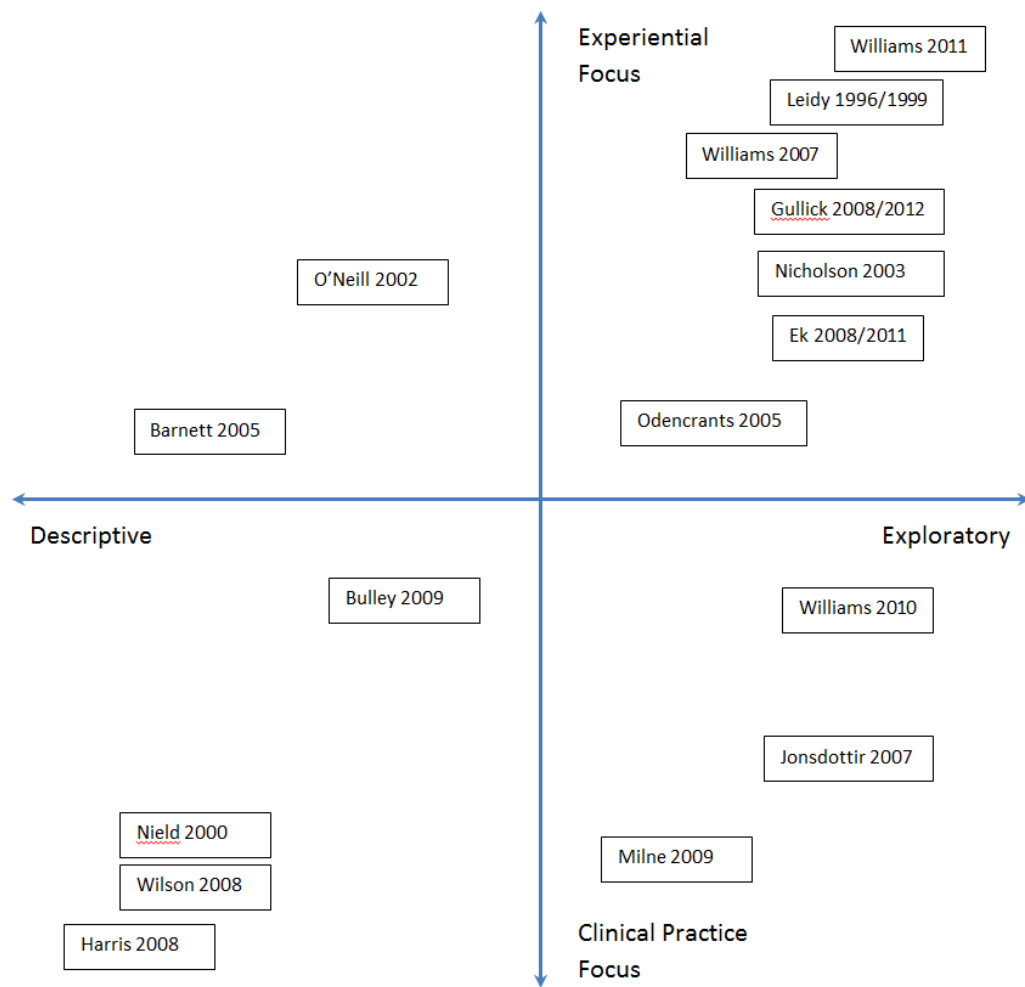
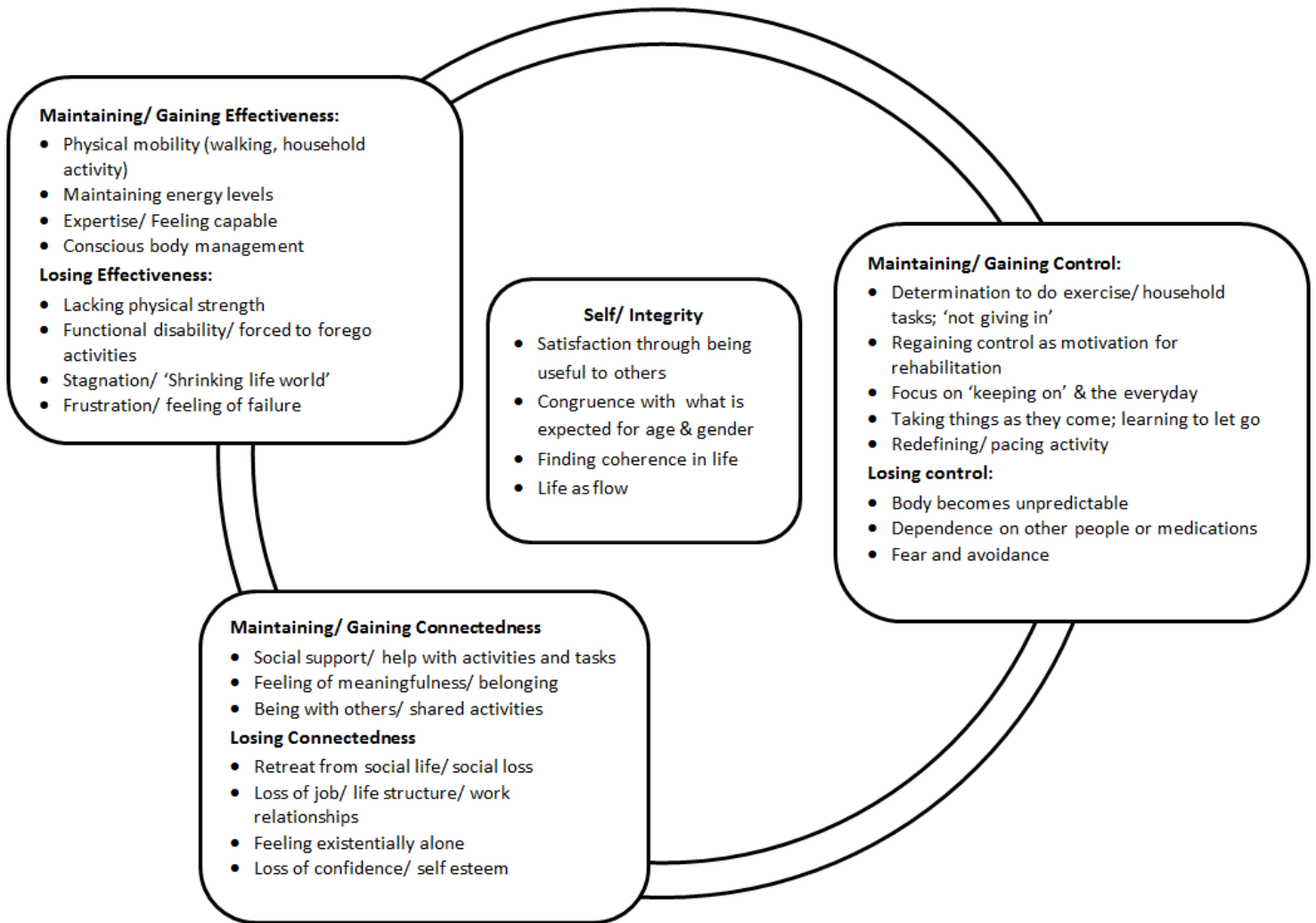


Figure 2: Map of included studies





**Table 1: Characteristics Of Studies / Main Concepts**

1 <sup>st</sup> Author/ Year	Participant Context	Guiding Concept	Data Collection	Caring for the body	Caring for environment	Moving between spaces	Social interaction	Selfhood across time
Barnett, 2005	10 patients using hospital chest clinic, UK	Hermeneutic phenomenology	Unstructured interviews	Basic self care takes time/ help from others		Walking in garden/ fresh air are important	Relationships outside family are lost	Continuing to wash/ dress, 'not giving in'
Bulley, 2009	9 patients enrolled for pulmonary rehabilitation, UK	Interpretive phenomenology	Semi-structured interviews		Keep on cleaning the house/ making the bed	Trying to keep moving even indoors		
* Ek, 2008	8 patients with advanced COPD eligible for oxygen therapy, Sweden	Hermeneutic phenomenology	5 open ended questions		Small household chores/ pottering about	Able to get out with help from others	Helping others/ being with family if possible	A 'normal life' adds to feeling of meaning
Ek, 2011	4 patients living alone and receiving oxygen therapy, Sweden	Hermeneutic phenomenology	Repeated interviews, 17 in total	Need to entrust body to changing carers				Listening to friends telling stories
* Gullick, 2008/ 2012	15 patients choosing palliative surgery & 14 carers, Australia	Hermeneutic phenomenology (Lifeworld)	In-depth interviews, 58 in total	Women carers help w. washing/ dressing	Gendered roles mirrored in household tasks	Frustration on having to plan activities	Shrinking lifeworld as COPD worsens	Relationships important for sense of self
Harris, 2008	16 patients with COPD on primary care practice list, UK	Grounded theory	In-depth interviews		Hard to give up households or pay others	Outdoor activity possible with help from family		
* Jonsdottir, 2007	10 married couples where wife had been hospitalized for COPD	Research-as-if- practice approach	Open dialogue with couples			Activities as a couple e.g. swimming	Social isolation when disease is active	Aiming to find coherence in life
* Leidy, 1996/ 1999	12 patients using hospital chest clinic, USA	Phenomenology (Colaizzi)	Interview guided by participants		Tension between relaxing control/ doing tasks right	Inability to go out with family is distressing	Useful activities with/for others give satisfaction	Being useful gives life continuity and meaning
Milne, 2009	15 patients with severe COPD who had been hospitalized, Australia	Interpretive Phenomenology	In-depth interviews			Going for walks/ walking in own garden		Hope is found in being able to remain active
* Nicolson, 2003	20 patients with COPD on primary care practice list, UK	Thematic analysis	4 focus groups			Knowing places for resting aids mobility	Difficult to run/ play ball with grandchildren	Confidence loss as social roles are abandoned

Nield, 2000	15 African-American patients pulmonary using hospital chest clinic	Thematic analysis	Semi structured interviews	Getting dressed/ shaving may take a long time				Aiming to appear outwardly the same
Odencrants, 2005	13 patients with COPD on primary care practice list , Sweden	Thematic analysis	Semi-structured interviews and food diary	Difficult to shop, cook, eating little and often	Doing kitchen tasks sitting down	Going food shopping using walking frame	Eating as social activity can be problematic	Remembering past meals
O'Neill, 2002	21 women enrolled for at-home rehabilitation, USA	Thematic analysis	Semi structured interview	Difficult to wash/ dry; coping strategies	Doing housework but adapting e.g. sitting down		Loss of job/ social/ sexual relationships	
Williams, 2007	6 patients visiting respiratory doctor/ nurse, UK	Grounded theory	In-depth interviews		Housework, maintenance, tinkering	Walking as recreational and functional		Holidays/ trips associated with past good times
Williams, 2010	9 patients enrolled for pulmonary rehabilitation, UK	Grounded theory	Semi-structured interviews		Rehab to take up housework/ gardening again	Walking enables getting out/ getting around	Physical activities in context of social activities	
* Williams, 2011	18 patients using Breathe Easy Clinic, UK	Thematic analysis	Semi-structured interviews			Aiming to get to countryside/ seaside		Concepts of self and life linked to fresh air
Wilson, 2008	12 patients with advanced COPD on continuous oxygen therapy, Canada	Thematic analysis	Semi-structured interviews, 36 in total			Tied to home by oxygen; indoor exercises		Hobbies 'expected' for retired people