The ties that bind us: how existing relationships, health and gender shape family care in chronic obstructive pulmonary disease

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Abstract

Chronic obstructive pulmonary disease (COPD) changes family roles and relationship dynamics and the experience of the disease is influenced by family functioning. Merleau-Ponty's existential philosophy of the body provided the framework for this Heideggerian phenomenological inquiry. Fifteen people with COPD and 14 family members engaged in 58 semi-structured interviews either face-to-face or by telephone. This study identified a difference in the essence of the lived experiences between male and female carers, and between spousal and non-spousal carers in relation to severe COPD. Previous reciprocity framed the level of acceptance of the caring role and perception of care burden. The stories highlight the self-perceived need for women carers to be *conscious micro-managers* of illness. Male family members would care alongside, lending support and caring in a reactive way as specific needs or crises arose. Caring in COPD required a *binding vigilance*; a constant need of the carer to monitor the physical and emotional well-being of the sick person that bound them emotionally and cognitively to the task of caring. Carers were the managers of crises and families cared from a perspective of possible death. Family was perceived as the best thing in life. Health professionals should consider the influence of gender, family relationships and the impact of reciprocity when planning support for family caregivers. Further research is required to identify the similarities and differences in family caring between COPD and other chronic illnesses, and to further understand the specific needs of male carers.

Introduction

Chronic obstructive pulmonary disease (COPD) is experienced within the context of the family. Like many chronic illnesses, COPD limits the capacity of the person to fulfil their previous roles, and thus impacts on those people who are closest to them. A recent American Lung Association survey revealed that half of all COPD patients felt their illness limited their ability to work and restricted their physical exertion, household chores, social activities, sleeping and family activities.[1]

The seminal research of Barstow[2] established that a supportive significant other is probably the most important factor in adjusting to the disease. Others have demonstrated that a satisfying relationship prior to illness is associated with better family functioning and quality of life, and a lower perceived burden of care.[3,4] Where family members exhibit poor self-identity and are unable to respond flexibly to change, the family's ability to manage COPD is undermined.[5]

The characteristics of caregivers and the risks for caregiver burden are suggested to be similar across chronic diseases, with more female family members providing care.[6,7] Family carers in COPD are known to experience challenges to health, strength and quality of life.[8-10] while informal carers across chronic illnesses experience emotional strain, loneliness and depression.[6,11,12] The confining nature of caring in COPD, the prolonged deterioration and an uncertain prognosis makes it difficult to plan for the future.[9,13] Many older COPD carers are socially disadvantaged with less access to services and benefits and less money to outsource household tasks.[14,15]

It is evident that family relationships influence patient outcomes in COPD. As family care giving is such a multilayered concept, shaped by a number of facets of human behaviour,[16] it is important to seek further understanding of the current experiences of family carers so that we may support that caring role in surgical and non-surgical management. This paper describes the relationship dimensions of families living with COPD that emerged in a larger study of people who had chosen palliative surgery for emphysema.[17]

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Materials and Methods

Philosophical framework and mode of inquiry

Much health care research is framed by a biomedical view of the body. Rene Descartes' philosophy of mind-body dualism claims that we are aware of the mind only because it thinks and perceives and otherwise, the mind is independent from the physiological functions of the body.[18] It is with this notion of separateness of the mind and body that much COPD research is designed.

An alternative mode of inquiry provided by Heideggerian phenomenology informed this study.[19] Heidegger rejected notions of a body's *objective* presence in the world proposing that human experience is shaped by our existence in relation to the people and the surrounding world nearest to us. Heidegger's idea of *being-in-the-world* makes way for the lived experience of the person and family as a source of meaningful data. His philosophy acknowledges the *intentionality* of the person where their lived experience is drawn to, and shaped by, those things that matter to them.

The existential philosophy of Merleau-Ponty[20] is chosen as the philosophical framework to complement Heideggerian phenomenology with a focus on the person, living within a body that has a distinct social situation. Merleau-Ponty held that the body cannot exist in itself, but is fixed to a certain world; percep-

tion is always embodied and influenced by the context of that person's world. It was found that the context for the person with COPD is created by a loss of physical predictability and spontaneity as they perceive their world through a breathless body.[21,22] Their experience is also shaped by the relationships and concerns that define that person's life-world.[23]

According to Merleau-Ponty,[20] the person experiences their body's day-to-day functions as taken-for-granted. This is the known body of the person that perceives and connects with the family unit and the community. As the once taken-for-granted body with COPD becomes less effective and reliable,[21] there is potential for the family unit to perceive and experience changes in their life-world. True to this existential philosophy, the study was conducted within the family as the context for the experience of living with and managing COPD.

The research participants

This study recruited 15 people with COPD and 14 close family members using non-probability, purposive sampling.[24] Participants were sampled across three hospitals and comprised all known, available patients having a lung volume reduction procedure for COPD in New South Wales, Australia, during the two year study period.[17] Family participants included seven wives, three husbands, two siblings, and two adult children. There were more men in the patient cohort (9:6) reflecting the higher frequency of men with severe COPD.[25] There were more women caregivers (10:4), again reflecting normal caregiver demographics.[26] Six of 15 family units lived in a large Australian city, and nine of 15 lived in rural or regional areas. Eleven patient and carer units (79%) were in co-dwelling relationships with ten of these being spousal relationships. Two couples also had a supportive adult child who was living with them but was not described as integral to the caring process. Two parent-child units lived separately, but geographically close, with frequent caring contact. One sibling carer was geographically distant to the patient, but provided care during times of crisis. Sociodemographic characteristics of the participants are listed in Table 1.

Ethical considerations

Participant Information Statements were provided and written consent was obtained. The three participating hospitals and the supporting university granted the ethics approval. The participants are de-identified by the use of pseudonyms. It was understood that participants could become extremely breathless over the duration of the study. The participants discussed the study with the interviewer prior to data collection and this allowed an assessment of their capacity to participate. At subsequent interviews the family participants were interviewed first so that we could again gain insight into the patients' ability to participate. The interviews were tailored according to the participants' needs so that, in the case of severe breathlessness, the interview was of shorter duration or paused to allow time for recovery.

Data collection

Participants were interviewed on two occasions, with six months between interviews, in line with an aim of the larger study to understand the impact of palliative surgery on COPD over time. Fifty-eight semi-structured interviews were tape-recorded and transcribed verbatim. An interview guide led the participant through experiences of life before and after the onset of COPD (Table 2). Eighteen interviews were conducted in face-to-face mode and 40 by telephone. Telephone interviews were a more appropriate form of access for our more distant rural and regional participants. In addition, the effectiveness and quality of telephone interviews in qualitative research have been demonstrated in several studies.[27-29] Family members and patients were interviewed separately. Typically, the interview duration was about 40 minutes, but the follow-up interviews could be shorter with the briefest being about 5 minutes where severe breathlessness made speaking difficult. The longest interviews lasted approximately 90 minutes.

Data analysis

After reading the transcriptions many times and grouping common experiences into themes, the essential dimensions of the experience became apparent. These provided a lens through which further interpretation occurred, and were used as a reference point for entry into what Heidegger[19] referred to as the hermeneutic circle. This circle framed a process of constant back-and-forth comparison of contradictions within and between interviews and relationships between individual participant quotations, in order to gain a thorough understanding of the whole. In this study, the whole was constituted of the person, within their family and the community.

The trustworthiness of the findings were strengthened by the inclusion of quotes from participant stories. We sought to carefully integrate these quotes with our philosophical interpretation to support the analysis.[30] A deci-

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Table 1. Characteristics of participants.

Patient pseudonym and age	Family member and age	Rural, regional or urban dwellers	Patient working	Family member working	Who patient lives with
Jim 60 years	Helen (wife) 58 years	Rural NSW	No	No	Wife
Eric 73 years	Mary (wife) (age not available)	Suburban Sydney	No	Yes	Wife
Peter 66 years	Margaret (wife) 64 years	Regional NSW	No	No	Wife
Albert 72 years	Agnes (wife) 73 years	Suburban Sydney	No	No	Wife
Chris 67 years	Anna (wife) 66 yrs	Rural NSW	No	No	Wife and daughter
Sam 55 years	Karen (wife) 52 years	Regional NSW	Yes	Yes	Husband and daughter
Garth 65 years	Therese (wife) 60 years	Regional NSW	No	No	Wife and daughter
Catherine 58 years	Paul (husband) 71 years	Suburban Sydney	Yes	Yes	Husband
Eva 58 years	Daniel (husband) 59 years	Rural NSW	No	Yes	Husband
Matilda 77 years	Philip (husband) 82 years	Suburban Sydney	No	No	Husband
Frances 55 years	Anita (daughter)29 years	Suburban Sydney	No	Yes	Lives alone, daughter lives close by
Simon 60 years	Stephen (son) 38 years	Regional NSW	No	Yes	Lives alone, son lives close by
Alex 57 years	Elizabeth (sister) 62 years	Urban Sydney	No	No	Sister, only since becoming very ill
Tina 63 years	Monica (sister) 62 years	Rural NSW	No	No	Lives alone, sister lives in Sydney and supports during crises
Petra 63 years	No family available for interview	Regional NSW	No	N/A	Lives alone. Daughter lives overseas

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sion trail documented research-related decision making and formalized a process of methodological reflection.[31]

Results

Two overarching themes described the caring experience; *binding vigilance* and *conscious micro-management* of illness and emotions emerged as a response of family carers to the unpredictable course of COPD. This response was mediated by gender and shaped by the previous reciprocities in spousal relationships as opposed to non-spousal relations. It was also mediated by the health and ageing challenges faced by the carers. Family was identified as the best thing in life.

Binding vigilance

Nine of the women carers (90%) described a process of *binding vigilance*; a need to closely monitor the physical and emotional well-being of the sick person that bound them emotionally and cognitively to the task of caring. Binding vigilance was underpinned by the past experiences of crises and perceived near-death. Almost all of these families had experienced a near-death event. One caregiver, Anna (66 years), had to cope with several night-time emergencies with Chris and recalled,

He woke, and said 'I'm in trouble.' … He stood. We couldn't even sit him down. He lost control of his bladder, and I just hit the button for 'triple 0'.

The experience of near-death placed actual death closer to the foreground for people living with breathlessness. The resulting need for close observation, this *binding vigilance*, could add to the shrinking life-world of the family in a psychological sense, by keeping them close and focused on breathlessness. Margaret (64 years) revealed, *I listen for his breathing, I've been doing that for years. I'd lie there and think to myself, 'Please take another breath'*. The all-encompassing need for vigilance could rob the carer of their personal space and time. Anna became desperate as she became more tied to the total care and responsibility for her husband, Chris. This is illustrated by her statement,

Oh God! I'm losing track of the days here with him. I'm frightened to leave the house, that's how it's getting.

For Agnes (73 years), her perceived need to monitor Albert bound her to the home and reduced her opportunities for social connection. This was exemplified by her recollections,

We used to go over to our children's…We used to go out to the markets every Sunday, … but now, he doesn't like going out at all … I want him to join in. But he won't… and I don't like leaving him.

Some methods of vigilance took the form of *checking in*, allowing the boundaries of this vigilance to expand. Anna found a strategy that allowed her to move out of earshot of Chris while she did the gardening: *I've got a pair of beepers for us. So if he needs anything, he just hits the button*. Elizabeth (62 years) took the risk of leaving her brother Alex for periods so she could assist her disabled, pregnant daughter. She maintained her vigilance by finding excuses to make a phone call to him.

Binding vigilance led to a new way of perceiving the person, framing a new relationship dynamic within the family. Children of COPD patients could experience a reversal of previous roles, as they became bound to an unaccustomed level of parent monitoring. This was the case for 53-year-old Sam whose whereabouts were followed by his children and is exemplified in his narrative, *I'd go for a walk down the road… if I wasn't back by a certain time, they'd come looking for me.*

Gendered differences in managing care

The caring role was experienced differently between men and women among the study participants. Male family members cared *alongside* and lending support but caring in a reactive way as specific needs or crises arose. Women carers of men stepped up to a management role and were more likely to own and intellectualize that role, indicating a *micro-managed care.*

Female *carers* were more likely than their male counterparts to assist with washing and dressing and to take on extra jobs around the home, whilst female *patients* with COPD tried to continue their household tasks as long as possible. Women patients with COPD persisted with tasks related to traditional gender-roles (*e.g.,* shopping and cleaning) more so than the males with COPD (*e.g.,* lawns and maintenance). The result was that women carers were more likely than men to take on extra duties. In this study, women carers frequently described themselves as *doing everything*. For Agnes, it was not only the increased workload but also her husband Albert's temperament, and the gender-specific roles within their relationship stretched her. This is supported by her assertions

He's a very demanding man, and he likes things done. So you can't be in two places at once - clean up outside, do the washing and give him a cup of tea when he wants it.

Elizabeth felt trapped by her brother Alex's

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Table 2. Interview guides.

Interview guide for people with COPD	Interview guide for family carers
1. Can you talk to me about when you first started to notice your breathlessnesss? What sort of things started to change for you then?	1. Can you talk to me about when you first started to notice his/her breathlessness? What sort of things started to change for you then? What was that like for …(carer)? What was that like for … (patient)?
2. Can you tell me about the exercise program you attended? What sort of things started to change for you then? What was that like for …. (carer)?	2. Can you tell me about the exercise program he/she attended? What sort of things started to change for you then? What was that like for … (patient)?
3. Can you talk to me about your surgery? What sort of things changed for you then? What was that like for …. (carer)?	3. Can you talk to me about the surgery? What sort of things changed for you then? What was that like for … (patient)?
4. What are the best/worst things about having emphysema?	4. What are the best/worst things about him/her having emphysema?
5. What were the best/worst things about having the surgery?	5. What were the best/worst things about him/her having the surgery?
6. What are the best things in your life now?	6. What are the best things in your life now?

COPD, chronic obstructive pulmonary disease.

total dependence on her as she described, *…trying to do more myself, hoping this awful business of not being able to do anything would stop…Shopping, cleaning, cooking… Everything!*

The male carers in our sample were more likely to *help* rather than to take over household tasks and did not describe assisting with body care. Matilda (77years) had debilitating COPD and described being so breathless she would have to hang onto things as she walked. Her husband Phil (82 years) stated,

[Her breathlessness] depressed me a little bit, but I just had to cope with it and hope for the best. She does all the washing, and hangs it out. She cooks. …I'll cook twice a week… and that's a bit of a break.

Fifty-eight year old Catherine, a stylish and driven woman who ran a luxury boutique, was the only patient with COPD who was still working. Her ability to remain productive defined Catherine both to herself, and within her relationship to husband Paul. Whilst Catherine described herself within a caring marriage, there was little adjustment in the balance of home duties since her illness. For example, *I don't think it has affected him at all. It's a terrible thing to say, but it hasn't… I cope, and even if I'm puffing I don't say anything, I just go upstairs and have my nebuliser quietly.*

It seems that this situation may have been partly of Catherine's choice. Her husband Paul (71 years) explained,

She does get out of breath…. but she's very proud and active, she doesn't let on that she's got a problem…. I don't do much around the house… If I try to do it, I do it wrong, so better not to do it.

The female spousal carers took energetically to the role of conscious micro-managers. Women carers did not trust their husband's intentions of dealing with breathlessness on their own. They actively organized medical review and sought access to interventions such as surgery, oxygen therapy and early management of infection. A highly synchronized coordination of care allowed them to maintain a sense of control.

Agnes, who frequently described yielding to her husband Albert's strong personality, took assertive ownership over the management of his lifestyle, recalling, *His tobacco … I tossed it in the garbage!* Margaret coordinated and coaxed husband, Peter, with his diet, analysing the nutritional benefits of his limited intake. This was apparent in Margaret's explanation,

So he's having the Ensure™… I'm getting four of those into him a day… I was told to give him fatty food. Well, you've got fat in pies and sausage rolls… and he has Corn FlakesTM with cream on it… He's getting the vitamins with the Vegemite™.

Helen (58 years) often ensured medical oversight and recalled

I say to Jim, 'I'll ring the doctor and I'll make an appointment.' [He says],'No, don't worry. Leave it till tomorrow.' … [I say]'Leave it 'til bloody tomorrow and it will be ten times worse' …So you just ring up. You say, 'You've got an appointment at twenty past ten.

In the context of relentless deterioration, the conscious micro-management of food intake, exercise and other lifestyle factors gave carers access to the limited number of disease control that they could manipulate. For the women, this appeared to be an extension of their comfortable and familiar nurturing role.

Micro-management was not apparent in the approach of the male caregivers. Daniel's caring role for his wife Eva was reactive rather than proactive, explaining, *You just do it! You just go with the flow.* Paul's connection with Catherine's illness also revealed a less proactive stance. It wasn't until she was considered for a lung transplant that he sought more involvement. This is evident in Paul's words,

I don't think she hides it from me, but she doesn't like me going to the doctor with her… last time, she was told, 'This is quite serious and you're going to get worse, and your life is going to be shortened'… but I wasn't there, so I didn't hear what was said and I wasn't able to ask questions. But I'm going next time

For Stephen (38 years), the caring role was expressed more as social support and management of tasks, rather than management of illness. His father Simon lived alone and had difficulty walking, dressing and cleaning his house. Stephen explained about his caring role, for example, *…it was always on our minds….I'd to come up and mow the lawn … I'm only a couple of minutes away. We'd go out and watch the football, or he'd be over here having a barbeque…*

Managing emotional well-being

Women carers became conscious *micro-managers* of emotional well-being. They were more likely to intellectualize their approach to interpersonal interactions with the breathless person. They consciously avoided situations that could bring on extreme emotions by making light of grave situations and by finding ways to reinforce the person's sense of self-worth.

Seven carers described consciously avoiding conflict situations that could heighten emotions, and therefore worsen breathlessness. Mary explained, *I don't let situations arise… it's not good for him*. Women carers tried hard to instil a sense of effectiveness by delegating a useful task within the person's capability, or finding strategies to delay their inevitable dependence. Adjusting to the breathless person's slower pace, or covertly doing the heavier jobs were other common strategies. Elizabeth explained that *it was important to allow him to feel important so, although I was terrified, I would let him drive my car.* She paid a conscious attention to Alex's gendered experience of illness, revealing a symbolic understanding of maleness that can only be embodied in bodies which are always gendered.[32] Elizabeth said

He couldn't make his bed, but I'd wait until he was having a shower... I tried as far as possible for him not to see me doing thing things, which for him would have been humiliating… Even men who have a view that denotes the woman's role to do housework, like to be able to make their own beds.

Families described managing emotional well-being by *consciously making light of things*. Elizabeth's comments exemplified how, without breaks for humour, there could be an unremitting intensity to the life-world of both the breathless person and carer. For example, *Alex had the oxygen and periodically, I'd deliberately step on it… and then we'd have a huge joke about him dying instead of me saying 'What would you like for dinner?'*

The male family members did not describe formulated strategies for managing emotional aspects of care. Stephen expressed the difficulty he had with his father Simon's emotions. For example, *He's just turned into a cynic… no good words about anything any more. … We try our hardest.* Daniel felt at a similar loss to support his wife Eva and said,

She's gone through a fair bit in her life. None of the kids have been real kind to her… I think she's just nearly given up… What can you do?

Caring shaped by reciprocity

The family relationship of the sick person to the carer, and the extent of reciprocity that preceded the illness shaped the caring experience. For spousal carers, there was a conscious fostering of *give and take* as an expression of intimacy. Spouses framed their caring roles as a natural extension of the reciprocity within marriage. In the past, Anna had undergone surgery for severe arthritis in her hands. Her poignant description of bathing her husband Chris who was debilitated with COPD demonstrated the redefining of a caring *task* into a loving and intimate gesture. She recalls,

He got frustrated at first. But he knows I had ten months there where I couldn't do a thing for

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myself... So I leave my shower to his time – we get in there together. After 45 years, if we can't do that…

Eva and Daniel, both in their late fifties, also described a supportive relationship and saw the changing of roles during illness as part of the reciprocal nature of marriage. Eva who was experiencing a worsening of her COPD condition explained,

He's a great help… he cooks tea and if I cook tonight, he's got to wash up… As he said – he's been married to me long enough now... He's willing enough to do anything for me, because it's for better or worse, isn't it?

Whilst Agnes and Albert's long relationship was characterised by conflict, there was a history of appreciation and reciprocity. This relationship was illustrated by her comments

Although we fight and argue … he does most if the bookwork, he does all the paying of the bills, and I rely on him a lot. He relies on me here.

Alternatively, Mary was angry about husband Eric's long smoking history and his lack of commitment to his exercise program. Whilst she gave care to his body, she did not see him reciprocating through care and responsibility for himself. This influenced her acceptance of the increasing intensity of her caring role. She explained, *I have never had so much to do… Ever! I get angry because he's brought it all on himself.*

Spousal carers did not refer to a lack of extended family help and seemed to take ownership of the caring role in a different way to siblings or children. In the siblings' or children's caring relationships, particularly where a perception of reciprocity did not pre-exist the illness, the tasks were performed more grudgingly. This was certainly the case for Elizabeth as she explained,

The worst thing is that Alex (brother) and I have little in common... And having to live with somebody who's very sick… I'm sure people do similar things for husbands, but they do have something in common... The thought went through my mind, 'Where were you when I was left with two tiny children, to give me a break just for one day?'

Stephen described his sister's perception of a one-sided relationship with her breathless father Simon, explaining, *My sister is up there all the time, cleaning his house… She was getting really upset, saying, 'That's all he ever rings up for… to say "When are you coming to do my house?*

Even where the care was given happily as it was by Anita for her mother Frances or by Stephen for his father Simon, it was noted when the other people in the family weren't contributing. Anita (29years) vented her frustration with her brother and his wife, exclaiming,

Lazy! They think they do it all, but they do nothing… We're both working, but we've got to go around and do Mum's lawns and everything there … and they just drink alcohol all weekend and party!

Caring shaped by health and ageing

In this sample, the health and ageing of the carer often came to the forefront of their experience. Some carers would play down their health needs. Anna's debilitating arthritis had resulted in her early retirement and she only presented her intensive caring role as a difficulty when her need for hospitalization clashed with that of her husband, Chris. In contrast, Mary was frustrated that her husband Eric's COPD retained precedence when she herself was unwell and said, *When he was sick, I got plantar fasciitis in my feet… I just couldn't walk. But I had to look after him… shopping… it was difficult for me.*

When both the husband and carer were disabled, even maintaining food in the house could seem overwhelming to the carer. This was a daily dilemma for carer Agnes, as she described,

I've got to look after him… try and do the shopping, and my legs and back's gone… Sometimes I get half way down the shop and I can't go either way.

Caring shaped by anger and frustration

The family carers frequently experienced anger and frustration. Helen became angry when husband Jim would not seek early care for a chest infection. For Mary, it was a combination of the restrictive effects of Eric's breathlessness and the context of self-infliction that stirred her emotions. Mary recalled, *I hated it! …there were always things we did together and that stopped. Angry? Yep!*

There were times when COPD sufferers Jim, Albert and Chris expressed despair and almost wanted to give up on their treatment. This frustrated their wives who, in response, expressed a desire to physically lash out. Helen said *I'd like to cut his bloody throat sometimes,* while Anna laughed*, I've felt like hitting him a couple of times!* Agnes revealed that *Sometimes I feel if I had a gun I would shoot him!* Anger, frustration, worry, and fear were usually suppressed in the presence of the breathless person to avoid conflict.

Family as the best thing in life

When asked the question *What are the best things in life now?* all of the participants with close relatives cited family as the most important thing to them. This emphasis situated the family unit as the context that gave meaning to both experiencing disability and managing care. As breathlessness worsened, the participants described a greater appreciation of each other. Jim remarked to his wife Helen after a period in hospital, for example, *You don't realise how precious your grandkids are. Helen (58 years) observed, I think Jim sort of values things more now… With life, we take too many things for granted.*

Discussion

This study has expanded our understanding of the meaning of caring for a person with chronic illness within the context of the family. Previous research has described the person with COPD as living within a shrinking life-world. With the increasing loss of physical effectiveness and the visibility of unacceptable body behaviours such as coughing, spitting and oxygen dependence, the person may become more and more bound to the home. They lose opportunities for self-expression and consciously contain their emotions to avoid distressing breathlessness.[21] Such shrinking of existence is described in the writings of Merleau-Ponty[20]

…the move towards the future, towards the living present or towards the past, the power of learning, of maturing, of entering into communication with others have become… arrested in a bodily symptom, existence is tied up and the body has become 'the place where life hides away.' (p. 164)

It is within this situation of physical and emotional containment that family caring in COPD occurs. This study builds on the gender-linked differences in roles, stressors and access to resources amongst caregivers described by other researchers into chronic illness.[33] The binding vigilance of the females' experiences revealed in this study may explain why some researchers report both a higher care burden[7] and a greater risk of psychiatric morbidity amongst female carers.[6,33,34] The findings concur with previous research, revealing that women are immersed in ongoing vigilance and unrelenting responsibility[35] and carry out more personal care and household tasks than male caregivers.[7] This requirement for focused care increases exponentially as the illness progresses, leading to a shrinking life-world for the family.[21] Even the women *patients* in our study seemed less able to relinquish their own maternal history as carers and housekeepers. Wider research into different

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chronic illnesses is recommended to support the notion that gender may influence both the experience of illness and caring. The gendered differences in the illness experience expressed by the female patient participants in this study are similar to the findings of a large Dutch study of elderly couples. Those women experienced higher levels of distress regardless of whether they were a patient or caregiver, suggesting that gender may be a stronger factor in the perception of burden than the patient or carer role.[36]

This distinction between being female and being tied to a particular notion of caring, particularly caring within a spousal relationship, may be born of a certain embodied female consciousness. Merleau-Ponty noted an embodied understanding of ourselves:

… existence…cannot be anything – spatial, sexual, temporal – without being so in its entirety, without taking up and carrying forward its 'attributes' and making them into so many dimensions of its being 20 (p.410).

The difference in the caring narratives between the male and female family members in this study resonated with previous research,[37] with men relating to the care recipient in a distinct way. Men are more likely to be long-distance carers and more likely to be employed. They provide different types of care with less focus on activities of daily living and complex illness management,[36] which makes their care seem to be *alongside* that of the person with his or her illness.

In this study, the male carers' lessened proximity to and concentration of care appears to lessen their experiences of *binding vigilance*, and this differs from the experience of *doing everything* and the micro-management approach of our female carers. Men are known to call upon previous marketplace management skills with well-developed strategies around delegation and coordination of outside service provision.[38,39] Male carers more commonly seek time on their own as a way of adapting to carer burden.[39] Further research is required to clarify the essence of the experience for male carers in COPD.

This interpretation of the differing caring experience of women and men is not intended as gender-based value judgement or hegemonic analysis. Rather, it shines light upon a particular way of being female or male, and married or unmarried, for participants within a specific culture and of a specific generation. Merleau-Ponty's philosophy supports the idea that this embodied orientation towards the world for carers in COPD may not be self-evident or easy to move beyond,

We must recognize a certain sedimentation of our life: an attitude towards the world, when it has received frequent confirmation, acquires a favored status for us…… I am situated in a social environment, and my freedom, although it may have the power to commit me elsewhere, has not the power to transform me instantaneously into what I decide to be.20 (p. 441and p.447)

It was not only gender but age, and the nature of the family relationship that influenced the caring experience. This study found a lower perceived burden of care for spouses, and for those in relationships with higher levels of reciprocity. The difficulties for younger, non-spousal caregivers have been demonstrated in other settings, with adult children more likely than spouses to perceive poor family support and higher care burden,[6] and younger caregivers being constrained by family and work obligations, and by social roles and responsibilities. The increased workforce participation of married women may have influenced the traditional patterns of inter-generational family support. Younger working women may be unable to make the radical economic and lifestyle change required to care for elderly parents and may feel reluctant to make personal sacrifices to carry the burden of informal caregiving.[40] The findings in this study around reciprocal relationships help us explain that a greater subjective stress level may be experienced by younger, non-spousal carers.[41,42]

The discovery that reciprocity in marriage relationships can enhance the caring experience is consistent with those of a Finnish COPD study[15] that identified the getting and giving of help as a *reciprocal joy to both parties.* Improved reciprocity has been reported following surgery for COPD due to a regaining of self, improved mood and communication and regaining of intimacy.[17] This reduces what Pearlin *et al.*[43] described the perception of caring as *occupying the entirety of the relationship*.

Implications for practice

There is a growing understanding that management of chronic conditions is not in the direct control of health professionals but, is substantially managed by both patients and their informal carers.[44] Family carers are able to contribute their caring insight based on shared personal meanings of the illness and caring experience. Body care in severe COPD requires a complex and integrated pattern of skills to keep the person's breathing under control whilst optimising their comfort and well-being.[45] This study provides insights into how families manage and communicate caring within the context of one chronic illness. It may assist multidisciplinary health care teams in forming meaningful partnerships with these families based on mutual understanding of home caring styles that can support precise, continuous care in hospital setting.

It is possible that health professionals may encounter the phenomenon of *binding vigilance* in women carers of hospitalized patients. These women may seek regular updates and active involvement in planning, and this would be consistent with their role as *conscious micro-managers* of care. Their highly coordinated management approach explains their active role in family decision-making for invasive therapies such as lung volume reduction surgery and endobronchial valve insertion. The subtle improvements experienced by people after surgery for emphysema do not always release carers from a perceived need to manage illness in this way.[17]

The findings of this study also provide insight for health professionals to identify those family carers who require additional support for their role. There are obvious cases of need, for example, where carers are elderly and less mobile. It is evident, however, that it is children or siblings who may require higher levels of support due to their lower perceived levels of reciprocity and/or the resulting higher perceived burden of care. Similarly, those patients who do not have a spouse as their carer may require increased access to some services.

This study confirms the earlier findings of Scharlach[45] that the negative aspects of combining work and caregiving may be outweighed by a sense of accomplishment and enhanced interpersonal relationships. Health professionals may be important facilitators of home help or respite care that can assist carers to continue in the paid workforce, if desired.

These new understandings call for a reflective and considered approach to a partnership in care planning. Jonsdottir[47] discussed the notion of partnership when interacting with COPD families and contrasts this with the common construct of nursing practice that focuses on interventions and nurse-initiated problem solving. The findings of this study refocus on the importance of partnerships in illness management with plans of care built on an understanding of the resources and needs within each family caring unit, and the person and family's ability and right to create the direction of that management.

Strengths and limitations of the study

The philosophy of Merleau-Ponty and the research approach of Heideggerian phenomenology allowed our focus on the personal concerns of the family as the context in which a chronic illness is experienced and controlled. Staged interviews also allowed an expression of the temporality of caring for families in chronic illness. It is possible that the difference in findings between male and female carers might be affected by the relatively lower number of male caregivers in this sample, and

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a possible difference in the severity of COPD for those in their care. It is also acknowledged that further research is recommended on the male and female caring roles and sharing of home duties, which is expressed differently across families and cultures.

Conclusions

Health professionals should incorporate these new understandings of the influence of gender, family relationships and the impact of reciprocity when planning support and care for family caregivers of patients with COPD and other chronic illnesses. Further research is required to clarify the experiences and specific needs of male carers in COPD. There is also a continued need to study chronic illness in family context, where ever-evolving caring roles reside in contemporary health care systems.

References

1. Confronting COPD in America. Schulman, Ronca and Bucuvalas Incorporated. 2003. http://www.aarc.org/resources/confronting_copd/exesum.pdf Accessed: 2 February 2008.
2. Barstow R. Coping with Emphysema. Nurs Clin North Am 1974;9:137-45.
3. Ashmore J, Emery C, Hauck E, MacIntyre N. Marital adjustment among patients with chronic obstructive pulmonary disease who are participating in pulmonary rehabilitation. Heart Lung 2005;34:449-51.
4. Steadman P, Tremont G, Davis J. Premorbid relationship satisfaction and caregiver burden in dementia caregivers. J Geriatr Psychiatry Neurol 2007;20:115-19.
5. Kanervisto M, Paavilainen E, Heikkilä J. Family dynamics in families of severe COPD patients. J Clin Nurs 2007;16:1498-505.
6. Douglas S, Daly B, Kelley C, et al. Impact of a disease management program upon caregivers of chronically ill patients. Chest 2005;128:3925-36.
7. Covinsky K, Newcomer R, Fox P, et al. Patient and caregiver characteristics associated with depression in caregivers of patients with dementia. J Gen Intern Med 2003;18:1006-14.
8. Booth S, Silvester S, Todd C. Breathlessness in cancer and chronic obstructive pulmonary disease: using a qualitative approach to describe the experience of patients and carers. Palliat Supp Care 2003;1:337-44.
9. Seamark D, Blake S, Seamark C, Halpin D. Living with severe chronic obstructive pulmonary disease (COPD): perceptions of patients and their carers. an interpretative phenomenological analysis. Palliat Med 2004;18:619-25.
10. Tomasa L, Shirai Y. Older caregivers and transitions study: aging and transitions project. OCAT Summary Report. Sonoran University Centre for Excellence in Developmental Disabilities. 2008 http://sonoranucedd.fcm.arizona.edu/sites/sonoranucedd.fcm.arizona.edu/files/OlderCaregiversandTransitionsStudy_SummaryReport1.pdf Accessed: 2nd February 2011.
11. Kara M, Mirici A. Loneliness, depression and social support of Turkish patients with chronic obstructive pulmonary disease and their spouses. J Nurs Sci 2004;36:331-6.
12. Eriksson M, Svedlund M. 'The intruder': spouses' narratives about life with a chronically ill partner. J Clin Nurs 2006; 15:324-33.
13. Barnett M. Chronic obstructive pulmonary disease: a phenomenological study of patient's experiences. J Clin Nurs 2005;14: 805-12.
14. Parnell H. Caring for the carers of chronic lung disease sufferers in the community. JCN Online 2001. http://www.jcn.co.uk/journal.asp?MonthNum=05&YearNum=2001&Type=backissue&ArticleID=346 Accessed: 6 July 2010
15. Kanervisto M, Kaistila T, Paavilainen E. Severe chronic obstructive pulmonary disease in a family's everyday life in Finland: perceptions of people with chronic obstructive pulmonary disease and their spouses. Nurs Health Sci 2007;9:40-7.
16. McCullagh E, Brigstocke G, Donaldson N, Kalra L. Determinants of caregiving burden and quality of life in caregivers of stroke patients. Stroke 2005;36:2181-6.
17. Gullick J, Stainton MC. Taking a chance: the experience of lung volume reduction procedures for chronic obstructive pulmonary disease. Chronic Illn 2009;5:293-304.
18. Descartes R. Meditations on first philosophy: philosophical writings of Descartes. Cambridge: Cambridge University Press; 1984.
19. Heidegger M. Being and time. New York: Harper & Brothers; 1927. p. 1996.
20. Merleau-Ponty M. Phenomenology of perception. London: Routledge and Kegan Paul; 1945. p.1962.
21. Gullick J, Stainton MC. Living with COPD: developing conscious body management in a shrinking life-world. J Adv Nurs 2008;64:605-14
22. Gullick J. Conscious body management of breathlessness: living with COPD and choosing surgery. Saarbrücken: VDM Verlag; 2008.
23. Husserl, E. The crisis of European sciences and transcendental phenomenology: an introduction to phenomenological philosophy. Evanston: Northwestern University Press; 1936. p.1970.
24. Llewellyn G, Sullivan G, Minichiello V. Sampling in qualitative research. In: Minichiello V, Sullivan G, Greenwood, K and Axford R, editors. Handbook for research methods in health sciences. Sydney: Addison-Wesley; 1999.
25. Varkey A. Chronic obstructive pulmonary disease in women: exploring gender differences. Curr Opin Pulm Med 2004;10:98-103.
26. Rice K, Walker C, Main A. Gender impact assessment: woman and informal caregiving. Women's Health Victoria, Gender Advocacy Framework. 2008. http://whv.org.au/static/files/assets/2aaa851d/Women_and_informal_caregiving_GIA.pdf Accessed: 2 February 2008.
27. Sturgess J, Hanrahan K. Comparing telephone and face-to-face qualitative interviewing: a research note. Qual Res 2004;4:107-18.
28. Stephens N. Collecting data from elites and ultra elites: Telephone and face-to-face interviews with macroeconomists. Qual Res 2007;7:203-16.
29. Holt A. Using the telephone for narrative interviewing: a research note. Qual Res 2010;10:113-21.
30. de Witt L, Ploeg J. Critical appraisal of rigour in interpretive phenomenological nursing research. J Adv Nurs 2006;55:215-29.
31. Lincoln Y, Guba E. Naturalistic enquiry. Beverly Hills: Sage Publications; 1985.
32. O'Loughlin,M. Intelligent bodies and ecological subjectivities: Merleau-Ponty's corrective to postmodernism's "subjects" of education. Philosophy of Education Society, University of Sydney. 1995. https://blogs.aalto.fi/researchinart/files/2012/01/OLoughlin.pdf Accessed: 11 August 2011.
33. Pinquart M, Sörensen S. Gender differences in caregiver stressors, social resources, and health: an updated meta-analysis. J Gerontol B Psychol Sci Soc Sci 2006;61:33-45.
34. Yee J, Schulz R. Gender differences in psychiatric morbidity among family caregivers. Gerontologist 2000;40:147-64.
35. Hutchinson S. The lived experience of women providing care for their husbands with severe COPD in rural Saskatchewan. [Dissertation] University of Saskatchewan. 2011
36. Hagedoorn M, Sanderman R, Ranchor A, et al. Chronic disease in elderly couples: are women more responsive to their spouses

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health condition than men? J Psychosom Res 2001;51:693-6.
37. Navaie-Waliser M. The emerging male caregiver: successful strategies for outreach and support. Proceedings of the National Aging I&R/A Symposium, AIRS National Conference, 2004. http://www.authorstream.com/ Presentation/Miranda-41888-9-MNWMaleCaregivers Str-ategies-Emerging-Male-Caregiver-Successful-Strategies-Outreach-Support-OVERVIEW-PRESENTATION-a-mnwmalec-Entertainment-ppt-powerpoint/ Accessed 14th August, 2009.
38. Russell R. The work of elderly men caregivers: from public careers to an unseen world. Men Masc 2007;9:298-314.
39. Nordtug B, Holen A, Similarities and differences in caring burden of home dwellers with partners suffering from chronic obstructive pulmonary disease or dementia. Home Health Care Management Practice, 2010. http://hhc.sagepub. com/content/ early/ 2010/08/10/1084822310368633.full.pdf+html Accessed: 3 April 2010.
40. Glezer H. Cycles of care: support and care between generations. Fam Matters 1991;30:44-6.
41. Cain C, Wicks M. Caregiver attributes as correlates of burden in family caregivers coping with chronic obstructive pulmonary disease. J Fam Nurs 2000;6:46-68.
42. Kim Y, Kashy D, Evans T. Age and attachment style impact stress and depressive symptoms among caregivers: a prospective investigation. J Cancer Surviv 2007;1:35-43.
43. Pearlin L, Mullan J, Semple S, Skaff S. Caregiving and the stress process: An overview of concepts and their measures. Gerontologist 1990;30:583-91.
44. Lindsay S. A sociological focus on "expert patients". Health Sociol Rev 2009;18:139-44.
45. Lomborg K, Kirkevold M. Curtailing: Handling the complexity of body care in people hospitalized with severe COPD. Scand J Caring Sci 2005;19:148-56.
46. Scharlach A. Caregiving and employment: competing or complementary roles? Gerontologist 1994;34:378-85.
46. Jonsdottir H. Research-as-if-practice: A study of family nursing partnership with couples experiencing severe breathing difficulties. J Fam Nurs 2007;14:443-60.

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