

## **Caring for a Parent with Pulmonary Fibrosis in Malta: The lived experiences of daughters in mid-adulthood**

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### **Abstract**

Idiopathic pulmonary fibrosis is a progressive fibrotic lung disease that is on the rise globally. The disease is associated with significant morbidity and hence poses significant challenges for their informal carers, particularly daughters in mid-adulthood, who struggle with their own personal demands and that of their ill parents. Yet there is a dearth of literature on the experiences of these specific carers. Hence, the purpose of this study is to explore the lived experiences of daughters caring for a parent with pulmonary fibrosis within a community setting. This was explored using a phenomenological qualitative framework that was conducted between January and April 2017. Semi-structured audio-recorded interviews were conducted with six adult daughters who provided care to a parent having pulmonary fibrosis. Purposive sampling was used to recruit study participants. Transcribed data were analyzed using Interpretative Phenomenological Analysis. Three main themes were extracted which communicate the essence of the daughters' lived experiences: "Walking on tiptoes", "Flooded by emotions" and "Shifts in family dynamics." Participants described experiencing the toll of being constantly vigilant for symptoms. They also expressed a range of emotions that included guilt, helplessness and worry related to their care experience. However, these emotional struggles were suppressed in order to present an external facade of strength and control. A shift in roles was also described where the daughters became the informal carers/support for both their ill and well parent, albeit in different ways. Caring for a person with pulmonary fibrosis is an emotional and life changing experience and hence, there is the need for individualized interventions

that target the unique perceptions of these informal carers.

**Keywords:** pulmonary fibrosis, informal carers, daughters, lived experiences, qualitative, interpretative phenomenological analysis.

### **What is known about this topic**

1. Carers were perpetually vigilant to symptoms in persons living with pulmonary fibrosis
2. Carers experienced ambivalence, striving to maintain a semblance of normality, whilst preparing for the future
3. There is a gradual role shift with carers taking over the responsibilities of the person with fibrosis.

### **What this paper Adds**

- Daughters in mid-adulthood provided care to both the well and ill parent, whilst supporting their immediate family as well
- Carers actively search for causal triggers of symptoms and ensure that they are avoided in an effort to exert some control
- Interventions should target particular domains of the Common -sense model namely the perceived consequences; emotional impact; uncertainty relating to symptoms and treatment options.

## **1.Introduction**

Interstitial lung disease (ILD) represents a heterogeneous group of lung diseases causing variable degrees of scarring and inflammation. Idiopathic pulmonary fibrosis (IPF) is a common form of ILD (Lindell et al., 2000) that appears to be on the rise

globally (Hutchinson et al., 2015). It is characterized by a progressive decline in lung function and an inability to maintain normal blood oxygen levels. IPF is reported to be more common in males and in older adults (Overgaard et al., 2016) with 227.2 per 100,000 persons aged 75 years and over (Raghu et al., 2006). Currently no treatment has been identified that can reverse or cure the damaged lung (King, 2005). The median survival of persons with IPF ranges between 3 to 5 years from the time of diagnosis (Lindell et al., 2000), which is comparable to that of aggressive cancers (Vancheri et al., 2010).

Living with IPF has an impact on the health-related quality of life of the person with challenges relating to functional independence, a heavy symptom burden (Bajwah et al., 2013), and an impaired daily life (Lindell et al., 2000). Consequently, persons with IPF are at an increased risk of developing anxiety and depression, with a study by Lee et al. (2017) identifying 25.9% and 21.4% of patients with IPF displaying symptoms of depression and anxiety respectively.

However, the progressive disability in a person with IPF, coupled with the lack of effective treatment to control/cure the illness, proves distressing not only to the patient, but also to their informal carers (Vancheri et al., 2010), who often are either the spouse and/or daughter (Pickard, 2011). Such carers are at a higher risk of developing physical and emotional problems (Aneshensel et al., 1995), particularly daughters who may face additional burdens relating to both ascending (i.e., care of parents) and descending lines (e.g., care of children) (Hämäläinen & Tanskanen, 2019). Yet there is a dearth of research relating to the experiences of daughters caring for a parent with IPF, as extant literature either focuses on the perceptions of spouses and daughters collectively together (Bajwah et al., 2013; Lindell et al., 2017; Overgaard et al., 2016) or lacks details regarding carer status (e.g., Sampson et al., 2015; Vallejo et al., 2007).

Furthermore, the influence of age on carer experiences is rarely acknowledged in the literature. For instance, female carers in mid-adulthood are reported to potentially struggle with parenting responsibilities of children, in addition to caregiving responsibilities towards a parent or parent-in-law (Health and Social Care Information Centre, 2010). This phenomenon for midlife carers, may have a considerable impact on their finances, health, employment and interrelationships (Larkin et al., 2018) and occurs at a time when they increasingly engage in reflections about the meaning of life (Santrock, 1998) and where opportunities for employment and social relationships are more limited (Payne, 2007).

The prevalence of ILD in Malta is estimated at 24.9 per 100,000 population (Gouder, Fenech & Montefort, 2012). Hence, considering an estimated local population of about 514,564 inhabitants (National Statistics Office, 2020), one would expect that approximately 128 persons in Malta have ILD, however this may be an underestimate, as patients having pulmonary fibrosis secondary to connective tissue diseases or those under the care of other physicians were not included in the previous audit. The public health-care system available in Malta is funded through general taxation and national insurance, with primary and acute health-care services also offering free services and community care being available at a highly subsidised cost. Moreover, Malta's relatively small population size further meets the criteria of a face-to-face community (Abela, Frosh, & Dowling, 2005), where families remain physically close to each other. This scenario offers scope for the investigation of informal caregiving of persons having IPF within this context.

## **2. Method**

### **2.1 Study Design**

As a methodological framework, IPA was used as it enabled the researcher to obtain a rich narrative and understanding of a phenomenon, based on the lived experiences and the meanings that the participants attached to them. IPA is based on three principal theoretical underpinnings, which are phenomenology, hermeneutics and ideography (Smith et al., 2009).

Phenomenology addresses the subjective experience of how individuals make sense of their own life experiences. Hermeneutics incorporates the interpretative process with the researcher “making sense of the participant, who is making sense of x” (Smith et al., 2009, p. 35). This is known as ‘double hermeneutics’ which incorporates the participant first interpreting their own experience and the researcher then interpreting the meaning of the participant’s account. Ideography addresses the importance of understanding the unique experiences of the individual, within a particular context. An idiographic enquiry thus requires homogeneous samples with individuals who have experienced the phenomenon. In this study, the participants represented a homogenous sample, as they were all adult daughters in the mid- adulthood phase and caring for a parent with IPF.

## **2.2 Theoretical Model**

A useful framework to explore carer beliefs is the Common-sense model (CSM) (Leventhal et al., 1992) that acknowledges the role of the carer in the life of the patient. This model posits that individuals generate illness representations that enable them to “make sense” of their experience with a disease and to manage the 'threat'. This model states that illness representations consist of five cognitive elements: identity (label and symptoms associated with the illness), causal triggers of an illness, consequences (severity of illness and impact on functioning), time-line (duration of the illness) and controllability or cure. Emotional representations such as fear are also generated and

are processed in parallel with the cognitive components of the CSM.

### **2.3.Participants**

The first six participants approached by a physiotherapist who worked in the respiratory clinic (intermediary) accepted to participate in the study and were recruited. This sample size is congruent with the ideographic nature of an IPA study (Smith & Osborn, 2003). The inclusion criteria for this study were daughters: (i) caring for a parent who has IPF and (ii) aged between 35-60 years (i.e., mid-adulthood phase as defined by B.M. Newman and P.R. Newman, 1999).

### **2.4 The Research Tool**

A pilot study was first conducted with one participant prior to commencing with the actual interviews. The semi-structured interviews were conducted face-to-face with participants by the first author (D.S). Semi-structured interviews were selected as they provide a flexible method allowing the researcher to probe any emerging aspects raised during the interview producing richer data (Griffiths, 2009). The interview schedule consisted of nine open-ended questions that explored various aspects, amongst which the impact of providing care to persons with IPF. Open ended questions were set as they provided the participants with an opportunity to elaborate on their experiences, thus obtaining an in-depth account (Smith et al., 2009). The introductory question 'Can you tell me a little bit about yourself?' was worded to assist the participants to feel more at ease during the interview. Another example of an interview question is 'Can you describe your experience of caring for a parent having IPF? Probing questions were also used when further clarification was required. An example of a probing question included was 'What does this experience mean to you?'. The interviews were audio-recorded and conducted in the setting requested by the participant, with most of the interviews occurring in an outpatients clinic in the general hospital and the remainder occurring at home. The duration of the interviews was

between 45-80 minutes.

A reflexive journal was utilized throughout the data collection phases in which the researcher listed any assumptions, interpretations or biases that could be bracketed to ensure that any preconceptions would not influence the data collection process.

## **2.5 Data Analysis**

Data analysis followed the guidelines recommended by Smith et al. (2009). This involved analyzing the transcripts case by case manually, followed by a cross-case analysis for similarities and differences, thus enabling the researcher to observe patterns emerging across cases, as well as highlighting the unique aspects of individual cases. For this study, the first author (DS) was responsible for the primary analysis of the interview transcripts, whilst the remaining authors (C.B.X; J.S) audited the data analyzed by reading of the transcripts and ensuring that the themes extracted were grounded in the transcripts and that each theme was well represented through relevant excerpts.

Trustworthiness of the study was ensured using the 4 criteria suggested by Lincoln and Guba (1985) namely credibility, transferability, dependability and confirmability. Credibility refers to providing a detailed description of how interpretations of the data were made. This was enabled by providing excerpts from the transcripts to support each theme, enabling the reader to recognize how interpretations were made from the data collected. Transferability was ensured by providing a description of the context in which the study took place, thus enabling the reader to decide whether the data could be transferred. Dependability incorporated providing a detailed description of decisions taken in the study with their rationale and these are outlined in the method section. Whilst confirmability describes the extent to which the findings were shaped by the

respondents and not researcher biased. This was ensured through the inclusion of open-ended questions in the interview schedule, that allowed the participants to voice their own experiences

## **2.6 Ethical considerations**

Ethical approval was obtained from the relevant Faculty research ethics committee [SWB-147]. To safeguard participant confidentiality, pseudonyms were used in the study and audio-recordings of the interviews were stored in a locked cabinet and destroyed on completion of the study. Participants were also informed that they could withdraw from the study at any time and without providing justification. To reduce the risk of coercion, six potential participants were approached by the intermediary and handed an information letter describing the nature of the study. They were also informed that they would be requested to provide informed consent, should they be willing to participate. The intermediary then forwarded the details of these six persons to the first author (D.S). The services of a clinical psychologist was also available should any person experience distress due to participation in the interview.

## **3 Findings**

This section presents details regarding the lived experiences of daughters of persons with IPF. The mean age of participants was 41.2 years, with an age range between 35-50 years. Four of the informal carers were employed, with one working in a family friendly environment. The remaining two carers had resigned from their workplace to support their parent with IPF. Three of the carers had children of their own, with two of them in a stable relationship.



Three themes were extracted from the data collated. The first theme 'Walking on Tiptoes' delves into the constant state of vigilance experienced by the informal carers. The second theme 'Flooded with Emotions' explores the gamut of emotions experienced by these participants. Whilst the third theme 'Shift in family dynamics' explores how the informal carer gradually took over the role of both parents (i.e., parent with IPF and their well spouse), albeit to different degrees.

Table 1 illustrates the themes and sub-themes extracted targeting the lived experiences of daughters caring for a person with IPF.

### **3.1 Walking on Tiptoes**

All the participants described being highly overprotective towards their ill relative. This included constantly monitoring their relative's symptoms, particularly attacks of coughing that were perceived as potentially fatal. Such symptoms were also perceived as ongoing and relentless, providing no respite to the carer and ill relative. Such a burden of caring was described as negatively influencing the health-related quality of life of these carers, as described by one participant:

"It's daunting, there is no respite, I am always on edge, it is all the time because when she [ill relative] gets up even to go from one room to another, she ends up out of breath, she's coughing all the time, you don't know when it's going to stop, if it is going to stop ...I am scared that it can be fatal..." (Rita)

In addition to respiratory problems, two participants described their preoccupation at their mother's increasing weight loss. For them, the effort exerted by their ill relative in striving to breathe, left them with little remaining energy for other vital activities, as expressed by Rita:

"The main challenge that I have is trying to get her to eat. She has lost her appetite since her lungs are so bad. Her body is working hard just

to breathe... her consultant informed me that things aren't good at all [for her]" (Rita)

The need for oxygen therapy in the case of three of the patients, was also an overwhelming concern for the carers. It also served as a constant reminder of the frailty and vulnerability of the person with IPF. The provision of oxygen was perceived as an essential lifeline and hence the carers exerted extreme caution to ensure that this 'flow' was not disrupted. One respondent commented that:

"I get upset always seeing him [ill parent] with a pipe [for the delivery of oxygen], he is totally dependent on it. Even for myself I am always terrified of tripping in the pipe or pulling it and pulling his face along as well... I struggle continuously with these thoughts." (Tina)

In a scenario of uncertainty, the carers strived to exert some active control by ensuring that any perceived triggers of the disease were avoided. Such perceived triggers included contact with bacteria, viruses, dust, odours and pets. One carer (Sarah) emphasised the importance of decreasing exposure to pathogens and gave strict instructions to her mother to turn her face to the side when a person coughs, 'with your ear facing them and not your face'. Four other participants stressed the importance of avoiding dust or particular odours at all costs, as exemplified in the following excerpt:

"I really worry about dust... carpets and curtains are avoided at all costs. I only use summer sheets at home, even in winter I do not use blankets, only quilts as blankets trigger breathing difficulties. The sheets that I use are of cotton and I use them both in summer and winter. They are the best as they don't trap dust. We also have a dog at home, but he can only stay in the kitchen" (Martha)

This perceived need of these carers to be the 'voice' of their ill parent influenced their interactions with professionals, as the latter were expected to maintain the same high standards of care. For Annette, health professionals should work in tandem with the carers and hence should not expose their ill parent to any triggering factors, however this she felt, was not always the case.

"I constantly wash my hands before I touch my mother and afterwards. I expect that professionals should maintain the same standards, as they need to protect her. If they don't ... I bring it to their attention. It is my responsibility." (Annette)

This overriding vigilance expressed by carers also necessitated that they maintained constant contact with their ill parent. This enabled them to respond immediately should the need arise. As a consequence, their social life was impacted and this left them feeling isolated and lonely. For instance, according to Rita:

"...It [being a carer] affects friendships. I don't have many friends as I am not able to go out with them and keep up with the friendship. You see I don't want to be far away from her [ill parent] so that if something happens, I can quickly reach her. I am just scared that she won't have the chance to contact me by phone" (Rita).

### **3.2 Flooded by Emotions**

Caring for a relative with IPF was a highly emotional and life changing experience. The relationship that existed between the carer and the ill parent was described by three participants in terms of caring for a baby, with one participant (Elena) comparing feeding her mother to the act of breast feeding a baby. This highlights the strong bond that existed between the ill parent-daughter dyad, as well as the significant dependence of the ill parent on her daughter:

"It is as if you have a baby, similar to when you are feeding a baby breast milk, when I am feeding my mother, she is aware when I am tense and begins to get breathless. A person with fibrosis also needs to be given time..." (Elena)

Yet although caring for a baby was a stressful experience, Elena reflected that parents were aware that this phase was transient, as the child became increasingly independent. However, this was not the case for these carers as IPF is a degenerative

illness, with persons becoming increasingly dependant over time. According to Elena:

'Caring for a baby is stressful but you know that the baby will grow and become more independent. But when you are caring for a person with fibrosis, it is a different matter, as they [persons with IPF] become more and more dependent on you as their disease progresses' (Elena)

In this scenario, carers further strived to present an outer façade of emotional strength and control to family members. Yet they confided about their internal struggles to suppress the deep, emotional turmoil raging within them. One participant explained:

"The feelings, they are there ...deep down... like I am trying to suppress them and not let them surface. I need to be strong. I always ruminate on how to ease her [ill parent] suffering. Just watching her suffer, although I do my utmost to help her and knowing that there is no cure that can make any difference ...that is so tough" (Rita)

The carers also highlighted the pain that they experienced at seeing their 'well' parent who was once a pillar of emotional strength and resilience, now metamorphosised into an emotionally weak, distraught and dependant person. One respondent commented:

"At times I find Dad [well parent] crying at home and I tell him Dad let me get someone to speak to you and he tells me no, I can speak to you [his daughter]. My Dad was such a resilient man, he was always so strong [emotionally] and to see him distraught like this..." (Elena)

All the carers expressed frustration at having so many queries that were left unanswered. Such questions targeted the aetiology of the illness and any treatments that could hold promise. Consequently, the carers resorted to browsing the internet in the hope of gleaning information about the disease and any novel developments relating to treatment:

"My mother knows that I often search the internet for any treatment and that I read a lot [about the disease] so she trusts me when I phone abroad enquiring about any treatment available. Lately, I enquired about a clinical trial that I had read about and that was being conducted

abroad, but my mother could not be included, as the state of her disease is too advanced” (Elena)

Feelings of guilt were also highlighted by the carers. Guilt was cited in relation to two aspects: loss of patience with their ill parent and the lack of sufficient time to devote to their own children:

“Sometimes with the pressure of everyday life you get frustrated and sometimes it gets so overwhelming that it's scary because you don't want to take it out on her [ill parent] but you do, you know and then you feel that you shouldn't... and I also have a family of my own. One of my kids is 14 and the other is 16 and it's an age where they really need you and depend on you” (Rita)

Rita further emphasized an additional preoccupation that her children were carrying a heavy burden on their shoulders, a burden that weighed them down, as demonstrated in the following excerpt:

“I worry a lot seeing how my kids constantly worry about my mum and that they stay checking up on her throughout the day” (Rita)

### **3.3 Shift in family dynamics**

Three participants expressed having to juggle their time supporting both their parents (the ill and well parent) and their immediate family, mainly their children. Martha in the following excerpt described taking over roles such as cleaning, cooking and driving the person with IPF to hospital for clinic visits and physiotherapy. Her mother [ill relative] throughout adopted a passive role, with Martha comparing her experience to that of caring for a ‘big doll’:

“My daily routine is that after my son leaves for school, I bathe my mother and I care for her, I prepare a meal for my mother, I make her some fresh orange juice, some tea and prepare her medications. It is as if I have a big doll because I also dress her up” (Martha)

Two participants (Annette and Rita) described that they had to stop working to care for their mother who had pulmonary fibrosis. This had both financial and social implications for themselves and their family, whilst another three participants described their struggles and state of exhaustion with full time employment and the need to support both parents:

“I am always tired. I work long hours and after work I visit my parents to help them in their housework and cooking. Mentally this has stressed me out to the extreme and I am left with hardly any strength for anything else, including myself and my partner” (Tina)

## **4 Discussion**

The present study provides an insight into the experiences of daughters in mid-adulthood who care for a parent diagnosed with IPF. Three themes were extracted namely ‘Walking on tiptoes’, ‘Flooded by emotions’ and ‘Shift in family dynamics’. The findings generated will be interpreted in the context of Leventhal’s Common-sense model (Leventhal et al., 1992). This model proposes that when individuals encounter a health threat due to an illness, they simultaneously develop cognitive (i.e., illness perceptions) and emotional representations about the illness, that can influence the way they appraise and manage an illness. Section 4.1 discusses findings relating to the following cognitive domains, namely the symptoms associated with the illness (identity); the causal factors; the consequences in caring for a person with IPF and the perceived controllability of the condition, whilst section 4.2 describes the emotional representations generated by these carers.

### **4.1 Walking on Tiptoes**

During an illness experience, carers strive to determine whether any symptoms experienced by their ill parent relate to the specific illness. The carers' perceptions of symptoms attributable to IPF in the present study, were found to be consistent with the conventional clinical views about the illness. The carers associated symptoms such as coughing, breathlessness and weight loss with the disease and expressed being hypervigilant to these symptoms, a finding that concurs with extant literature (Bajwah et al., 2013; Lindell et al., 2017; Overgaard et al., 2016). However, whilst the carers in the study by Bajwah et al. (2015) were not aware that such symptoms could escalate rapidly resulting in death, in the present study three carers expressed being constantly on edge in fear that their ill parent's condition could escalate rapidly, leading to death. These discordant findings may be influenced by the disease severity of the ill relative, where three participants in the present study provided care to ill relatives at an advanced stage of IPF and who had experienced various hospital admissions.

Another core component of the person's cognitive representations of their illness, relate to identifying the likely cause/s of the illness and symptoms. Such causal and symptom attributes have been identified as having a critical influence on the emotional reactions of the person; on the development of mastery and perceived control and in providing meaning about the illness (Janoff-Bulman et al., 1983; Taylor 1983). This search for meaning occurs in a context where for incurable diseases such as IPF, the medical discourse used by professionals creates an air of uncertainty and where medical answers are not readily available (Bury, 1982). The carers in the present study attributed symptoms of IPF to dust; odours, pathogens and the presence of pets. Moreover, the present study contributes to extant literature, by highlighting the extreme vigilance exerted by carers to avoid any causal triggers perceived as exacerbating symptoms. In

this manner the carers could gain some control and predictability that would also have a positive impact in fostering adjustment in carers (Pakenham, 2008; Payne, 2007).

## **4.2 Shift in family Dynamics**

Findings in the present study also concur with those obtained by Overgaard et al. (2016) in that the carers gradually took over much of the daily chores of the ill-parent. However, the present study extends the extant literature by demonstrating that these daughters actually support both parents, i.e., the ill and well parent. The uptake of these additional roles should be interpreted in light of a meta-analytic review of illness perceptions (as described in the Common-sense model) linking greater consequences or impact on the person with a more negative impact on their role and social functioning and psychological well-being (Hagger & Orbell, 2003).

Two participants in this study also described their distress at observing their well parent who previously represented a pillar of emotional strength, now transformed into a fragile and vulnerable person. These parents were not willing to seek assistance from professionals but rather preferred to rely on their daughters for such support. In these circumstances, the carers strived to present an external facade of emotional strength and control, whilst deep down they struggled to suppress any emotions, a fact that according to Le and Impett, (2016), promotes additional emotional distress to the person.

## **4.3 Flooded by Emotions**

As described in the Common-sense model (Leventhal et al., 1992) when encountering a health threat due to illness, people also make simultaneous emotional



representations of their illness. Such emotional representations may also influence illness outcomes (Moss- Morris et al., 2002). Findings in the present study and that cited in the extant research (Lindell et al., 2017; Overgaard et al., 2016; Vallejo et al., 2007) all identify the gamut of emotions experienced by carers of persons with IPF. The experiencing of such emotions relating to an illness have been identified as being positively correlated to anxious preoccupation (Price et al., 2012)

In the present study, two of the daughters described feeling frustrated at the neediness of the person with IPF, however unlike the participants in Bajwah et al.'s study, these feelings of frustration were also associated with strong guilt feelings due to their impatience. Three of the carers perceived that being gainfully employed coupled with the need to support both parents (albeit in different ways), posed a significant burden on them. This was exemplified by Tina's excerpt where she described the burden of returning from work and the need to assist both her ill and well parent, whilst struggling to find personal time for her partner and herself. Such struggles should be interpreted in a context where carers at mid-adulthood gauge their self-worth from their contributions to social units, including family, work and the community (Newman, 1999).

The Common-sense model further highlights that carers may refer to experts and lay sources in their effort to search for meaning and information (Hagger & Orbell, 2021), thus enabling them to gain some degree of control (Williams et al., 2014). This was exemplified in the present study by participants browsing the internet for information and treatments that included clinical trials, as this presented them with some degree of hope and with answers to their queries. The use of the internet as a source of illness information has become particularly popular as it provides 'immediacy of information access, the accessibility at any time of the day or night, the potential continual updating

of information and the wider range of information available' (Cotton and Gupta, 2004, p.1797).

Hence, there is a need to expand community awareness relating to both the impact of caring and the services required (DeRigne & Ferrante, 2012). This requires an understanding of how carers make sense and give meaning to what is happening from 'their individual perspective, psychosocial context and social role' (McCance & McCormack, 2017, p.54) and the formulation of interventions that target these unique perceptions. Moreover, there is a need to explore how carer perceptions are influenced by the degree of severity of the parent with IPF and by the developmental stage of adulthood (e.g., mid versus late adulthood).

#### **4.4 Limitations**

As typical of IPA studies, a small sample size was included. However, although the sample may appear small the aim of this study was not to generalize the findings but rather to provide an in-depth exploration of the experiences of a homogenous group of informal carers.

#### **4.5 Conclusion**

This study highlights the importance of understanding the carers cognitive and emotional illness representations (as identified in the common-sense model). Carers in this study expressed how the lack of knowledge on specific symptoms, causes that can exacerbate these symptoms, as well as the progression of the disease, led to the constant surveillance of any potential indication that could worsen the condition of their ill relative. Moreover, as part of the caring mantle that the daughters took on and due to the strong family ties in Malta, participants in this study also took up the role of a carer with the 'well' parent. This highlights one of the indirect consequences of this disease, that even the 'well' parent (i.e., partner of the 'ill' parent) requires the provision

of psychosocial support. Lastly, findings also emphasised the emotional spectrum participants faced, from the experience of guilt feelings to the emotional turmoil of trying to maintain a healthy work-life balance.

This study emphasises the need for interventions that target specific illness domains highlighted, such as the need for information and the perceived consequences and emotional impact of providing care. Such interventions could include Cognitive behavioural therapy that targets the restructuring of negative thoughts and appraisals, such as the perceived need to maintain constant contact that prevented carers from having a social life. Whilst, psychoeducational interventions may also be used to address the concerns and uncertainty that carers experience and provide updated information on the disease and treatment options.

Moreover, there is a need for qualitative research focusing specifically on homogenous samples of carers e.g., daughters specifically, rather than grouping all carers collectively together. This study has demonstrated that daughters in mid-adulthood face unique challenges as carers and at a time when they increasingly reflect on the meaning of life and on their contributions to family, work and society.

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Table 1 Themes and sub-themes extracted from an analysis of participant transcripts

Themes	Subthemes
Walking on Tiptoes	<p>Monitoring of symptoms</p> <p>Perpetually vigilant to perceived triggers</p> <p>Maintaining constant contact</p>
Flooded by Emotions	<p>Helplessness due to a lack of control</p> <p>Upset due to suffering of their parents and children</p> <p>Suppression of emotions to appear strong</p> <p>Frustration at queries left unanswered and the neediness of ill and/or well parent</p> <p>Guilt due to loss of temper</p>
Shift in Family Dynamics	<p>Occupying the role of main carer to the ill parent</p> <p>Supporting the well parent</p>