LEVEL 3: QUALITATIVE RESEARCH EVIDENCE:

IN-DEPTH SUMMARY OF FACTORS AFFECTING CAREGIVER MENTAL HEALTH

Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
1. Patient condition		
Patient decline	*Fear of decline*	Caregivers were themselves worried about the effects on their own health and also how they would cope if the patient's condition deteriorated, especially in partner relationships in which the caregiver was older. McPhearson 2013 Participants described their emotional stress in observing and comforting the sick family member suffering distress in facing their incurable illness. Heidenreich, 2014. "But the reality that this isn't going to get better, there's no light at the end of the tunnel on this one and those things all weigh heavy on a caregiver" Ferrell 2018 Several commented on being unsure about how they would cope in the future: "What will it be like if the worst comes to the worst? How will my life go on?". Ugalde 2012
	Distress in observing physical decline	*Feeling anxious, stressed, helpless and overwhelmed: Its exhausting… Its heartbreaking to know, youre, like sitting on your hands. Theres nothing I can do for my mom… Watching her suffer I suppose is the hardest part Ferrell 2018* Severe everyday breathlessness of advanced COPD [Chronic Obstructive Pulmonary Disease] incurred an emotional toll on participants. A sense of helplessness and frustration pervaded *'just watching someone not able to catch their breath and [trying] not to panic and keep calm for X [spouse]': Hynes 2012* For these participants, the severe everyday breathlessness experienced by the person with COPD was matched by the strain of bearing witness such that the caregiver and care recipient become enmeshed in their mutual suffering. For one participant, this shared burden was likened to the metaphor of '*taking a life of its own…it's like this third person*'. The mutual suffering against this third person served to further isolate the caregiver and care recipient from the wider world. Hynes 2012

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Theme	**Sub theme**	**Supporting quote or text**
Predictors of psychological morbidity		
PATIENT CONDITION (*continued*): **Patient decline**	*Distress in observing physical decline*	The uncertain disease trajectory, limited explanations from health care professionals (HCPs) and ever-present threat of severe breathlessness: ‘*you want to breathe for* X’ fuelled a constant state of anxiety: ‘*just the constant worry all the time asking are you alright will you be able to go there’*. The threat of a severe breathlessness attack without warning governed every day activities: ‘*X can go from being very well to very badly within a day’* Hynes 2012 Caregivers described the strain of ‘*watch[ing] someone else that you care for in pain all the time and be sick’* and their feelings of helplessness and lack of control, leading to ‘*a level of anxiety that never really goes away*’ McDonald 2018 The pain for caregivers originated from witnessing and sharing in the experience. Some caregivers’ responses to patients’ pain indicated that they perceived themselves as experiencing more distress from the pain experience than did patients. Commenting on his wife’s pain, one caregiver stated: *I think that very frequently, it is as hard or harder for me than for her because I know that she is usually very tough on her body then when she says that she has pain, I know that she has a lot of pain*. (family caregiver) McPhearson 2013 Caregivers described the distress they experienced witnessing what they viewed as suffering. Recalling her reactions to seeing her mother in pain, one caregiver stated: *It [the pain] kind of brings me down yes definitely I have noticed that it’s hard because there is no improvement it is constant … it is personal yah it’s your mother and you know you feel bad and everything and I don’t want it to get me depressed either. Get me down all the time*. (family caregiver) McPhearson 2013 The sense of helplessness described by caregivers in trying to manage uncontrollable pain was upsetting, as the following response conveys: *I’m a man who likes to see things settled, to find a solution ... if I don’t have a solution, I’m despondent”*. (family caregiver) McPhearson 2013 A sense of powerlessness became apparent as the significant others felt that they were not able to alleviate the sick relative’s suffering. “*And it was very hard on her but also hard to watch. Well, you couldn’t do anything to. so to speak, take away what is hurting, you stand totally helpless and alone*.” Pusa 2012 *“My mother was most concerned with not being able to talk — that really made her frantic. She didn’t want us to leave her alone but you still have a house to run and there’s a lot of stuff to do.” Waldrop 2011* the patient’s constipation, powerlessness to alleviate it, and weakness caused great distress and emotional tension.

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
PATIENT CONDITION (*continued*): **Patient decline**	*Distress in observing physical decline*	*"She was so weak and in such bad shape mainly because of the medication she was on — she was constipated almost like a bowel obstruction. I screamed and yelled for help all weekend — they moved her to hospice on Monday. Waldrop 2011* I'm giving her every bit of attention that I can possibly give her. I find it difficult watching what's going on, as to the way she's deteriorating. It's tough to watch that. Ward-Griffin 2012 Unwilling to watch his wife if she were to die a protracted or painful death, another bereaved carer reported having considered carrying out assisted suicide if it had been required: '*If it had been necessary as she deteriorated I would have taken her life and I would have gone to prison if necessary, but I would have ended it for her. Let's put it that way. Yes, I was very thankful she went when she did'* (male former carer, 5 years post bereavement) Whitehead 2012 Among the issues that proved to be most troubling and anxiety-producing for caregivers were the infections that the care recipients experienced. Five of the caregivers described the emotional difficulty associated with seeing their loved ones suffer from the infections. "*My wife had it twice, the infection, and it's a lot of pain. When you see them going through it, it bothers you extremely bad*". Williams 2017 Immobility of the care recipient was a common feature with the individual unable to leave the bed, and in one instance, unable to hold up their head. ''. . . *all the muscles were gone, she couldn't hold her head up, you know, I had to hold her head to pick her up . . .* ''. Brazil 2010 Carers themselves could feel anxious and panicked, finding it difficult and distressing to witness a breathlessness attack: *"A bit more information. . . because for a start it was scary. He would come in the bedroom in the night. . . 'I can't. . .' and he couldn't even tell me he couldn't breathe, and I'm thinking what the hell? You just come out and you grab the phone. You don't know what to expect"* (Carer). Farquar 2017 Declining physical function, reduced mobility, impaired cognition/behaviour and communication contribute to difficult experiences for the caregiver. The extra tasks included assistance with activities of daily living, washing, cleaning and personal care "*if he has to go to the toilet I think 'Oh my god'; sometimes he doesn't make it in time; I struggle through that*" (female spouse/partner, 75 years). Galvin 2016 The psychological and emotional impact of exposure to suffering and deterioration of the person with ALS [amyotrophic lateral sclerosis] is a major subtheme in this analysis… "*just seeing her distress, that's the worst part. Only having so*

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Predictors of psychological morbidity		
PATIENT CONDITION (*continued*): **Patient decline**	*Distress in observing physical decline*	*many things to say to comfort her*" (male spouse/partner, age 65 years). There is emotional distress at witnessing the loss to the person with ALS and then also the loss of that person to the caregiver, for instance: "*it's upsetting seeing her not being able to talk, seeing her feeling lost and isolated and not having a conversation with her*" (daughter, 41 years). The patient's condition deteriorates and the caregiver loses the person they knew and the life they may have shared together, "*watching him go downhill, losing power in his arms and legs. It's upsetting for you to see your husband going like that. The fact that he has his mind, that he knows what's happening to him, it's unbelievable*" (female spouse/partner, 52 years). Galvin 2016 Participants referred to the tensions between increased disability for the care recipient as illness progressed and striving for normalisation. However, participants also acknowledged that striving for a normal life in the face of increasing disability was inherently difficult to achieve: '*lost interest in walking, lost interest in going on holidays, X just lost, X's confidence went*'. Hynes 2012 The emotional trauma of watching someone you love deteriorate was mentioned Kutner 2009
	Uncertainty over how the illness will progress	Several family caregivers described this uncertainty as "exhausting" and "heartbreaking," remarking on the helplessness they felt when watching their loved one suffer and being unable to relieve that suffering. Ferrell 2018 Maria expressed a strong sense of loss of control in her life and fear in experiencing the new circumstances alone, she said, *"[I'm] Just scared that he one day will pass away and I didn't know [it has happened] in here [her home]"* Heidenreich, 2014. A pervasive feature of carers" experience in this study was living with uncertainty, which stemmed from the lack of information provided. "*The fact that no doctor would come and discuss his case and nobody would give us information to go home with*". (bereaved caregiver)
	Uncertainty over how the illness will progress	There was a sense of uncertainty and fear about the future "*emotional, practical and financial*" (female spouse/partner, 51 years), of not knowing what is likely to happen or how to cope with what lies ahead: "*not knowing how long the process is, and for how long he [patient] is in this state. I would like to know what's down the road for us and what we can do*" (female spouse/partner, 70 years). Galvin 2016

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
	Uncertainty over how the illness will progress	The future is laced with uncertainty about coping, possible future tasks and managing the evolving condition: “*Not knowing how long the process is and for how long he is in this state. I would like to know what’s down the road for us and what we can do*”, and summed up as “*the uncertainty of the future - emotional, practical, financial*”. Galvin 2016 Anxiety about the future was evident in terms of care implications: ‘*I do kind of worry am I in over my head or do I know what I am doing or if X just keeps deteriorating*’; Hynes 2012 Emotional burden was prominent, and was related primarily to the uncertainty of the illness trajectory, which was described as ‘*sitting on a time bomb’*: “*Every morning when I get up, it’s how will [patient] be today and what will tomorrow bring. […] It’s all those complications that come with the unknown. That just gets to a person after a while*”. McDonald 2018 Described an underlying fear, coupled with an uncertainty of how they would cope and a lack of knowledge of available supports: “*I believe he is heading towards the end of his days. I’m terrified of that. What’s that going to look like? I’m terrified”*. McDonald 2018 “*I still feel a little bit like my fate is cast to the wind a bit, because we don’t know what happens next. I’m very afraid of, very afraid of the time, which will come, when [patient] is increasingly incapacitated. I’m very frightened about that*”. McDonald 2018 “*Parkinson’s just destroys your life. At times you cope well with it and at times you can’t cope at all. That’s just being honest. You dwell on the thing, thinking ‘what is to come*?’ (IC26) McLaughlin 2011 The uncertainty of how much time they had left and the variability in prognoses was anxiety provoking for many people. Carers also often voiced worries and fears for the future. These focused on feelings of uncertainty about what was to come and whether they would be able to cope as the disease advanced: “*I mean I know there has been a vast deterioration in the last three months and I keep thinking what’s it going to be like in the next three months and the three months after that, I don’t know how I will cope, I will cope but I don’t know how I will cope, and I am worried”*(male carer of wife diagnosed for 11 months) Whitehead 2012

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
	Impact of the patients cognitive decline	The caregivers' own Quality of Life (QOL) was thus markedly affected by that of the patient: '*As soon as I see him struggling or losing energy or being depressed, everything in* ***my*** *world, my own quality of life, comes to a screeching halt*'. McDonald, 2018 The caregivers have to face the patients' mood swings, fears about death, and the loss of being in control of one's own body and actions. One caregiver described this aspect: *'So, and what is naturally the worst, although in the beginning it wasn't like that at all but of course there was a disorientation and absent-mindedness which now has become extremely bad. So, and now I have someone in front of me, who's got nothing to do with the person I was with 2 months ago'* [crying]. (47-year-old man, spouse) Wasner 2013 The caregivers' level of hope was influenced by the mood of the care recipient and the care receiver's state of health. For example one participate wrote: "*He is confused and it hurts so much to hear him!*" Duggleby 2013 Caregiving impacts on the psychosocial and emotional well-being of the caregiver. Participants indicated anger, worry, stress, fear, frustration, and uncertainty associated with providing care. There can be frustration at the inability to restore previous quality of life of the person with ALS, and limited communication with the person with ALS [amyotrophic lateral sclerosis], as illustrated by the quote: …"*I now understand housewives being frustrated about not being able to have proper adult conversations, it is always [like] caring for an infant*" (son, 46 years). Galvin 2016 *"He can get very depressed at times and actually that can be very depressing for the carer. Oh, I find it very difficult. I think the most difficult is when they get depressed. It is very difficult and when they're up and down to the toilet all night because you're wakened up out of your sleep and you can't get back to sleep again*" McLaughlin 2011 "*He changed so much. Before he was funny, always had a joke ready, and now? [break] He has practically no interests while earlier so many things used to be important to him—hobbies, lots of friends, and the family was always at the center—he was such a good man. I don't know how it should go on, what I am going to do without him. Our family, our little universe, is about to fall apart*". (49-year-old woman, spouse) Wasner 2013 When the disease recurred carers might empathise with the worry the patients had at that stage, but sometimes had to deal with difficult behaviour along with their own concerns that their partner might suddenly die: "*He went through a phase where he [husband] was really aggressive and very moody and he was terrible —it just drives me crazy"* Murray 2010

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Predictors of psychological morbidity		
PATIENT CONDITION *(continued)*: **Patient decline**	*Impact of the patients cognitive decline*	Particularly exhausting and troubling were changes in the patients' personality and aggressive (unpredictable) behaviour. According to one caregiver: "*I've been doing this whole thing for 18 months now. Sometimes I don't believe it myself, all the things I've done. The worst is, that sometimes he's so aggressive, so much changed from the feeling and sensitive person he used to be. Sometimes I think I don't matter to him anymore... he's just so totally changed. Actually, I'm afraid [that] I'm going to collapse and have a breakdown"*. (41-year old woman, spouse) Wasner 2013
2. Impact of caring responsibilities		
	Supporting other family members who are struggling in their caring role	Another man remarked that his father with ALS [amyotrophic lateral sclerosis] was not '*the problem'* rather "*my mother, she feels the need to still be in control, she has violent outbursts at me and is angry I'm not working. There's been a shift in the caring role and that's changed the dynamics of the family, he [patient] is not the problem at all; I'm worried I'm going to have to look after my mother and will have no life*". Galvin 2016
	Conflicting responsibilities	Another caregiver stated that because of caregiving for her husband, she had very limited time for her sick adult daughter: "*I have to not only find someone to give me a ride [to the hospital to be with my daughter], but I have to find someone to stay with [my husband] because he just cannot be left alone [at home]. My daughter's having more surgery on Monday.... I feel so bad because I haven't been there for any of her surgeries*". (A 76-year-old wife) Chi 2018 "*For about a year I felt like I needed to visit my son who is overseas. I was trying to get help from the family to place her somewhere while I was visiting. This went on for a whole year. The tension was increasing to the point that I knew that I was walking a fine line between giving care and also, you know, I didn't want abuse, I did not want that to happen but I knew I was reaching the edge. We contacted several nursing homes and we filled out the paper work. Then we heard nothing about them.... So I told the doctor and he was frustrated also. He made a phone call and we finally got a placement*". McCurry 2013 Many family caregivers in home hospice care struggle with managing multiple obligations simultaneously and do not have adequate social support to help them balance their personal life, work, and caregiving tasks. Chi 2018

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Predictors of psychological morbidity		
		Activities outside the home added to the stress as typified in this quote: '…*most of the time I'm at work and I tend to try to get home about three times a day'*. Hynes 2012 It was difficult to get all of the ''real-life'' stuff accomplished while giving care 24 hours per day 7 days per week Kutner 2009 "*It is a lot of mental stress for me especially at the last stage of his illness. I have no time to spend with my children*". (Caregiver) Shanmugasundaram 2015 *"I had to take care of my daughter as well because she's doing what she has to do to take care of herself. So it was hard. It was hard".* (Participant) Williams 2017 *"It was messing with my mindset because now I'm trying to take care of myself. Got a new baby, trying to take care of my child. Then, I'm trying take care of her, and all of this was coming on me and trying to work at the same time. It was a lot. It had me extremely tired" Williams 2017*
IMPACT OF CARING RESPONSIBILITIES *(continued*)	*Exhaustion*	The overwhelming daily chores, everything that is outside the normal routine, together with the unexpected stress, threatened their ability to cope. Heidenreich, 2014. *You're tired all the time … exhausted.* Oliver 2017. A frequent theme expressed by family caregiver (FCGs) was being present to offer support even when they lacked the emotional energy to do so. Ferrell, 2018 Some FCGs reported lack of sleep and exhaustion because the ill patient required their full and immediate attention. Ferrell, 2018 **"***Basically I probably have pneumonia. It's probably about the third or fourth time I've had it since he's gotten cancer because I can't rest or do anything … I woke up Thursday and I was so ill … he can't even get out of bed to watch the kids for a minute so I don't get a chance to lay down or anything and if I don't sleep well, so he called and asked (grandparent) to come for a little bit and she came like two hours thank God and I laid down. But it was awful... It was just one of those days where it's like I just want it to be over with*". Oliver 2017

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Predictors of psychological morbidity		
		All the caregivers reflected on their role as being ‘‘24/7.’’ They were living with caring responsibilities 24 hours a day, there was no such thing as a day off, and they were constantly watching the patient, waiting for something to happen. “*I find that he is very unsteady on his feet so I am 24/7 keeping an eye on him. Where he is going? What he is doing?*” (current caregiver) Fitzsimons 2019 The sheer physical burden of caring for someone with advanced HF was demonstrated in the following extract, as was the pressure of a ‘‘*24 hour a day, 7 days a week’’ responsibility. “I just think it has taken an awful lot out my health. Is that normal? Is that part of looking after somebody? Not being well myself. I don"t know*”. (current caregiver) Fitzsimons 2019 Caregivers felt problems were endless, and given how unpredictable HF symptoms can be, they found it difficult to cope day-to-day with their loved one"s condition. “*Just panic and hopelessness. Not able to do anything and sad, all the emotions that go with this I suppose*” (current caregiver) These emotions had a negative impact on caregivers" quality of life and daily living, with sleep disturbances, depression, and anxiety being widely reported. Fitzsimons 2019 The relentless aspect of the caregiving role was summed up as “*it just never stops. There’s always something. You never feel that there’s time to rest*” (female spouse/partner, 41 years), Galvin 2016 Physically, lack of sleep was frequently cited as a challenge; many felt they were physically and emotionally exhausted while they were giving care and were not truly able to assimilate what was happening: “ *I don’t think I slept through the night for the last year and I don’t think one realizes that you’re at a point of total exhaustion. . . when he finally died . . . suddenly you realize . . . it suddenly hits you that you were physically and mentally finished off to the point where . . . you can’t even really take in what’s happening”*. Kutner 2009 Physical burden was described mainly in terms of fatigue, loss of energy, and feeling generally ‘run down’, partly due to ‘sacrific(ing) sleep to accomplish things’ (Carer): “ *Well, it’s probably affected my energy level. I just don’t have quite the energy I had because I guess I’m still kind of thinking, as much as you try not to, you’re still thinking, what’s coming next or where is it going*”. (Carer) McDonald 2018

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Predictors of psychological morbidity		
IMPACT OF CARING RESPONSIBILITIES *(continued)*	*Exhaustion*	“*Tired of it! Yes, you get fed up . . . it’s going on a long time and . . . yes. I think we do feel that the pressure is getting to us really. It has been hard, it’s not easy for us to say that. . . . But yes, it is difficult*” (carer) “*Yeah . . . I’d say now, a wee bit depressed, eh, wearing you down, kind of thing, you know? Oooh!*” (carer) Murray 2010 The dying person’s functional abilities decreased, requiring more frequent and more difficult care**.** End-stage care became unmanageable when complicated overlapping symptoms were compounded by the need for 24-hour care. The crisis often combined a rapid decline, untenable symptoms, and patient resistance Waldrop 2011 *“We put a bed in the living room and it was horrible for the first few weeks. I was getting up 8 to 10 times a night to help her go to the bathroom. She couldn’t use a bedside commode. It was embarrassing to her. She worried about spilling on the rug. Then she got worse. I couldn’t lift her”* .Waldrop 2011 Caregiving was described as “hard,” “challenging,” “inconvenient,” and “overwhelming.” Participant explained: “*I would go drive from [the college] campus to their home, get in their truck, take him to the clinic, take their truck back, get in my car, and drive back to campus. So I was driving 100 miles a day*.” Williams 2017 They felt “affected,” mentally tired, and bothered “on the mental side” (Participant). Another participant commented that The experience was “*playing a toll on me because it was to the point where I felt like I didn’t have a life*.” Caregivers described feeling overwhelmed – “*Sometimes you get to that point of that you just want to scream*” (Participant) – and mentally exhausted: *“It was messing with my mindset because now I’m trying to take care of myself. Got a new baby, trying to take care of my child. Then, I’m trying take care of her, and all of this was coming on me and trying to work at the same time. It was a lot. It had me extremely tired. But in doing what you have to do, somewhere along the way, you’re going to stop, and you’re going to sit down, and your body is going to be tired; your mind is going to be tired.* (Participant) Williams 2017
	Impact on mental health	“This is therapeutic for me because not until now that I realize I actually could be considered as being depressed sometimes” (Participant). Williams 2017 *“I knew I was depressed. I didn’t want anybody around me. I didn’t want to talk to anybody or anything like that because I’m a very social person. It’s just I got to the point where I questioned myself, ‘What if I wasn’t doing this, where would I be or what would I be doing?’* (Participant) Williams 2017

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Predictors of psychological morbidity		
IMPACT OF CARING RESPONSIBILITIES *(continued)*		"*Every night I woke at 1am or 2am and cried and cried and can't stop … I scared all the time and my neck's swollen…and I couldn't breathe (rapid huh huh huh-anxiety attacks)… The doctor gave me Sinequan to make me slow down, make [me] not stressed too much, you know*". (Maria) Heidenreich, 2014.
	No energy to socialise	The emotional and physical burdens also had social consequences, as caregivers described lacking energy to socialise and feeling more withdrawn. McDonald 2018 Caregivers described becoming reclusive and feeling somewhat compelled to withdraw from their social lives because of the demands of caregiving. Physician appointments, dialysis treatments, and surgeries, as well as other caregiving responsibilities. were tiring and mentally taxing. "*Well, it makes you withdraw because [you're] tired; you've got other things on your mind. You're thinking about doctor's appointment that you may have to go through, or like I said, I was going through it when she was having a lot of surgery. That was dealing with my mindset, concerned about her not knowing what the outcome was going to be.* (Participant) Williams 2017
	No time for self-care *No time for self-care*	The majority of FCGs were neglecting self-care and were too busy taking care of their loved ones to care for themselves Ferrell, 2018 A variety of emotions are involved, "*some days I am happy and willing to take on things, and other days I am angry*" (female spouse/partner, 47 years). Galvin 2016 Plans are postponed and a way of life changes "*I haven't had any holidays and [am] afraid to go far away. It's a constant call on your person - having to be around, having to be available*" (female, other family/relative, 70 years). Galvin 2016 "*Increased demands on time, make it a limited and restricted commodity, time is taken from the caregiver and given to the patient "the time you have to give, the time you don't have for yourself*" (female spouse/partner, 71 years). Galvin 2016 "*Being responsible for anything and everything, having to check and think of everything. There's so many*

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
IMPACT OF CARING RESPONSIBILITIES *(continued)*		*things…"* (Female spouse/partner, 68 years). Galvin 2016 As patients became progressively unwell, the carer often felt less and less able to leave them alone, restricting their normal social contacts, hobbies, work, and even holidays: Murray 2010 Furthermore, the participants prioritized their caregiver activities over other work and social activities: "*You just can't think about those other [activities you used to enjoy] . . .You may think of them but you can't do them . . . What you have to do is be here mainly*". Ward Griffin 2012 Self-neglect was also a common topic thread throughout the discussion. "*I'm sitting here just listening, and I'm seeing myself in trying to take care of everything and make sure everything is okay, but at the same time, I'm neglecting myself*" (Participant). Williams 2017
	Lack of respite/ maintain Quality of Life (QOL)	The sick family member's increasing physical dependency and inability to meet personal needs unaided added to participants' emotional distress and left them scarce time for personal respite. Heidenreich, 2014. "*With him at home I can't even go out* … "(Lin) "*I care for him for many hours. I'm scared to leave him home alone*." (Maria) Heidenreich, 2014. Lack of support and limited time for personal life and respite were consistently mentioned as challenges. The caregivers were often distressed and exhausted dealing with all the tasks. One caregiver felt it was difficult balancing caregiving with her other responsibilities and finding time to manage her own quality of life: *"[I have] so many other household things and family events that [I] need to focus on and be good at time management…My goals are to be able to still maintain my own household and have a quality of life*." (A 65-year-old adult child) Chi 2018 "*It has made a huge difference to our lives…I cannot leave X [spouse] alone, I am afraid to. It has led to a life which is very restricted and isolating. X is now fully dependent on me*" Hynes 2012 A high level of dependency on carers was also present and most carers did not feel able to leave their family member for a long period. Many spoke about their frustration at not getting time away from the caring role, even for short periods. McLaughlin 2011

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
	Sleep deprivation (carer required through the night)	*"I'm taking care of everything and that means changing her every two hours. I can't do it all night and I can't take care of people and then not sleep … "* Oliver 2017 They noted the worsening of conditions because they could not attend to them, the need for medications, fatigue, or the toll of caregiving on their health. Fatigue was the most common complaint. Oliver 2017 "*When she got her surgery… it was kind of hard. Like getting my rest and stuff like that because I was constantly getting up, checking on her and getting her to the restroom*" Ferrell, 2018 Most caregivers reported on challenges of caregiving; lack of sleep and associated fatigue were common experiences Brazil 2010 The condition was so unpredictable that the caregivers were afraid to leave the patient alone and, when they did, they felt guilty. "*He would start sitting up in bed and get out of bed, but he couldn"t stand, so he would just fall on the floor. I am here on my own. I had nobody, no backup, no nothing and I had to sleep on the floor to stop him getting out of bed*". (bereaved caregiver) Fitzsimons 2019 Giving priority to the needs of the client over their own needs frequently undermined their own physical and mental health: "*I don't sleep a lot. And I think about going to the doctor and getting sleeping pills and then I think, no, that would not work because if I go into too deep of a sleep and he got into distress, I wouldn't be able to hear him so it is important that I am aware . . . you have to be prepare to put your own life on hold. To realize that your first and main priority is your spouse, or whoever you are taking care of*". Ward Griffin 2012 All caregivers agreed that lack of "sleep" and feeling "tired" were primary issues. One caregiver recalled: "*I almost had an accident, you know, driving off the road because I was working so much, sleeping three hours a night*" (Participant). Williams 2017 Three caregivers reported developing high blood pressure after beginning their caregiving career. "*You know, everybody usually gets, what, seven to eight hours of sleep. I was looking at the trend, what four or five hours of sleep. It affected me. My high blood pressure, it came along*" (Participant). Williams 2017

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
IMPACT OF CARING RESPONSIBILITIES *(continued*)	*Impact on physical health*	“I’ve been to my family doctor. He gives me the medicine for the stomach. Then my tongue, I get the cold sores because I’m worried you know … I’ve got it [stress] inside. That's all because of the worry. (Ting) Heidenreich, 2014.
	Impact of employment	(Work) added additional stress at times, especially if their workplace did not offer flexible arrangements: *“[I’m] not [working] much . . . One day it might be okay and one day it might not . . . People want you to work every day. They don’t want you to have to call in sick 2 or 3 days in a row. I was working for a little while when he first took ill but I was in constant worry about whether he had remembered to take his medication, hoping he didn’t go too far and things like that. It was just very stressful*”. Ward-Griffin 2012
	Cannot make plans (for leisure or respite)	*“You have no idea when it’s going to be over, you have no idea how it’s going to be over … you can make no plans; and I would say with that not only can you not make plans for the future, because you don’t know when your future is going to start again, often you can’t make any plans for the day”.* (Oliver 2017*).* Cancer brings uncertainty to the lives of patients and family caregivers (FCGs) that may never go away Ferrell 2018 FCG spoke of the difficulty of gauging when he could “get away” by himself, referring to the emotional state of the patient and when being away would “be acceptable.” Ferrell 2018 Heart failure limits not only the patient’s life but also the caregivers", which led to caregivers feeling their life was no longer their own but ‘‘ruled by the patient"s condition.’’ The following extract reflects these feelings: “*It was very strenuous. For me it was very strenuous. The long hours that you had to sit with her and I am thinking that I could be down in my own house but she needed me so that was it*”. (current caregiver) Fitzsimons 2019 It was a common feeling among caregivers that the patients" needs were their first priority, and they often made reference to putting things on hold because of the patients" health. “*I don’t have a life. My life is sitting in the chair watching*”. (current caregiver) Fitzsimons 2019

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
	Cannot make plans (for leisure or respite)	Providing care and being a caregiver can be restrictive in time and place. A lack of freedom means "*I have to be around, I can't be away from the house for too long. I have my phone always*!" (Male spouse/partner 67 years).Galvin 2016 The relentless aspect to caregiving, time limitations, restricted freedom and constraints associated with patient dependency, for example: "…*I have to be around, I can't be away from the house for too long*……..", being totally tied down. "*She's got to have somebody within minutes to be with her*"; "*You have to be there to keep an eye on him. It's always on my mind. All of my time. Not that much time to myself*". Galvin 2016 "*When X's clear of infection X can walk from one end of the room to the other. It's with a pushchair thing, or holding onto me. But when X has an infection X wouldn't be able to get out of the bed hardly; it would be to the commode to go to the toilet*" For all participants, this everyday uncertainty rendered difficult any effort to plan even routine everyday activities outside the home such as shopping. Hynes 2012 Unexpected complications would thwart social plans: '*If you wanted to go out somewhere and she doesn't feel well that day, then that's it. It impacts on your life. […] It affects, the illness affects everybody'*. McDonald 2018 The significant other had to make adjustments to his/her everyday life resulting in feelings of limited freedom and suppression of the person's own needs. "*During his time. under the illness period. you could say that life just revolved around him.*" Pusa 2012 *"Make sure I got the right amount of boxes for the right amount of days that we had. It was kind of tearing me down…[the disorder] interfered with everything. I used to love to go to the beach. Me and my children will be on the beach enjoying ourselves, but my wife, like I said, she would either be in a hotel sick or she would be at my grandmother's house sick. So that just interferes with everything, you know*? (Participant) Williams 2017

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
3. Relationships		
Relationship with the patient	*Change in roles*	The family care giver (FCG) stated that when she returned home at night from work, she did not know what kind of mood her husband would be in. Regardless of his mood, she could not share her day with him. Ferrell 2018 The topic of role reversal arose several times. Husbands took on expanded household roles, and a daughter tried to adjust to taking care of her mother, who had always assumed the role of parent and caregiver. The daughter said it was hard to see her mother in a weakened state Ferrell 2018 *But all of a sudden the relationship of husband/wife was gone*... The transitions resulted in a disruption of their lives resulting in anxiety, distress and uncertainty Duggleby 2010 "*I really just felt like a nurse myself... That, that was how I felt. I mean, I used to work as a nurses aide in a nursing home... and I do have some... you know, knowledge... of that kind of thing... But all of a sudden the relationship of husband/wife was gone and it was nurse and patient for me... That was our, a big change*." (Family Caregiver) Duggleby 2010 ª*I feel like I'm not married, you know? Where you've always been married, all these years, and all of a sudden you're doing it, walking about, on your own. But he's adamant he's not having one [mobility scooter]*º (Carer) Farquar 2017 Spousal carers talked about how they struggled to keep the patient upbeat, and how they struggled with the impact of this on their quality of life as a couple. They wanted strategies, ideas and suggestions to boost the patient's confidence and ideas for activities they could to do together. Farquar 2017 The increased workload and the role of the caregiver at times decreased the closeness between the significant other and the sick person. "*But I was never, not for a moment, there just as his wife. As his closest.instead I was just the one who should dry up, get changed nightshirt, etc. etc. all, all, all the time, which I did.*" Pusa 2012 Caregiving changes existing relationships, and presents new expectations and role reversals "*that it is my mum. I shouldn't have to be in the bathroom with her*" (daughter, 28 years). It is hard for some to reconcile the care provider

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
RELATIONSHIPS *(continued)*: **Relationship with the patient**	*Change in roles*	and care recipient relationship with their prior relationship “*The role of a caregiver takes over, then wife. You forget you’re not his minder, you’re his wife*” (female spouse/partner, 44 years). Galvin 2016 Identity, role change and for some, role reversal, can be accompanied by a change in how the caregiver sees him/herself: “*he is my husband, yet I am now becoming his carer. It changes how I see him or how he sees me*” (female spouse/partner, 47 years). Galvin 2016 “ *It’s the shrinking of your world that I find the hardest. All this stuff we can deal with. I mean there’s equipment, medicine, change in priorities that you can deal with. The social aspect of it is the hardest because most people get a lot of their social life at work or from doing other things. And with MS [multiple sclerosis] there’s no talking to her over dinner, ‘‘How did your day go honey?, ’’because we both had the same day.... It’s hard, the isolation is hard...That camaraderie is gone. You miss that; you miss it*”. McCurry 2013 “*My husband and I always did everything together.... He would help with the dishes, he would vacuum, he would wash clothes. We always did everything together, and I really miss that, I really miss that*”. McCurry 2013 Caregivers described marked changes in their relationship with the patient, especially if the patient was their spouse: ‘*My relationship with [patient] is now, more or less, she’s the patient and I’m here to help her […]*’. The illness and resulting dependency of the patient represented a strain, which in some cases was experienced as a loss: “*I believe I also am doing some grieving because we’re not the same couple. He’s not the same person and our life is not the same”*. McDonald 2018 In some cases, the patient was described as withdrawing, becoming less engaged, or even venting anger: *“[H]e just didn’t want … he just kind of walled himself away. His personality really changed. His attitude and … he just wanted to be by himself. I can understand that in many ways, but it’s just difficult for the rest of us around here”*. McDonald 2018 The significant others experienced feelings of loss of intimacy both in relation to the sick relative and in relation to other social relationships. Pusa 2012 Difficulties in communicating were experienced, and the significant others felt unable to share their emotions with their ailing loved one. This led to feelings of suffering .Pusa 2012

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
RELATIONSHIPS *(continued)*: **Relationship with the patient**	*Change in roles*	In addition, caregivers also reported the need to assume household responsibilities that had typically been held by the care recipient. Brazil 2010 When end-stage caregiving became the central focus it changed communication between caregiver and care recipient and their relationship dynamics. Ways of coping changed with the stress of new and different needs and roles for family members. *"It was stressful when my mom was losing her balance and I was taking care of her at home. We would get into it like you wouldn't believe. We'd bicker back and forth."* Waldrop 2011 "*Ah so, actually, ah, it's like this, before the illness, we had a relationship, and now, my partner as a partner doesn't exist anymore … . Ah, it's just endless worrying, never a day, waking and being able to say, "Today is a good day." … instead I say, "hopefully, we'll all be still alive tonight" or something like that*". (53-year-old woman, spouse) Wasner 2013
	Taking on extra responsibilities/ roles	"*I had to assume his (responsibilities). He used to pay the bills... he used to know when to call the oil man, and now I have to be on automatic delivery because I don't always have time to check when that oil's empty...Not only my things, I have his things*". McCurry 2013 One husband, who was also a father, began shouldering the 'mother' role. Because his wife could no longer work, he maintained two jobs, cared for their young daughter, and functioned as caregiver, all of which was mentally and physically taxing. Despite having mothers and adult siblings, two sons assumed primary responsibility of caring for their fathers. The stress of these changing roles and additional responsibilities were, for some men, overwhelming at times. Williams 2017
	Quality of relationship	In two partner relationships that were not strong, the losses associated with having to provide care lead to resentment toward the patient and a loss of freedom, as one caregiver stated: " *Well our whole life is just around him now you know it's just pretty much every day it's all about him. I guess he's a victim*".(family caregiver) As the relationship had broken down, the sense of responsibility for the other person had diminished. Out of necessity, the partner had become the caregiver, and there was anger and bitterness. McPhearson 2013 "*You've got to have some love to do it. Everybody can't be [a] caregiver. Yeah, you got to care. The word speaks for itself*" (Participant). Williams 2017

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
		For some participants, the relationship between caregiver and care recipient played a significant role in caregiver stress, and subsequently, helped to determine their perspective of the experience. Williams 2017
RELATIONSHIPS *(continued)*: **Relationship with the patient**	*Patient's emotional needs*	The emotional aspects of providing care were experienced as sometimes more difficult than the physical ones. One patient's son felt uncomfortable with the emotional needs of his mother as she "wants more conversations and discussions, I have a more practical approach to caregiving, she needs more of a friendship type of thing" (Son, 48 years). Galvin 2016
	Lack of understanding or gratitude about the impact of caring from the patient	The lack of acknowledgement for efforts made could be both frustrating and hurtful, this was summed up as "*lack of understanding from [patient] of the burden placed on me…*" (Female spouse/partner, 66 years), and "*the pressure that my mam [patient] puts me under, her expectations …*" (Daughter, 42 years).
	Patient non compliance	"*He just would not listen to me or the doctors, it was very hard on me watching him do what he did, he missed out on so much … the grandkids. I am mad at him for how poorly he cared for himself and the hard time he gave me for trying to do it*". Kitko 2015 Incongruent perceptions were also evident when family caregivers thought about their future role and increasing care demands the fear that they will not be able to continue to provide adequate care: Caregiver: *"I will say to (patient's name) do you know what the outcome is going to be if you don't take your insulin … you are going to lose your leg or something else. Yep that's what he says to me. Yep that might happen. I said I'm not going to be able to care for you. You're going to go into a nursing home … he might be thinking about that stuff but he is not really dealing with it. He does not want to talk about it and I don't want him to get upset with his heart being weak*". Kitko 2015

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
	Patient non compliance	Incongruence with advance care planning between the dyad was commonly reported. Incongruent dyads reported more psychosocial issues, tension, and distress individually and within the dyad. Kitko 2015 Patients' noncompliance with the medical regimen led to a high level of discord in the dyadic relationship. A spousal caregiver of a patient with frequent admissions due to noncompliance with the medical regimen expressed her frustration when asked what happened during visits to the doctor: Caregiver: "*He looks at me sometimes and tells me to keep my mouth shut*". Kitko 2015 Caregiver: *"(Patient's name) could care less … I think sometimes he gets pleasure out of just the shear I don't want to say argument but the combative. So there are times when you know it's like God give me patience because I need it with him … I find that extremely frustrating*". Kitko 2015 A caregiver described her feelings of frustration throughout several different interviews regarding her husband's refusal to stop smoking: Caregiver*: "You haven't asked me about the smoking … I don't know why he went back to it. I'm just very upset about it … You know it's a sad tough thing to go through because he's frustrated with himself and I get frustrated because he gets frustrated. It's a dramatic thing for both parties. I look at it this way he's made his choice and he just doesn't give a damn".* Kitko 2015 "*He's very stubborn. I mean I'm just telling you the truth. He doesn't exercise. He doesn't do what he is told. He still eats the same way. So that's the challenge*" (Participant). Williams 2017 In the majority of the cases, caregivers were proactive in adhering to the prescribed regimen, which often conflicted with patient's views. This led to tension in the dyad and role confusion/frustration for the caregiver: Caregiver: "*I knew he was getting short of breath and needed to be seen but he refused to let me call the office. It got to the point where I called 911 … I am worried (patient's name) will be upset with me when he realizes what I did*". Kitko 2015

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
		Patient unable to make sensible decisions regarding their care Feelings of loyalty in relation to the relatives' integrity and autonomy resulted in conflicting feelings and distress. The sick relatives' right to decide for him-/herself was sometimes questioned in relation to his/her capacity to "knowing what was best in the situation." Pusa 2012
4. Finances		
FINANCES	*Current financial pressures*	Over half of the caregivers experienced financial challenges Oliver 2017. **"***and I need to look at what I'm going to live on after Jim dies and there's no income ….***"** Oliver 2017 the majority said they were struggling, balancing disability payments with housing expenses or using savings to get by. Ferrell 2018 The costs associated with medical care were abundant, but the most common ones reported by family care givers (FCGs) were the expenses associated with last-minute flights, gasoline, overnight hotel stays, restaurant meals, and vehicle maintenance. Ferrell 2018 "*There were days when I was like, wow, how am I going to do this*" Ferrell 2018. Now, the current increasing financial responsibilities of the participants caused enormous emotional stress. Stella acknowledged she had financial difficulties in paying the doctor's bills, medical treatment costs and extra expense of her husband's care, she honestly said, *"Yes [I have experienced financial problems], because my husband does not have a pension and concession card"*. Heidenreich, 2014. **F**inancial stress associated with caring for the care recipient. Most of this stress was associated with the purchase of private home care to supplement the formal care that was provided. ''*The [agency] couldn't guarantee that private nurses were available [on weekends or 24 hours a day]. They should realize that some people are on a budget and can't afford it [pay for private nursing care]*'' (caregiver) Brazil, 2010 Several caregivers reported the stress of continuing to work while acting as a caregiver. In 2 instances, caregivers reported reducing their work hours or stopping work all together. ''*So I left that position to take care of my dad*, . ."Brazil 2010

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
FINANCES *(continued)*		Caregivers expressed financial concerns due to reduced work hours, necessary earlier retirement, long-term medical costs, and co-payments for multiple medications Chi 2018 Financial implications such as for essential home renovations ‘*not in your wildest dreams could we come up with that [estimated cost]*’; Hynes 2012
	Cost of equipment	Some caregivers spoke of the financial stress of caring for their loved one. Caregivers noted that the costs of medical equipment such as wheelchairs, batteries for hearing aids, and drugs were considerable, and some participants had difficulties coping with the costs. Caregivers acknowledged great frustration dealing with the high costs of medical equipment. Shanmugasundaram 2015 Many condemned the lengthy timeframe to obtain and access supportive equipment for people with PD [Parkinson’s Disease]. Consequently, this resulted in many carers paying privately for trained carers to assist with activities of daily living, equipment and respite relief, adding to the financial burden of caring. McLaughlin 2011
	Impact on work	“*My husband was the only earning member in the family. Now he is suffering with cancer and admitted to the hospital. I do not know anything about the outside world. I have no money for the treatment. I stress about finance*. (Caregiver) Shanmugasundaram 2015 Those who remained employed struggled with balancing work and caregiving; others who lost or gave up their jobs to become full-time caregivers tended to miss not only the income but also *‘just having something to do every day that’s for me*’: “*I do miss the work. I think if mom had been living in [the same province] when she was first diagnosed, I probably wouldn’t have had to quit, but having to be off for six months, that’s a long time to have a leave of absence”*. McDonald 2018 As the person’s illness advanced, carers spoke about how they and the person with PD [Parkinson’s Disease] had to give up work, which resulted in a serious loss of income. McLaughlin 2011 Another caregiver explained that she could not cope with the long-term caregiving process and had to seek treatment for her psychological problems. She said that: “*Because my husband was sick, I had to give up my job, I was very depressed, and I went to a psychiatrist for treatment”.* (Caregiver) Shanmugasundaram 2015

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
FINANCES *(continued)*	*Impact on work*	“*Because my husband is sick, I have to give up my job and take care of him. Lots of financial problems. Sometimes it gives me so much stress and frustration with the cost*”. (Caregiver) Shanmugasundaram 2015 “*At work, they told me, “It’s not possible to keep you any longer because you always ask for a leave and that, with short notice.” That was the worst for me, losing my job because of my husband’s illness plus the whole financial situation. When he’s gone, I’ll desperately need a job, otherwise I won’t even be able to pay the rent”*. (55-year-old woman, spouse) Wasner 2013 Care - givers spoke of transferring to a different university, retiring from a job, leaving work often to provide care, and feeling much “heartache” because of job-related issues. “*I would have to leave my job and go to the house and assist her. A couple of times, she had to get the ambulance. So it affected my work. So I just went on and retired from my job. But my job was giving me a hassle with that because I was needed, and so it was causing me a lot of heartache”.* *“Like I said, as I sit back and just think about it while I was going through it, dealing with my supervisor because they’re not [going to] really just believe that you have to take off all the time”.*(Participant) Williams 2017 Several caregivers had other concurrent responsibilities such as a full-time job, taking care of their own children, or being a caregiver for another family member. As a result, some caregivers had to make significant accommodations to their work schedule to provide care. Chi 2018 Caregiving responsibilities, especially for adult children or other relatives who provide care, often compete with their work and/or other family commitments. Galvin 2016 The horror stories where someone is supposed to come, they don’t show up.... I decided to work part-time so I could stay here, and then finally, not work at all. McCurry 2013
	Difficulty accessing benefits	There were difficulties accessing information about entitlements, benefits and equipment. Most were not aware what help was available, to what they were entitled, or whom to contact and were unsure how to complete the necessary forms, viewing the process as very time consuming. This resulted in some not even claiming for support with others only finding out by chance what was available. Those who did apply for assistance found requests for help rejected, which caused them further upset and frustration. “*Benefits! (we) knew nothing about that at all. We lost 4 years of benefits and I just happened to find out about the way about them*” McLaughlin 2011

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
FINANCES *(continued)*	Distress over future financial situation	*I get worried about … how I'm going to live after [patient] dies and what's my health going to be like and I do live with some fear of not wanting to be … wanting to have enough money to take care of my needs …* (Oliver 2017*).* Even those who said they currently were financially stable and had healthcare coverage voiced serious anxiety about the future of healthcare coverage. Many also spoke about insurance concerns: deductibles and co-payments, sudden cutbacks or changes in coverage, or concern for the political environment that was threatening insurance, Social Security, and Medicare benefits. These considerations caused family caregiver distress and additional burden. Ferrell 2018 "*Umm [I am feeling the financial pressure], so then I start to think if he goes into a nursing home and I will not get the carer's pension and I don't go to work what are we going to do as income and finance? If he goes into a Nursing Home and my care pension stops, then surviving is a problem for us*". Heidenreich, 2014.

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
5. Carer internal processes		
	Loss of self-determination and autonomy	They experienced feeling out of control ("...*everything I guess was out of control*"), or did not know what to do or what to expect ("...*it was way beyond my knowledge...didn't know what to do*") Duggleby 2010 It was difficult to live in the patient’s ‘world of illness’: ‘*Sometimes that’s very hard because it’s not my world we’re in, it’s his world. It’s all about him, not me. I have trouble with that. It’s difficult*’. McDonald 2018 “*You do have a certain nagging that you’re being robbed . . .. . . there’s something that has come into your life that is both robbing you and robbing your wife . . .. . . and it’s not going to get any better*” McLaughlin 2011 Caregivers appeared to struggle to maintain a sense of self, feeling connected with the patient to the extent that they had trouble in stopping thinking about caregiving, as demonstrated by this quote from a non-spouse caregiver: “*I need to separate myself, but I also need to feel like we’re one. How do I detach, knowing I have a life too? That was hard, working out what to do with myself* “ (Ugalde et al, 2012) “*I as a person do not exist anymore*” (46-year-old woman, spouse). Wasner 2013 “*You’re putting your life on hold for someone and its ok to be mad about that … your brain is going through something horrific … the stress of it will do horrible, irrational things to you*” (Oliver 2017*)*.
	Why me?	Furthermore emotions of anger and unfairness were expressed regarding the suffering that the disease had afflicted on the family. Pusa 2012 As a result, carers felt ill-equipped to deal with the demands of the situation in which they were placed. “*I was scared; I was angry. Why is this happening to me? Why is this happening to [patient]?* (current caregiver) From the carers" perspective, there were many unanswered questions: “*Again I wasn"t told very much. I found it frustrating*”. (bereaved caregiver) As these extracts articulate, carers felt a pervasive sense of uncertainty but perceived that they had no one to turn to for information or support, leaving them isolated and concerned. Fitzsimons 2019

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Theme	**Sub theme**	**Supporting quote or text**
Predictors of psychological morbidity		
CARER INTERNAL PROCESSES *(continued)*: **Lack of care experience**	*Administering medications*	One caregiver felt uncomfortable administering narcotic medications, explaining, "*I'm not looking forward to giving [the patient] morphine and things like that to make [the patient] more comfortable and dope [him] up to where he's too incoherent to talk*." (A 54-year-old family caregiver) Chi 2018 The family caregivers found it difficult to carry out a variety of medical and nursing tasks for patients, manage symptom and medications, and support patients' activities of daily living. Chi 2018 They were anxious about responding helpfully; they wanted to feel confident about their response. They wanted to know what was best for the patient in that situation or reassurance they were doing the right thing. They wanted practical tools and advice. Farquar 2017 The decision of whether or not to increase steroids was too much responsibility for some carers: one was concerned that it *"could have been fatal"* (Carer). Farquar 2017 The responsibility of knowing when to start emergency medications was a concern that was frequently mentioned: *"we never quite know [. . .]. . . it's like a balancing act whether to start the steroids or . . . I know they say leave it 24 hours, but you're still a bit unsure. . . you know?"* (Carer). Farquar 2017 *"The needle was scary, I did it with an orange first. I was scared when I hurt him, but the quicker you do it, the better is it. He was doing it himself at first, but then he got a bit shaky so I had to do it. I didn't bruise him. I just said, 'Not one bruise. All over here are where the nurses or you did it, but here is where I did it and there's no bruise'*. Ugalde 2012
	Anxiety around the quality of care they can provide	For some there can be uncertainty over their own capabilities as a caregiver and others are unsure if the care provided is adequate or sufficient. Galvin 2016 "*[I am] Not sure if I am doing the right things. Am I doing enough?*" Galvin 2016 The dying phase of the patient"s illness trajectory was often a lonely experience and they felt ill-supported to deal with it: "*It"s actually quite frightening, that you"re in charge of somebody so sick and you don"t know what to do for them and yet you know they need serious medical help*". (bereaved caregiver) Fitzsimons 2019

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
CARER INTERNAL PROCESSES *(continued)*: **Lack of care experience**	*Making decisions*	The caregivers of those with the most advanced disease acknowledged that, although they discussed the options with their partner, they frequently made the final decision alone secondary to their care recipients' cognitive impairments. These decisions, as described, were often very stressful for the caregiver. Reported anxiety and uncertainty seemed to escalate when the decision being made was for the convenience and/or improved quality of life for the caregiver. McCurry 2013 Healthcare decisions were made when caregivers triaged acute healthcare situations. These descriptions contained some of the most anxiety-laden decision making… The decisions detailed by participants involved circumstances requiring responses to side effects of medications, falls, and acute status changes. "*I was washing her in the bathroom...she fell on her right knee and broke her femur. So it was another decision. Do I pick her up or do I get the Hoyer or do I call 911?"* McCurry 2013 "*So, I was second-guessing how bad he was. It was a very, very stressful time. It was stressful because I felt completely, completely, alone. I felt completely responsible*". (bereaved caregiver) Fitzsimons 2019
Lack of control	*Anxiety about what they will be told at appointments*	Anxiety emerged… every time the patient visited the doctor. Pusa 2012
Transitions	*Transitions*	Transitions disrupted the lives of palliative patients and their families… (it caused) and anxiety ("...*It was hard, so very very hard... panic started to set in"*).
	Shock of diagnosis	"*It [the cancer] came too sudden. There was never anything wrong with her. My wife went for tests every year, she had no breast cancer, and the cancer did not show early enough for doctors to be able to treat it aggressively. I was overwhelmed with emotion and disbelief about the suddenness of the disease. . . even till now . . .* "(Eleazar) Penman 2018 "*You know this suffocating feeling when the air is sucked out of the room, that's how it felt when the doctor said, "We cannot do anything anymore." . . .We just sank into depression*". (Hilary) Penman 2018

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Predictors of psychological morbidity		
		"*It was hard. . . . The oncologist had a look at the x-rays and said, "Go home, it's palliative care, there's nothing we can do." Those exact words just knocked us to the ground. They [the oncology team] gave my husband 3 to 12 months to live. . . . I was confused and lost. I was depressed for a long time. . . .* " Penman 2018
	Grieving previous life	The emotional toll on carers was also evident, due to a sense of their own loss of future plans and restricted social life and activities: "*I feel very much a sense of loss really and you have to come to terms with it and in a sense we have lost the life that we once had and to all intents and purpose we will never have again*" McLaughlin 2011
	Becoming a carer	Coming to terms with 'becoming a carer' and its impact on self-perception, was expressed by one respondent who explained "*you become insignificant as a person yourself, you lose your sense of identity, you're defined as patient's wife and MND [motor neurone disease]. You nearly don't know how to behave anymore, you've had to become somebody else*" (female spouse/partner, 45 years). Galvin 2016
	Crisis	The caregiving crisis occurred when the needs of the dying person and caregiver outweighed available resources... The crisis period was characterized by heightened anxiety, exhaustion, and an urgency to arrange relocation and a future plan for the person's care. A caregiving daughter spent years trying to manage her mother's numerous chronic conditions — including Parkinson's disease, diabetes, hypertension, arthritis, and wound care — that required 24-hour care, with help from family and home health aides. She described the crisis point: *"My mom got an infection and ended up in the hospital. At that point we had to put her in a nursing home. Within about two weeks she almost died. They admitted her to the hospital in respiratory failure and [she] ended up in ICU. She lost a lot of her ability because with the Parkinson's you don't use your muscles you lose them. I was desperate. I couldn't put her back in this home that almost killed her. I couldn't quit my job because I have a family. None of my brothers could quit and social services wouldn't give me any kind of aides unless I committed to living with her."* Participants described the crisis as a difficult time of anxiety and uncertainty. Waldrop 2011 **Returning home following hospitalisation for a crisis.** Participants described being approached about developing a discharge plan because their loved one had recovered function. This contributed to ongoing anxiety, knowing that they could not cope with their loved one returning home. *"One of the nurses said if she's here longer than six months then we'll re-evaluate. And I kept thinking to myself, oh God I don't want that re-evaluation because what if they do and it's not that I wanted her to die… I just didn't know what I would do at that point."* Waldrop 2011

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
CARER INTERNAL PROCESSES *(continued)*: **Transitions**	*Preparedness for death/pre loss grief*	Readiness for the end: ‘*...you think right I’m ready, you know, I’m gonna cope and all but then like X does get really, really sick and I think God I’m not ready at all, do you know*’. Hynes 2012
6. Support		
Inadequate support	*Lack of professional/ formal support*	**Lack of professional support** Health care delivery. The absence of adequate support from the formal community care system was a consistent message from all participants. The limitations in the availability of home support services manifested itself in a variety of ways, including the reported need for but lack of availability of 24-hour nursing care. ‘‘*It just got very difficult as far as the amount of help that we could get. The availability of the help that he’d get. The restrictions on the hours that we would get a month when you’re dealing with somebody that has cancer of the brain and you know you’re dealing with behavioural and mobility problems . . .* ’’ (caregiver). (Brazil 2010) Many of the caregivers described instances when they were unhappy with the care the patient received from healthcare professionals. Experience and Needs of Current and Bereaved Caregivers: “*When he comes home ‘‘No’’, there"s nothing in place. Now I lost it when he came home, I just exploded. Burst out into tears and really got very upset*”. (current caregiver) Fitzsimons 2019 Living with uncertainty, and the resultant emotional burden help explain why carers found it so difficult and overwhelming to be responsible for someone dying at home: “*I was at that stage where I wanted somebody to tell me what to do. I was too stressed, too tired, too emotional. I don’t know what it was. Everything I suppose*”. (bereaved caregiver) Fitzsimons 2019 Formal support was viewed by all participants as almost entirely absent typified in this quote: ‘*One lady came from the health centre up the road and brought down an inflatable mattress for the bed but other than that we haven’t seen anyone*’. Hynes 2012

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Theme	**Sub theme**	**Supporting quote or text**
Predictors of psychological morbidity		
SUPPORT *(continued)*: **Inadequate support**	*Lack of professional/ formal support*	Respite was another subcategory under healthcare. Caregivers described decision making based on the difficulties in arranging respite and the stress that placed on the caregiver. Arranging respite was often described using terms that indicated frustration and feelings of isolation. Caregivers were concerned with the lack of information they received from healthcare professionals, regarding their loved ones' diagnosis, symptom management and prognostication. McIlfatrick 2018 Accessing supportive care was described as being extremely difficult, and for some people, it was provided at a very late stage in the disease trajectory Whitehead. "*They had to take it to a hearing, the district nurse had to go to a hearing, and they did a tremendous amount of work between them to get it set up. . . anyway he got it but he didn't live long enough to get anything from it, really it should have been brought out six months before, probably more care at an earlier stage and for longer than that,. . . the continuing care came in too late*"(female former carer, 2 years post bereavement). "*Some caregivers received psychiatric treatment for psychological problems. One caregiver explained: "I was left alone. There was no one to be concerned about me. I did not receive any mental support as a husband. I was really very upset about this. That worried me too much and needed to take psychiatric treatment*". (Caregiver) Shanmugasundaram 2015 There were also feelings of insufficient practical support and care resulting in feelings of being overloaded. Pusa 2012 **<u>Professional support is too expensive</u>** "*In China when my Mum's sick I still had to go to work … I had to get someone to help, a housekeeper. Not pay too much, not like Australia …. they live with you, eat with you together, and they help… but in here you can't*". Heidenreich, 2014.

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
SUPPORT *(continued)*: **Inadequate support**	*Lack of professional/ formal support*	**Support offered too late** One bereaved carer had been offered nursing care in the very final stages of his wife's illness. Leaving it to such a late stage to implement care led to difficulties, as the care staff struggled to become accustomed to the patient's needs and the carer found it difficult to become used to a new care set up. '*One of these ladies would come and stop through the night so I could get a nights sleep you see cause I was up two or three times a night. . .She came to stop the night before, but it didn't work really, . . .she got me up anyway [. . .], I don't know if it was more than she expected . . ., but it didn't go according to plan, I suppose it was new for both of* us'(male former carer, 1 year post bereavement) Whitehead 2012 There was a distinct feeling amongst bereaved carers that being able to access more nursing support would have made a real difference to the end-of-life care and have been of immense benefit; Whitehead 2012. '*Then right at the end we had the district nurse and she was very good, but, other than that, you are left to your own devices, completely'* (female former carer, 2 years post bereavement) Whitehead 2012
Healthcare system challenges **SUPPORT** *(continued)*: **Healthcare system challenges**	*Poor communication from health care workers* *Poor communication from health care workers*	Nearly half of the caregivers identified frustrations and problems encountered with various parts of the health care system. These frustrations resulted from experiences with hospitals, nursing homes and hospice agencies, and communication with physicians and other health care providers. *(*Oliver 2017*)* "*The surgeon never warned her of the consequences of doing radiation in the surgical area. As a result she has a hole in her shoulder … that will never heal. So that's part of my job is to replace the dressings on that everyday*".*(* Oliver 2017*)* Poor communication between the family caregiver and the formal care providers was a noted problem, where caregivers reported a lack of sensitivity with respect to communication, lack of involvement in treatment decisions: "*The other nurse, um, came but she didn't have the compassion and had difficulty lifting him. But anyway it ended up that I had asked her to call me at night if he turned for the worse and she didn't do that the last night. She called just, I did see him just before he died and he smiled. She said she would call me at 3:00 a.m. and this was 4:30 a.m., so you know, I didn't hear, she had an hour and half to call me so*".(caregiver) (Brazil 2010) Disagreements among providers around treatment options for the patient were discussed by caregivers. (Brazil 2010).

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
SUPPORT *(continued)*: **Healthcare system challenges**	*Poor communication from health care workers*	“*They did not have open and clear discussions and decision making regarding the patient’s prognosis and wishes for end-of-life care. One participant stated, “Well, it was a tremendous stress, despite the fact that we both agreed that [hospice care] is something that we were doing. We really had no idea what we were signing on for.” (A 61-year-old adult child)*” Chi 2018 Lack of information and poor communication with health care providers: "*...but nobody tells me anything... even the doctors*". Duggleby 2010 The need for timely communication about essential information was illustrated by this comment: "...*if we would have known more of what to expect, what the symptoms are...if we had known before, it would have been a lot easier".* Duggleby 2010 Participants expressed frustration at not receiving fuller explanations from HCPs of the disease trajectory and management. Some did not understand the term COPD: ‘*I looked it up and then to be honest just lately I am just wondering how much of it actually is emphysema and because again, it wasn’t really explained, how much of this was this disease and that disease or whatever*’. Hynes 2012 Caregivers wanted honesty from healthcare professionals, and this openness seemed an essential element in enabling the caregiver to face the reality of their loved one’s prognosis, allowing them to prepare both practically and emotionally for their loved ones’ death: “*Nobody said, ‘Your mother has progressive heart failure and is going to die’. I think consultants need to be honest, stop being afraid, if your loved one is dying, then say it*”. (bereaved caregiver) McIlfatrick 2018 Struggling for good care conveyed experiences of struggle and dissatisfactions concerning caring and the medical service. The significant others experience a lack of engagement. They felt that they had to push in order to receive appropriate care. They had to be demanding towards the care professionals, and they found this experience to be trying and frustrating. The significant others experienced a lack of support including insufficient understanding from care professionals, particularly during the illness period but also after the sick relative died. They felt that the communication from care professionals was deficient and that they were uninformed and “invisible”, while evoked feelings of isolation, uncertainty and aggression. “*You did not know what was going to happen the next day, what examination he would have or anything.*.” Pusa 2012 Communication skills are criticised as the use of inadequate language (specialised medical terminology) is mentioned and sometimes the feeling of being in a system that lacks empathy and even feels as

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Predictors of psychological morbidity		
		dehumanised arouses. “*People here are like, well, […] they are walking around like robots […]” Villablos 2018]* In cases where the caregivers are informed of the patient’s condition, it is often done in a condescending manner. One participant describes this kind of physician-family caregiver communication: “The neurologist here said to me, “Be happy, (if) you don’t know what’s going on, then you won’t have to get upset.” I raged when I heard this; then I already knew through the Internet that it could be a Glio IV and it was pretty clear to me what the consequences would be. It was totally idiotic to say to me, “Don’t worry.” That was the worst, this information block. They were incapable of making even a single statement”. (53-yearold woman, spouse) Wasner 2013 The interviews demonstrated that, above all, a solid relationship with the physician is expected and hoped for. The challenging question is how to establish that kind of helping relationship? Under the time pressure and lack of resources, people working in hospitals are constantly short of time and information (if any) is provided for caregivers without greater considerations. One caregiver described this kind of insensitivity: “*He was fresh out of surgery and, instead of talking directly to his wife; the doctors gave him the information about his condition for him to tell his wife. If not even the doctors in such a ward know that directly after an operation the connection to reality is estranged and not totally functioning and that you no longer can rely on it, then I don’t know who should. And then, I have to say, why don’t they just write a note and lay it on his night table, “Mrs. XY, please contact the nurses when you arrive.” Unfortunately, they don’t do it like that, instead they talk directly to the patient who’s not capable of understanding the information and who twists and turns the issues so that when my mother does meet with the doctors, there’s total confusion. She didn’t contact the doctors earlier because no one encouraged her to do so”*. (35-year-old woman, child) Wasner 2013 “*Suddenly, during a 5-minute talk with my mother in the corridor, she was told that a new tumor had been discovered and that she has to be prepared that dad has 4 months to live. I just can’t understand that*” . (35-year-old woman, child) Wasner 2013
SUPPORT *(continued)*: **Healthcare system challenges**	*Health Care Professionals (HCPs) not listening to the wishes of patients and carers*	There were concerns that patient preferences were not always honoured. One bereaved carer described the complete disregard of her husband’s Preferred Priorities for Care (PPC) by health professionals when he was admitted to the local hospital in an emergency : ‘*Well this is what my husband wants to happen’ and I showed him the part where it says in the event of serious collapse, the patient does not want to resuscitated, but the A and E doctor said “well its not worth the paper its written on, what are you talking about?*’ (female former carer, 2 months post bereavement) Whitehead 2012
	Lack of skill	There was criticism of the standard of the service provided by paid-for home care; staff often appeared unskilled in the care of the dying. Whitehead 2012

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Predictors of psychological morbidity		
SUPPORT *(continued)*: **Healthcare system challenges**	*Lack of empathy*	In addition, the significant others experienced that the care professionals perceived the sick patient as a burden and that their expression for compassion felt fake and not genuine. Pusa 2012
	Health Care Professionals (HCPs) do not recognise carers expertise	Others spoke of the knowledge they had built up overtime in providing care at home but which was not acknowledged by HCPs: " *It's so frustrating when she goes into the hospital and the nurses and the doctors say it's her condition, you know. I'm like I'm with her twenty-four hours a day, I know how breathless she is without infection and I know how breathless she is with an infection and there's a major difference*" In this quote, the intimate and nuanced knowledge of the caregiver is unacknowledged in the hospital setting. The caregiver remains backstage, while in-patient care of an acute exacerbation is managed as a discrete hospital event. To the caregiver, this represents a failure to assess exacerbation and recovery status in the context of the 'whole illness trajectory', what is 'normal in-between' exercise capacity and baseline breathlessness for a given patient. Hynes 2012 Caregivers often felt frustrated and disempowered, particularly if their concerns or issues were ignored by the homecare staff. This sense of powerlessness prevailed throughout their daily experiences in providing end-of-life care. Ward Griffin 2012
	Inadequate pain management	All caregivers were dissatisfied with the way pain was managed for their ill relatives. For example, caregiver observed his wife's unnecessary suffering: "*My wife was in pain for a long time. No one turned up. Finally, a nurse gave her morphine injection. I could not see her suffering. But they tried their maximum to keep her pain-free*". (Caregiver 1) Shanmugasundaram 2015 Caregiver claimed staff seemed to ignore pain, and she reported as follows: "*My mother-in-law had continuous pain from the beginning due to fracture, and then she had whole-body pain. Sometimes, the painkiller was not working for her. Then, the nurse gave her morphine injection and patch. She was all right for some hours, then the pain started; it goes on*". (Caregiver 4) Shanmugasundaram 2015 The majority of caregivers and their ill relatives believed pain management was ineffective. This largely impacted on the caregivers' role as they needed to constantly stay with their ill relative. Some caregivers expressed anger as their ill relative was suffering with severe pain, and the nurses could not respond to the patients immediately. The caregivers also expressed that the nurses are always busy, and they could not spend adequate time with the patient. In addition,

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Predictors of psychological morbidity		
		some caregivers mentioned that a few nurses are very rude and they could not ask them openly if the patient needed anything urgently, especially pain medications. Shanmugasundaram 2015
SUPPORT *(continued)*: **Healthcare system challenges**	*Disjointed care*	*I still don’t have a handle on [Hospice A] I did call them and I requested all the case notes but there never has been the one person to oversee her case, it’s a different nurse all the time.* *(*Oliver 2017*)* Caregivers also reported confusion about the number of different providers they interacted with and the lack of coordination among the different providers. ‘‘ . . . [X] didn’t like it either because she never knew, you know, who to expect and some of them she never seen before in her life and she felt uncomfortable’’ (Caregiver) Brazil, 2010 Most patients had comorbidities and were receiving specialist care from multiple disciplines, making caring for them at home more complex. “*It is that kind of feeling. They will palm you off to somebody else rather than sit with you and have a straight conversation*”. (current caregiver) Fitzsimons 2019 Caregivers expressed the need for improved service provision, in particular, better continuity of care within the HF [Heart Failure] services and better coordination between different disciplines. “*Then you ring and one tries to pass it off to the other. One Dr says yes, one Dr says no, one Dr says yes, one says no”*. (current caregiver) Fitzsimons 2019. These data illustrate the frustration that carers felt and their desire for a much more coordinated approach to care management in advanced HF. Fitzsimons 2019 Carers placed greater emphasis on accessing the neurologist for continued medical care, yet delayed or irregular medial reviews with specialists, combined with the lack of a continued and co-ordinated approach between and across service providers (both statutory and voluntary), appeared to have a negative impact on the person with PD [Parkinson’s Disease] and on the carers. For example, carers perceived that their relative’s condition and medication were not adequately monitored and this resulted in inadequate symptom management (i.e. constipation, fatigue and stiffness). In addition, communication with and access to health and social care professionals, such as social workers or occupational therapists, were not evident or linked to diagnosis and were often delivered on an ad hoc basis. This resulted in some relatives and carers not being aware of accessible services, until the development of a crisis. One carer would have preferred a linked care system so that all professionals were involved early in the journey: “*I think sometimes one hand doesn’t know what the other hand is doing . . . because I mean I have phoned up about*

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Predictors of psychological morbidity		
		things and its pass-the-buck sort of thing”. Some participants felt that more education and training were needed for health and social care professionals who worked with people with PD [Parkinson’s Disease], and that statutory services needed to link with voluntary groups to help inform patients and carers. McLaughlin 2011 Feelings of disappointment regarding the quality of health care were also experienced. Pusa 2012 Patients and relatives describe a wearisome journey by being sent to different physicians, receiving imprecise answers, and experiencing reluctance to talk about the cancer diagnosis. Some medical findings remain unaddressed, and some issues that seemed rather inappropriate at that moment are discussed. Participants frequently used the words “shock”, “disbelief” and described a feeling of being left alone. Villablos 2018 A number of people felt that they had to cope with very little support from services. Limited general practitioner (GP) involvement and lack of continuity of care were frequently cited difficulties at this stage. Whitehead 2012 ‘*I think the only down side was my own doctor’s surgery, their palliative care is rubbish, because (patient) had this chest infection, and three different doctors came to him, my daughter is the manager of a big medical practice so she knows, and she said they should always ensure that the same doctor goes, unless the doctor is off sick or something*’ (female former carer, 2 years post bereavement) Whitehead 2012
	Cultural barriers	Participants’ resistance to using an interpreter handicapped their encounters with medical and nursing staff and precluded supportive interventions. Heidenreich, 2014.
	Lack of information	*I told the nurse that I’ve got to find a way to fight these bed sores, I can’t turn her any more than I already am* (Oliver 2017). It was clear that caregivers understood they needed greater support: “*And they (family) should also be given contact numbers of every resource that is available to them, occupational therapy is a big one, for the wee practical things!*” (bereaved caregiver) Fitzsimons 2019

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
SUPPORT *(continued)*: **Healthcare system challenges**	*Lack of information*	*“They do things for the patient, but they don’t really do anything for the carer. . . he’s been on courses. . . but they don’t really tell you anything”* (Carer). The focus of existing interventions was on patients, but carers form a dyad or unit of care with the patient in terms of day to day management, therefore focusing educational interventions on patients alone may limit effectiveness. Farquar 2017 Carers wanted to be included in discussions of breathlessness management to enable them to support the patient to manage their breathlessness day to day: *“They [health care professionals] don’t necessarily ignore me but they don’t seem to talk to me. . .[it would be good] if a carer could be a bit more involved”* (Carer). They were rarely involved in advice-giving to patients or knew what the patient had been taught in terms of management strategies. Farquar 2017 They wanted information and knowledge to put them in a better position to help the patient and allay their concerns. They wanted strategies, work arounds, tips and tricks: *“You’re just sent home to deal with it on your own, find your own solutions”* (Carer). Farquar 2017 Many felt unprepared for the trajectory and its downward decline, coming blind to new aspects of the conditions e.g. the potential for pneumonia or for hospital admission. “ *.to know what stages we’ve got left to expect. . . knowing the progression of the illness and the stages. . . would be very helpful*” (Carer) Farquar 2017 “*He had obviously deteriorated, but nobody was saying what the deterioration was or what to expect when he got home*”. (bereaved caregiver). This lack of information led to problems for the carers. “*You are helpless, you can’t do anything, you don’t get told anything*”. (current caregiver) Fitzsimons 2019 In particular, the bereaved carers identified lack of clear communication as a major stumbling block to their overall caring experience. ”*Nobody would tell us that- nobody ever once said your mother is dying*”. (bereaved caregiver) Fitzsimons 2019 The quality and quantity of information presented to carers were not adequate and failed to facilitate their understanding of the clinical issues their loved one was facing, including symptoms, treatment options, and support needs. This lack of information negates the possibility of shared decision making for patients and their caregivers. Fitzsimons 2019

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
SUPPORT *(continued)*: **Healthcare system challenges**	*Lack of information*	Some caregivers stated that they asked healthcare professionals about what to expect but reported that the information they were provided with was ambiguous. This left many caregivers feeling vulnerable and unprepared, causing undue stress as they constantly worried about the significance of changing symptoms: “ *I said Is that a sign? Is he just going to get cold? We don’t know what you are supposed to do*”. (current caregiver) McIlfatrick 2018 “*Nobody really explained to me then when she was admitted into [Hospital] A&E. I said what is the cause of this foaming at the mouth? … I found out later it’s quite a common symptom of end stage dementia*”.(daughter) “*If I’d have had a session with me and someone at the beginning, face to face, to say “right your mum has been diagnosed; this is what you need to expect”. But in a very gentle kind of... Like the leaflet you showed me that time. That would’ve been brilliant… being ignorant isn’t going to save you in the long term…*” Moore 2017 Caregivers felt they were not seen as an essential component of the end-of-life care team. Some caregivers felt that they were not welcomed or intruding on the care recipient–nurse relationship if they asked for help or information: “*I think it would be nice to be involved and be aware of what’s going on (with spouse’s care) . . . I guess I could have made myself available (when nurses visit) and I would have liked to see what was going on, but I didn’t think that was what they wanted . . . I would think if it was from the initial visit, if the nurse would explain that if the spouse or caregiver, partner, was interested in just being around you know, observing, asking questions, even being allowed to ask questions, I think that would have to be something that would have to be said from the initial visit by the nurses.* *I think it would be nice to have things more like a couple to discuss things and to be involved and be aware of what’s going on . . . I would say they[nurses] just mostly come and see [husband] and talk to him and if I’m here and they’re saying anything that I should hear, I listen*”. Ward-Griffin 2012 *“Didn’t know the full extent of what was actually going on. I knew she was having issues with the infection there, the pain and everything. Also, she had it on one side, her exit site, but then they had to switch and put it on the other side. So I’m not knowing what’s going on. When I go to work, this stuff…this is affecting me”.* (Participant) Williams 2017 Participants in the control group tended to describe wanting to access help, but being unsure how to do so: “*So, I don’t really know whether I really need to talk to psychiatrist […] I don’t know what they… would it be psychologist or whoever they provide just to help people get through it. I don’t know what I’d say to them. ‘I’m having a hard time.’ Well, isn’t everybody? […] Sometimes you’re just sort of reaching for something, but you don’t know what*”. McDonald 2018

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
Lack of informal support		**<u>Feeling of being let down by extended family</u>** “*My son was married by the pastor in the church and he has lots of things to do… No time for me at all… For one month my son never rings, never come. I get so scared I ring him, I cried*.” Heidenreich, 2014. Poor family relationships and unsupportive behaviour came to the fore preventing participants from sharing their suffering. For example : ‘*Sometimes I tell my husband's brothers and sisters, but they don’t help me. Sometimes they get cranky to me. They go crook on me. So I keep it inside my heart you know. I can’t talk with someone*’. (Maria) Heidenreich, 2014 *“Because I have no support and I don’t really have any family that supports me … something that really upset me” (Oliver et al, 2016)* *“…. My mom told people [family members] that I was struggling … and yet nobody ever called me to see how I was doing. It was almost worse … it was devastating; I felt like they all abandoned me.* (Oliver 2017*)* “*They visit me less (friends and family) since he’s been on hospice, which is a phenomenon you should look at. What it says is we’re afraid of death. People on email write me a note and proclaim their friendship but they don’t show up here*”. (Oliver 2017*)* “*I have no words to say. It is an experience. It was so painful for me. I feel so much under pressure you know, I have sleepless nights, no one to support me, and no one is there to help me, so it is a lot of mental stress for me especially at the last stage of his illness. I have no time to spend with my children*”. (Caregiver) Shanmugasundaram 2015 The experience of feeling isolated was compounded further by friends or family who did not ask about their well-being, offer assistance, or invite them to join activities outside of caregiving. Ward-Griffin 2012 Conflict was reported in several families by caregivers, which manifested primarily in a lack of family support in caregiving. This was attributed by some cases to family discomfort in assuming caregiving responsibilities and on one

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
SUPPORT *(continued)*: **Lack of informal support**		occasion, to a prior estrangement in the family: "*Well my one sister called, I said, 'well [sister], you want to come?' But none of my family would come at the end to be with me. They, she said, 'I want to remember him as he is.' So why did she call then?*" (Caregiver) (Brazil 2010) Variability of relationship experiences, examples include an adult child who commented "*Now we're back as a family with the same roles as when we were kids; there are feelings that some siblings could do more than others*", Galvin 2016 Caregivers also cited the negative impact of caregiving on relationships including feelings of resentment toward family members who did not help. Kutner 2009 The lack of familial support from his siblings was particularly troubling for one caregiver. He indicated that his experience would have been better if he had received assistance from his siblings: *"My older brother is seven years [older] and my sister is almost 10 years older than me and I've always been the bearer of my parents. It would be nice if – like my brother, he comes home just to have fun, come in and out just to say, "Hey, Dad, how are you doing," smile, "Hey" – but he [doesn't] see the real movie, so to speak. He sees it, but he doesn't want to deal with it. My sister is even worse than that, honestly speaking. So it's all me.*" (Participant) Williams 2017 "*Being responsible for anything and everything, having to check and think of everything. There's so many things…"* (Female spouse/partner, 68 years). Galvin 2016 "*I have no one here in Melbourne with me to support and care for my children. All my families are in India. I have few friends, but they have their own business to look after, so they cannot help me with anything*". (Caregiver) Shanmugasundaram 2015 **Family and friends too busy to offer support** In China, the family network provides support as children continue to live with parents and are available to provide support: *"In China maybe much easier because you always have family relative. And because you can take the time to get someone to help her*". Heidenreich, 2014. "*But here there is no one because the family everyone is working. All the relatives and the good friends living far away… She [my mother-in-law] got two other daughters, but they all working and they've got kids at school so they can't come to care for mother and help [me*]". Heidenreich, 2014. There is nobody to help She felt undersupported: "*I am having a*

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
SUPPORT *(continued)*: **Lack of informal support**		*big depression and loss, because you have to care single handedly … you have to understand that if you are the sole person … having to shoulder all these responsibilities the pressure is becoming heavier and heavier …*" Heidenreich, 2014. Lin described "feeling isolated" due to loss of familiar values and family care-related cultural understandings Heidenreich, 2014 **Friends chose not to visit** Other family members might also be more reluctant to visit, leaving the carer feeling physically and socially isolated, as if they too had moved into a life centred on illness and were in a parallel world with the patient. This diminishment of existing social contacts added to the sense of loss and isolation Murray 2010 Caregiver mentioned that in his family females are meant to perform the caring role. Because of this extra and complex role, he was unable to take part in his social activities, and he lost the few friends he had. Shanmugasundaram 2015 "*I don't find my friends calling me . . . I know you are not supposed to feel like you should . . . I would be dishonest if I didn't say I'm starting to get a little pissed off. Yeah, I know that I am not supposed to feel that way, and I am aware of that, but I don't feel that way all the time, I am just feeling down and depressed . . . I have never ever expected anything from anybody, but a telephone call would be nice*". Ward-Griffin 2012
		You feel … very alone … (Oliver 2017) Described feelings of isolation: *"...so I guess, in that way, I suppose you're isolated a bit"*.. Duggleby 2010 "It has made a huge difference to our lives…I cannot leave X [spouse] alone, I am afraid to. It has led to a life which is very restricted and isolating. X is now fully dependent on me Hynes 2012 Emotionally, feelings of isolation and loneliness were mentioned, Kutner 2009 Other caregivers indicated that they often suffered from loneliness. Such feelings of loneliness can be outlined as a vanishing contact with the patient as a trusted and previously known person. Wasner 2013

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Theme	Sub theme	Supporting quote or text
Predictors of psychological morbidity		
SUPPORT (*continued*): **Loneliness/isolation**		**Fear of loss and future loneliness** Participants struggled with the impending loss of the family member and unbearable dread of an isolated and lonely future in being alone Heidenreich, 2014. "*You know I just feel why is my life like this? What's to happen? … Oh, no! I can't think about being alone. I just pray every day "Just God help me. Sometimes I tell the god "God if you like him, and you love me give him a little bit more time*". Heidenreich, 2014. **Spiritual distress** Confused that God did not seem to be present in their suffering: "*It kind of makes you a bit angry. You think, "is there a god?" Sometimes you think, "how can He do that?" I don't know, I'm kind of mixed up about all that*" Murray 2010

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Theme	**Sub theme**	**Supporting quote or text**
Strategies to support mental health		
5. Carer internal processes		
Time for respite	*Time for yourself*	Taking time for themselves, including for meditation, exercise, 'the opportunity for solitude' McDonald 2018 Some caregivers reported being able to take a break was important, no matter how small. A husband described how he got up early in order to be able to read the paper alone in an attempt to take a break: *"I've made time for myself. I've got into the habit of getting up early and reading the paper*". Ugalde 2012 Adaptive coping strategies used by the participants included exercise, meditation, reading, religiosity, solitary activities Williams 2017 Meditation and exercise were used as coping strategies. "*Meditating a lot helped me to take apart the negatives and see the positives in it… First thing, I was like I want to go get a salad, and I wanted to go running.* (Participant) Williams 2017 Caregivers were aware of the need to take care of themselves, so they could continue to take care of their patients. They employed both problem-based strategies such as exercise, as well as emotion-based strategies to reframe their stress and make it manageable. *(*Oliver 2017*).* Other family caregivers recognized they needed to care for themselves to take care of their loved ones *("I knew that I had to . . . make sure that I was . . . as healthy as I could be to take care of her*"), so they planned ahead for meals, exercised, went to doctors' appointments and check ups, took walks, participated in hobbies (e.g., quilting classes), or worked, all of which served as a refuge or respite from caring. Ferrell 2018 "*I have to go away once a day to my girlfriends and have lunch with her … or I would lose my sanity*". Kitko 2015 During the interviews, each caregiver described activities that they decided to participate in alone to destress. When caregivers decided they needed a break, they described engaging in activities that included spending time with friends, attending support groups, reading and drinking tea, driving around, visiting with family, reading self-help books, going shopping, occasional gambling at a nearby casino, watching television, attending local MS society activities, and going to work. Many of these activities the caregivers described had an obvious social component and allowed the caregiver to ''get out of the house.'' McCurry 2013

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Theme	Sub theme	Supporting quote or text
Strategies to support mental health		
CARER INTERNAL PROCESSES *(continued)*: **Time for respite**	*Employment*	The significant others further experienced that employment, routines and activities contributed to increasing their sense of wellbeing. "*And I'm very happy because I have a job, so I can come out and meet*" Pusa 2012
	Alternative therapies	"*For when I am down and out, I do reiki. It's a therapy that involves channeling the energy of the universe to me for healing*". (Nathan)Penman 2018
	Treats	Without exception, all participants spoke of ways in which they `treated' themselves or those they cared for either materially or intangibly. For some, this took the form of increasing the frequency of activities that would usually be regarded as luxuries such as a `*going out for a nice lunch*' or exchanging a small gift aimed at pleasing the recipient while for others it comprised behaviours which were essentially `normal' actions but simultaneously demonstrated thoughtfulness which was emotionally valuable. "*I think I've tried to be a bit more attentive, caring, well I've always been caring, but you know, yes attentive I think is the word, just holding hands and just yes*". *Walshe 2017* Both patients and carers spoke of `treats' but not always in the same way which was indicative of the relationship within the dyad. Whilst all participants appreciated the value of a `treat' in `lifting spirits' it was not always a `treat' for the person speaking. For some, the `treat' was for the other in the dyad and generated feelings of wellbeing either from the act of giving or from receiving something, particularly if unexpected. The `giving' of `treats' was most commonly enacted by carers, particularly where the patient was feeling unwell or anticipating a difficult event such as a clinic visit. Carers across the sample described how they would ensure that the patient was psychologically supported by them as much as possible by planning `treats' to coincide with difficult times. "*. . .if we get to [clinic] early enough . . . [there's a nice pub and] on a day like today you can sit out and see [the marshlands], it's lovely . . . or we go and see a little bit of different places when we go [to clinic] and make it a bit more interesting*". *Walshe 2017* Participants developed strategies to include low and non-cost `treats' even where material resources were very limited. *Walshe 2017*

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Theme	**Sub theme**	**Supporting quote or text**
Strategies to support mental health		
CARER INTERNAL PROCESSES *(continued)*: **Time for respite**	*Journaling*	*“My hope is seeing the positive and also the exploring and facing my fears for a defined period each day… journaling was a time to honestly address my fears, and to become a better person.”* Duggleby 2013
	Reducing the quality of care provided	*“You can give 100% care and that may require a lot to do and so the quality of life even though you are giving 100% the quality of every other part of your life is diminished. So you can bring that care down to maybe 90%...it may not be the best of everything, but you’ve got to bring your quality of life further up*”. McCurry 2013
Positive self-talk	*Looking to the future, knowing this will end*	*“When she dies, I won’t die and I have to remember that. This is not what she would want for me, she would not want me to lie down in a hole beside her and stop living.”* (Oliver 2017*).* “*I just remain positive. I mean there are just days when it’s like … I’ve been kind of feeling like there’s only so much I can do*”. (Oliver 2017*).* Used motivational audio recordings to help increase positivity while caring for his wife Ferrell 2018
	Coming to terms with the situation/thinking of what you still have	"...*thinking about your life and what you've got in your life*.") Duggleby 2010 *“Do we, you know, wallow in our pity and have what time we’ve got together, you know, we are not going to enjoy him, we don't want to remember it because it's that down? or do we make the best of everything and carry on as much as you possibly can, deal with it, being normal as normal as it is to get us through it? Walshe 2017*
	Gentle with yourself on bad days	Moreover, a positive attitude with insight into one’s personal strengths and limitations was found to reduce distressed emotions during both the anticipatory grief and the bereavement. “*Because it’s there, I must remind myself that, it’s like you might not manage as much.one day. but you have to tell yourself to try to take it easy, and that this day is like an upside down-day; that it doesn’t feels so good. So it is*.” Pusa 2012
	Positivity from others- feeling appreciated	Being thanked or appreciated was hugely supportive and encouraging, enabling them to carry on: ‘*When she thanks me for what I'm doing and appreciates what I'm doing for her. And calls me her rock. That's enough’*. Ugalde 2012

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Theme	Sub theme	Supporting quote or text
Strategies to support mental health		
CARER INTERNAL PROCESSES *(continued*): **Spirituality**	*Acceptance of a lack of control*	Several family caregivers voiced a "live for today" philosophy, not putting off trips or other things they wanted to do, because "*only God knows what he has ahead for us*." Ferrell 2018 "*I know God is in charge & we have to trust him, his ways are not always the way we want them to be*". Duggleby 2013 *'I just want peace of mind, nothing else. The rest is whatever God decides.' I said, 'So be it. No problem. We'll do it.'* McDonald 2018
Ignore own emotions and needs **(maladaptive coping strategy)**		Others reported being so focused on helping the patient that they had not spent time thinking or processing their own feelings about the diagnosis: "*I'm not focused on myself, I haven't had a think about everything. I don't allow myself the luxury of doing that*". Ugalde 2012 One caregiver, feeling a deep sense of responsibility and as if "*everything rests on my shoulders*," suppressed his emotions. *"It affected everything, and it used to actually bother me in my mindset. But what I did was I just kind of push that over to the side like you said and just did what I had to do*" (Participant. Williams 2017 *Maladaptive coping strategies* are unhealthy ways of dealing with stress in which an individual seeks to ignore or deny that stressors exist. Williams 2017 Caregivers also used maladaptive ways of coping with the stressors of caregiving, including avoidance, attempts to change the care recipient, excessive exercise, masking their feelings, and withdrawal. Williams 2017 Another participant who was particularly affected emotionally by caregiving circumstances yet convinced that he must stay strong for the sake of his wife, masked his own feelings. He stated: *It was affecting me extremely bad because I was like, man, I don't know how I'm going to deal with this, but I kept going on because I wanted her to see that I was okay, and I was strong with it, but at the same time when she is away from me, it was messing with my mindset.* (Participant) Williams 2017 "*was . . . on auto pilot . . . . I was just in motion physically doing what had to be done . . . trips to the emergency room and keeping my emotions under control and I felt like I wanted just to . . . break down but I felt like . . . for my son I needed to keep myself under* control" Kutner 2009

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Theme	Sub theme	Supporting quote or text
Strategies to support mental health		
CARER INTERNAL PROCESSES *(continued*): **Ignore own emotions and needs** **(maladaptive coping strategy)**		This often involved caregivers putting their own emotions aside: '*So, if I'm feeling emotional or* negative or whatever, I don't, I wouldn't let that show with her – because that's not what my role is. My role is to be supportive'. McDonald 2018 "*I just kind of went into administrative mode, automatic pilot, getting things organised, doing this, doing that and I couldn't be emotional. Otherwise, I'll just be crying all the time*". McDonald 2018 Providing end-of-life care to a relative with advanced cancer required family caregivers to prioritize the physical, emotional, and social needs of this person, often ignoring their own needs. As one spousal caregiver aptly stated: "*Everything has to orient around her basically, no matter what it* is." Ward-Griffin 2012 Avoidance-oriented coping includes strategies of avoiding, distancing and denying the situation, where the significant others felt that this was necessary in order to endure the circumstances. Pusa 2012

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Theme	**Sub theme**	**Supporting quote or text**
Strategies to support mental health		
6.Support		
SUPPORT: **Professional support**	*Mental health professionals*	The strong intensity of the emotional, physical and financial stress required medical intervention for some participants. Lin mentioned, "*I am suffering from serious insomnia and I take something to make me sleep … I am receiving counseling … I need to see a psychiatrist"* Heidenreich, 2014.
	Social workers, nurses and physicians	Social workers and physicians who listened to and responded to their needs to be invaluable. Ferrell 2018 Caregivers also identified resources that they felt would be helpful but were currently unavailable to them. These included ''hassle-free'' 24/7 access to healthcare professionals to assist with triaging acute situations, more training in emergency care, periodic home visits by occupational therapy to help the caregiver adapt care as the recipient's needs changed, and a printed list of all the resources available in their particular community. McCurry 2013 Health care delivery. Interestingly, the formal delivery care system was also reported as a support by family members. Most commonly in how care was provided, participants used frequent descriptions of sensitivity and compassion (Brazil 2010) A number of providers reported on the competence of healthcare providers in administering care, as well as the availability of physician home visits. ''*I think having, having a good doctor is, is very important. I would have been lost without [name]. He made house calls when [participant] could no longer get down to his office. And he was here every week. He said I could call him anytime. I called him a couple of times with questions. . . .He was one of the two doctors you could call at home, so''* (caregiver).(Brazil 2010) Family caregivers and palliative patients described the importance of information coming from whom they considered to be experts: *"And as the time went by, we realized that the palliative care nurse was so different than a registered nurse... had extra training and that was very evident every time they came to our house. ...it gave us a sense of being looked after".* Duggleby 2010 '*Our palliative nurse tries to do her best. Her encouragement is fantastic. She is such a nice lady to us so we are happy. Whenever she comes we are happy*.' Epiphaniou 2012

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Theme	Sub theme	Supporting quote or text
Strategies to support mental health		
SUPPORT *(continued)*: **Professional support**	*Social workers, nurses and physicians*	'*... a good relationship with the GP is another important [factor]. Bless him he is another support in the family …*' Epiphaniou 2012 '*I was quite fortunate that my GP helped me a lot and gave me information but without that help I would not know what to do ...*' Epiphaniou 2012 They valued the multi-disciplinary staff expertise (their knowledge and understanding of life with breathlessness), the characteristics of the Breathlessness Intervention Service (BIS) staff (their approachability and attentiveness) and their reassuring and positive approach, Farquar 2017 There were experiences of mutual trust and understanding between care professionals and significant others. The importance of professional support was highlighted and the significant others experienced both emotional and practical support primarily during the illness trajectory. This engagement from the care professionals increased the sense of wellbeing, providing feelings of safety and confidence. Sincerity, openness and flexibility were characterized as elements of good communication and care by the significant others. "*And then like that, yes that they had time to talk a few minutes with me also, so I felt I got out a bit out of my frustration. And then it felt easier after they had gone. So, it takes so little in order to give so much, I think*." Pusa 2012 It was essential to the significant others that their sick relative received adequate medical treatment and satisfactory nursing care. They felt satisfied and safe when their sick relatives received properly symptom relief and were met respectfully by care professionals. "*The palliative care, also that the. you can say they cure all the symptoms; you do not have to be in pain; you do not have to feel sick; they keep your intestines going, and so. So it is somewhat decent, and you may, of course, get some for anxiety too*." Pusa 2012 "*We went to see the GP and because he wants to die at home, he doesn't want any intervention or anything and the GP was very supportive, he was, which I must admit that was a big weight off my* shoulders' (female carer of husband diagnosed for 30 months) Whitehead 2012
	Palliative care referral/ nurse	Very few caregivers, from those interviewed, reported receiving a palliative care referral, and some outlined this as a very momentous experience: "*It was just like this angel had walked through the door. You knew, she came in and closed the curtains and did all sorts of wee things around the room, changed it and whatever and I just thought it was lovely. She made him very comfortable that night….it was just wee small things that were very attentive and* caring …"(bereaved caregiver)

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Theme	Sub theme	Supporting quote or text
Strategies to support mental health		
SUPPORT *(continued)*: **Professional support**	*Palliative care referral/ nurse*	"*He was almost reassured. I don't know what she said to him. When she had come out for that initial visit just to make herself familiar, she left and she spoke to us all and she was a great source of contact for all of* us". (bereaved caregiver) McIlfatrick 2018 "*The district nurses were, they were very good, and perhaps I shouldn't say, but more professional than the carers because they knew how to turn him and do things and experienced [. . .] and I could just ring them up and ask them to come if I was bothered. The Marie Curie nurse was wonderful as well*". (female former carer, 7 years post bereavement) Whitehead 2012 'The Marie Curie nurse came and stayed for two nights so I could get some rest. She was allowed to give him the oxygen. And he just died peacefully with all his family, which was wonderful'(female former carer,5 years post bereavement) Whitehead 2012
	Telephone helpline service	They complimented the City of Hope resource center and helpline telephone service, saying that these were resources they could go to for information and guidance regarding who could address their concerns. One family caregiver said, "*I did have some issues where . . . things had gotten overwhelming . . . and they sent me to the right people*." Ferrell 2018 Carer: '*It's nice to know it's there, that if I've got any problems or worries that I can phone up and say 'I think he's a lot, lot, lot worse today, what can I do?' … you know? […] Because you know… we're a long way from [hospital], and you can't just sort of keep popping up and going there because it exhausts him anyway…and it's nice to know there's someone at the end of the phone to say 'well try this, try this, and if it doesn't get any better do this …*" Farquar 2017 Both caregivers and hospice staff supported the use of telephone for counselling, appreciating its relative anonymity and convenience. Caregivers liked the idea that it would be someone who they would never meet and felt that they could express feelings of anger more openly than they could in person. One participant said: "*But don't you think as caretakers . . . that there's things we can't say to our neighbors, or our family, our kids, our grandkids or sisters or brothers or even parents if they're still alive? I mean for me there is*". Kutner 2009 The most helpful aspects of the program were predicted to be: having someone to listen without judgment, venting anger and emotions, knowing others have gone through it and feeling less alone, as well as informational purposes or to get answers to questions quickly. Kutner 2009

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Theme	**Sub theme**	**Supporting quote or text**
Strategies to support mental health		
SUPPORT *(continued)*: **Professional support**	*Homecare*	Furthermore, the input of home care is essential, as it changes the situation for family caregivers radically. One participant describes it: "*I have to work, and I thank God that two hospice volunteers from the CHV [home hospice care team] come by while I'm working so that he's not alone for more than 2 hours at a time. It works out really well and it's always the same helper which is good because he doesn't like it when new people come, it's difficult for him*". (46-year-old woman, spouse) Wasner 2013
	Private caregiver	*"I have (private caregiver) … I feel like there's a plan in place if something goes wrong and I'm not as likely to do something wrong that could cause him harm. I realize I'm living with less stress…less adrenaline ... I'm getting a chance to slowly decompress".* Oliver 2017. Whether they hired help or solicited family assistance, these strategies arose from necessity and often desperation. Oliver 2017 "At some point in time I'm going to need some supplemental help and its not going to be friends this time I'm going to have to hire some professional help.. Oliver 2017
Informal support	*Shared responsibility/ validation*	Informal supports. Caregivers reported on the importance of informal supports as represented through extended family, friends, and neighbours. These supports manifested themselves in a variety of ways including information support on the disease and of services in the community; in assisting in activities of daily living, household, or transportation; and providing opportunities of respite. "*I had a girlfriend that came at the end. A couple of times she came over. She was a personal support worker by trade and a long time friend of mine and she was aware of what we were going through and she offered to come over a couple of days just to sit over there with me, you know to catch up on things and she would listen to me on the phone, you know cry a number of times and she was just there to really listen*". (caregiver) (Brazil 2010)

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Theme	Sub theme	Supporting quote or text
Strategies to support mental health		
SUPPORT *(continued*): **Informal support**	*Sense of community*	"*And I think, on the farms, people know more about each other than in the city. You make friends in the city, so fine, but on the farm... in our area especially, if somebody was in... in some kind of problems... neighbors were there to help... So may, maybe a more of a sense of community there"* Duggleby 2010 A supportive network of friends and community was also beneficial as illustrated by this comment about a rural community: "*One thing I'll say about it all, like being in a small community, it was help in a sense to know that we had neighbors who we could call if we were in trouble"* Duggleby 2010
	Support from friends and family	"*We have such wonderful friends and family. They bring supper almost every day*." This support, brought hope to their day and to their lives. Duggleby 2013 Informal support, on the other hand, appeared an integral part of the care support system in the home. In some instances, this amounted to multiple carer involvement whereby '...*X is a great help like X'll give me a day off here and there and Y is there at night time so if I want to go out, I can go out*'. Hynes 2012 Caregivers in both groups expressed how building a 'support team' could lessen the strain of caregiving. McDonald 2018 "*You need friends to affirm and encourage you and spur you on a bit . . . but you need to change your outlook and your heart". (Barbara). "Friends distract you for a while, we talk, then cry, then talk some more. We draw on happy memories and imagine a time when there will be no more death and sickness*". (Diana) Penman 2018 The significant others highlighted the importance of emotional, and to a certain degree practical, support both from inside the family and from people outside the family such as co-workers and friends. Gaining support felt necessary for the significant others in order to endure the altered situation of the illness period Pusa 2012 Practical, but especially emotional support was experienced as essential, and this support was received from family, care professionals, friends and co-workers. Pusa 2012 Family carers also spoke of the enabling features of both sharing the practical burden of caring and how this relieved their own concerns when such support was offered by those who were trusted: *'I'm very grateful that she's got a good circle of friends. . . I know full well if my mother says she's going out with friend A from church then I'm quite happy with that. . . I can go and do something and not worry about how she is, where she is or is she planning on coming home this afternoon or is she getting the bus back'*. Walshe 2017

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Strategies to support mental health		
SUPPORT (*continued*): **Informal support**	*Support from friends and family*	For carers, seeking emotional support from others was seen as a way of enabling them to return refreshed to the demands of being a carer: *' . .when [husband] is down I have to leave the house go to my sisters and I'm heartbroken myself and she'll cry with me and [we comfort each other] then I have to come back and try and pick us up . . . so you really sometimes you force yourself to stay up there for the other person don't you?'* Walshe 2017
Support groups While the use of support groups was not widely reported, those caregivers who attended them reported generally positive experiences. *(Oliver et al, 2016)*	*Source of information*	*'... you learn a lot by going to the support groups or talking to people that are in the field' (Oliver et al, 2016).* *"I think that the support groups are probably the most important because I think, for me, going to the support groups, I heard people sharing their information, their techniques … [that] was probably the most helpful … those groups are really good … help you stay focused*". Oliver 2017
	Support from others in the same situation	*You learn a lot your self and it makes you thankful that our case isn't as bad as other people have it.* Oliver 2017*.* Group meetings for patients made up of "either survivors or [people who are] living it" were praised as a good source of patient support. An family caregiver said it was nice to talk with others who had faced similar issues to know they were not alone in their feelings: "*Some of your reactions are very normal, and it's OK to have them.*" Ferrell 2018
SUPPORT (*continued*): **Accessing information**		Caregivers emphasised the need to 'stay strong' and described numerous methods of coping. These included… taking control by getting informed about the illness, McDonald 2018 Whilst some carers wanted to know everything about PD [Parkinson's Disease] at the start, others did not want to know too much information in case they or their relative could not cope and become depressed. Therefore, participants suggested that information should be tailored to the needs of the patient and carer. McLaughlin 2011

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Strategies to support mental health		
		Some carers were satisfied with EOL {end of life] care if they felt adequately informed and involved, even when EOL care was not in accordance with advance care plans. Moore 2017 Carers who felt well informed about how dementia progressed, were regularly updated on their relative's health condition and felt involved appeared more satisfied with EOL care. Moore 2017
Spirituality	*Reduces a sense of isolation/ someone is listening*	Family caregivers (FCGs) expressed that they and their loved ones were relieved that there was a "*God to pray to and to know that he's listening*." One FCG stated that God answers prayers; these answers were "*not always in the way you want him to . . . but he does answer*." Another FCG stated that faith was such an important support and that a "deep-seated faith" allowed her loved one to "continue on this journey and not feel the depths of despair that some people do." Ferrell 2018 … *read the bible* … *be true to* your faith, spend time in prayer, quiet time … then you're able to keep caregiving. Oliver 2017 "*My spiritual beliefs helped me cope. . . . I found this paradise within myself. You need to find this peace within yourself*". (Hilary) "*To overcome feeling low, I committed to caring for my husband who was very sick. . . . My religion also played a big role in my coping*". (Isabelle) Penman 2018 "*We had church fellowship, prayers and communion. We get this love and support from family and friends. We prayed. . . . There was no time or reason to be depressed*". (Leah) Penman 2018 The two older men in this study, who were both caring for their wives, spoke freely about their use of religion to cope with the stressors and challenges of caregiving. Faith in God strengthened them to meet the demands and difficulties of providing care. "*I think my biggest help comes from the Lord though*" (Participant). "*I work through it – through the power of God*" (Participant). Williams 2017
SUPPORT (*continued*): **Spirituality**	*Provides a sense of community*	The act of having faith provided a community, which was a source of support. Ferrell 2018 "*It has been a support and a community for us*". Ferrell 2018

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