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This is the authors' version of an article accepted for publication in *Qualitative Health Research*.

Please cite this article as:

Lawn, S. and McMahon, J., 2013. The importance of relationship in understanding the experiences of spouse mental health carers. *Qualitative Health Research*.

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The Importance of Relationship in Understanding the Experiences of Spouse Mental Health Carers

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Abstract

The burden of caring for family members with mental illness has been researched extensively. However, knowledge of spouse carers' experiences is limited. In this article, we explore this from a carers' perspective, with 28 spouse carers, using qualitative open-ended semi-structured interviews using a grounded theory approach informed by the social interactionism tradition to collect and analyze the data. We present six interrelated themes around the central theme of this being "a real and genuine relationship". The findings indicate that caring for a spouse with severe mental illness is a unique role compared with other caring roles. First and foremost, spouse carers strive for the relationship with their partner, and accommodate mental illness into their lives to protect the relationship. Because of this, they often lead surreal lives marked by significant emotional pressure and isolation. This has implications for how mental health service providers work with and support spouse carers.

Keywords

Caregivers / caregiving; grounded theory; men's health; mental health and illness; relationships, primary partner

Informal carers provide unpaid care to family or friends with a disability, chronic physical illness, mental illness, or who are frail aged. Treloar and Funk (2011) called this “intimate labour” which they situated within the broader concept of “familialism” where, “Households are viewed as having the primary responsibility for members’ welfare throughout the life course” (p. 154). Some carers assume these responsibilities willingly, as part of familial connection with the person cared for. As Cormac and Tihanyi (2006) suggested

Underpinning the caring role may be life-long love and friendship, together with an acceptance of the duty to provide care. Carers can derive satisfaction and a sense of well-being . . . receive love and affection from the care recipient, (and) gain a sense of achievement from developing personal attributes of patience and tolerance (p. 162).

A significant group, bound to provide care through their chosen relationship, are wives, husbands or de facto partners of people with severe mental illnesses such as major depression, schizophrenia, bipolar disorder, post-traumatic stress disorder (PTSD) or personality disorder. Caring for someone with these diagnoses requires spouses to navigate many complexities within the spousal relationship and caring role.

Spouse Carers of People with Chronic Physical Health Conditions

Many researchers have looked at the experience of spouse carers of people with cancer (Kuenzler, Hodgkinson, Zindel, Bargetzi & Znoi, 2011), stroke (Coombs, 2007), cardiac disease (Mahrer-Imhoff, Hoffmann & Froelicher, 2007), arthritis (Roberto & Gold, 1997), asthma (Afari & Schmaling, 2000), Parkinson’s disease (Tanji, et al., 2008), Alzheimer’s dementia (Gilliam & Steffen, 2006) and chronic conditions generally (Baanders & Heijmans, 2007). This research has highlighted carers’ grief, burden, obligation, problems with service navigation and role implications, historically grounded in Role Theory (Davis et al., 2011) which emphasizes stressors arising from role changes and transitions.

Mental Health Carers

Addressing carers' needs generally, and mental health carers specifically, has become an increasing focus of health policy in Australia, and internationally (Australian Department of Health and Ageing, 2011; World Health Organization, 2010; Carers United Kingdom, 2011). However, research, policy, practice, advocacy and support continue to focus on carers as a broad group, parents with mentally ill adult children, or specific sub-populations (Children of Parents with Mental Illness, 2010), with minimal focus on spouses' experience. Mental health carers are central to community care, providing the bulk of support (Carers Australia, 2009). Outcomes for people with severe mental illness are therefore highly dependent on the quality of in-home support. However, few community-based support services exist in Australia, or in other countries, to aid the shift to deinstitutionalisation of mental health care (Cormac & Tihanyi, 2006; Erlingsson, Magnusson & Hanson, 2012; Mental Health Council of Australia, 2009; National Alliance of Caregiving, 2009).

Caring for someone with severe mental illness often comes with enormous personal physical health and wellbeing costs for carers (Carers Australia, 2009). They have much higher levels of depression and stress, and lower levels of subjective wellbeing than those without carer responsibilities (Chang & Horricks, 2006; Van Dor Voort, Goossens & Van Der Bijl, 2007). More than one third of Australian carers experience depression and their caring role is understood to be its leading cause (Cummins, et al., 2007); closely linked to how effectively services respond to carers' needs (Pagnini, 2005). Carer burden is a central theoretical construct within almost all carer research, and most researchers in this field have been unsuccessful at explaining the dichotomy between positive experiences and caring as burden and stress (Wuest & Hodgins, 2011). They also tend to talk about carers' experiences through an "othering" lens, as research objects (Krumer-Nevo & Sidi, 2012), rather than their story being told from their perspective, or by researchers who are mental health carers.

Spouse Mental Health Carers

Although there might be some shared burdens, needs and experiences between all mental health carers, spouses likely have unique experiences. The proportion of spouse mental health carers is not known (personal correspondence, Carers Australia, March, 2012). They remain largely invisible within larger carer groups. The few studies that exist have focused almost entirely on caring for a spouse with schizophrenia (Angermeyer, et al., 2006; Jungbauer, Wittmund, Dietrich & Angermeyer, 2004; Mizuno, Iwasaki & Sakai, 2011), bipolar disorder (Van der Voort et al., 2007) or depression (Benazon & Coyne, 2000; Levkovitz, Fennig, Horesh, Barak & Treves, 2000); or on experiences of wives of war veterans with PTSD (Dekel, Goldblatt, Keider, Solomon & Polliack, 2005; Lyons, 2001). These studies have focused on theories of objective and subjective burden and on measuring negative impacts on spouses' quality of life. We know that marriages to those with severe mental illness often lead to separation or divorce (Kessler, Walters & Forthofer, 1998). However, we know little about why some spouses stay in the relationship despite the burdens, or why some relationships thrive whereas others do not. Hence, we aim to look beyond the theory of carer burden.

The Research Context

Our interest in this research arose from the first author's accumulated reflections and conversations with carers for more than two decades. As a social worker within the mental health workforce, she observed that spouse carers' experiences did not seem to be acknowledged or understood. Working in acute locked psychiatric inpatient wards, she met many spouses who had been told by treating psychiatrists or other health professionals that the best thing they could do was to leave their spousal relationship. Likewise, she met many patients whose spouses had begun divorce proceedings during their hospital admission, or

else they were already long gone. This prompted developing reflections and questioning: Why do some people stay in the relationship?

Likewise, working in community mental health services and running support groups for family carers, she often noticed that spouse carers sat back quietly, often not engaging or returning at all. Becoming a spouse carer 10 years ago prompted her to ask more questions: Is the experiences of being a spouse carer different to caring for an adult child with mental illness? If so, what is different? Do spouse carers share similar experiences to each other? The second author, a person with mental illness, a carer and national advocate for consumers and carers, posed similar questions. Within the qualitative research tradition, we therefore declare our bias and closeness to the research topic, demonstrating reflexivity by declaring that this bias impacted on the lenses through which we viewed participants and the world that they described (Liamputtong & Ezzy, 2005). Mishler (1986) argued that this reflexivity is central to qualitative research because it enhances research authenticity. We therefore reflected continually and explicitly on these notions.

Methods

In this article, we explore experiences of caring for a spouse with severe mental illness. Our purpose is to increase acceptance, knowledge and understanding of the specific experiences and needs of this group of carers, and to inform better targeted support to spouse carers within mental health and primary health care systems. Put simply, we want to understand the lives of this group, to tell theirs and our story, and to help others to understand them too, so that better support is provided to spouse carers and their families. Ethics approval was granted by the Flinders Clinical Health Research Ethics Committee at Flinders University.

Design

We used qualitative grounded theory methodology, underpinned by symbolic interactionism, to explore the experience of being a spouse mental health carer and to develop a theoretical

understanding of that experience. Symbolic interaction provides the theoretical base for grounded theory, and originated primarily from the work of Mead (1934) Blumer (1969) and Denzin (1978). Mead (1934) theorized about how, through social interaction, the individual achieves a sense of self and how this capacity to see self as “other” is learned through social interaction. Blumer (1969) stated that, “Human beings act toward things on the basis of the meanings that the things have for them. . . . The meaning of such things is derived from . . . the social interaction that one has with one’s fellows” (p. 2). Denzin (1978) viewed social reality as a social production in which people engage in self-reflexive behaviour, interacting with one another in their interpretation and definition of the world. Their interaction is symbolic because it is learned, “through their basic symbols, their conceptions of self and the definitions they attach to social objects through interaction with others” (Denzin, 1978, p.7). We recognized the symbolic and embodied nature of the spousal relationship in the presence of severe mental illness and that, “if we are to understand why people do things, we have to understand the meaning they give to their actions” (Liamputtong & Ezzy, 2005, p. 8). We chose symbolic interactionism to underpin the research because its basic assumption is that social reality is a social production (Denzin, 1978), and its emphasis on meaning and identity formation within the social context in which these occur (Mead, 1934; Blumer, 1969).

Grounded theory (Glaser & Strauss, 1967) was chosen because of its emphasis on discovery through constant comparative analysis of data; that is, data collection and analysis going hand in hand. This framework is particularly suitable where little is known about a phenomenon, as is the case here. It involves coding, comparison and clustering, labeling and categorising, further data collection and coding, recoding where indicated and continual testing of hypotheses against the data as they arise (Strauss & Corbin, 1990). We did not begin with any explicit hypotheses to be tested. Instead, we began with broad sensitizing questions about the meaning spouses gave to their experience, to allow whatever was

theoretically relevant to emerge (Strauss & Corbin, 1990). Theoretical sensitivity, which is also a central value of grounded theory, was demonstrated by our immersion in the existing research literature and from our professional and personal experience (Glaser, 1978).

Sample and Recruitment

Participants were women and men living in metropolitan and rural South Australia. Inclusion criteria were: the carer was 18 years old or more; the person cared for had one or more clinically diagnosed severe mental illnesses; and the carer lived with their spouse in a relationship (married, de facto or same sex couple). Spouse carers were excluded if the spousal relationship had existed for less than two years, because we wanted to ensure that their relationship was well established. Carers were also excluded where involvement in the research could put them at risk of verbal or physical abuse from their spouse, should their involvement become known to the spouse. Recruitment occurred through advertisements in carer organization electronic and hardcopy newsletters. Both convenience and snowball sampling were used. This latter method was important because trust could then be built with this “hidden” population. It is well suited when investigating sensitive issues (Liamputtong and Ezzy, 2005). Spouses of Vietnam veterans with mental illness responded particularly well to snowball sampling, with five veteran carers recruited this way.

Data Collection

We conducted open-ended interviews aided by an interview guide, with early questions being more exploratory, following participants’ lead. This informed later questions, guiding the formulation of concepts. We employed theoretical sampling (Glaser & Strauss, 1967) as the evolving theory of spouse carers’ experience emerged. This involved actively seeking different types of participants, such as young spouses, male spouses and ceasing recruitment of veterans’ spouses so that their unique experience would not unduly bias results.

Theoretical saturation is said to be complete when the researcher ceases to hear anything new

from interviews (Glaser and Strauss, 1967). However, as Strauss (1987) argues, there will always be new information to pursue. Therefore, we decided to end data collection on theoretical grounds, once the core category or theme was clearly established. Examples of preliminary questions were: What role do you perceive for yourself and your relationship? How do you think others perceive your situation? Has your spouse's mental health changed your relationship with them? If so, how? If not, why not? What keeps you going in your relationship and role? What are the best and hardest things about caring for your spouse?

All interviews were conducted by the first author to ensure consistency of the interview process, and were conducted face-to-face or by phone at her office, at participants' homes or other agreed places convenient to them. All interviews were audio-recorded and professionally transcribed, where carers consented. Extensive reflective notes (or memos) were taken immediately after each interview. These and further memos captured the impact of the interviews on the interviewer, particular nuanced observations and also general reflections on the meaning of what participants said as a whole and as component parts. This included reflections on what they did not say, but might be expected to say according to the existing research on carer burden. One example was the absence of expressions of resentment about their circumstances. Participants were given the opportunity to view and verify transcribed interviews for accuracy, to reflect and make further comments if they wished. Given the potential to discuss highly sensitive information, we offered debrief and support to link with carer support organizations, if participants wished to, following their interview.

Data Analysis

We analyzed the data manually, first using open (or descriptive) coding. This involved each author reading and re-reading the first two transcripts independently, then meeting to discuss them, noting any patterns and shared reflections. This helped us to establish initial descriptive codes and note emerging relationships across transcripts (Miles & Huberman, 1994, p. 148).

We read and re-read the next four transcripts independently and captured our reflections in memos, again noting initial categories and patterns across the transcripts. We met to discuss our preliminary analysis of the first six transcripts and then together performed axial coding of these six transcripts to more rigorously specify the categories and the tentative order of categories, making connections between categories and sub-categories to ensure that each category was fully elaborated and delineated (Strauss & Corbin, 1990). The decision to move from open to axial coding was based on us reaching the point where we felt we had to stop reading transcripts and look more closely at the memos, to step beyond the individual descriptions of experience to what began to appear to be more major categories or patterns occurring in the data (Strauss & Corbin, 1990).

The first author then coded the remaining transcripts according to the agreed criteria determined from these meetings. We met again to discuss, debate and interpret the meaning of the categories (or themes) that emerged as part of the grounded theory cyclic process (Strauss & Corbin, 1990). We then applied a process of selective coding, also known as theoretical coding (Glaser, 1978), to unify all categories around a tentative core category (Strauss & Corbin, 1990). This involved us each offering insights from the literature, our reflective memos, and our expertise and experiences of longstanding contact with carers and of being carers (Strauss & Corbin, 1990). The core category was repeatedly verified and revised after re-checking the transcriptions and checking with participants. These layers of coding were supported by us each keeping reflective memos of thoughts and feelings throughout the analysis process. Trustworthiness of the interpretations was enhanced by providing direct quotes from participants.

We integrated data collection and analysis using four key processes to enhance overall rigor: team and peer debriefing; checking interpretations with participants and presenting preliminary results at national conferences; transcribing and coding early data;

and, writing memos throughout the process (Liamputtong and Ezzy, 2005). One example of how debriefing informed the research process was contact received by a former spouse carer who expressed a strong desire to participate, suggesting they still struggled with their decision to leave the relationship. Explaining why they could not participate forced the authors to reflect on the interview analysis, and discussion of these reflections made them even more determined to explore aspects of the marital relationship that might help to explain why some carers stay in the relationship. This was one of several examples of the non-linear nature of the analysis in which the first author then sat with the full set of transcribed interviews, absorbing them into her consciousness, writing further memos, talking about them with others and exploring ideas and hunches (Orona, 1990, p. 1249).

Results

Twenty-eight South Australia spouse carers were interviewed for this research. Individually identifiable details have been altered to preserve participants' anonymity. Interviews averaged 90 minutes in length (range 60-210 minutes). Eighteen participants lived in metropolitan areas and 10 lived in rural areas; nineteen were women and nine were men. Three participants were in their 30s, with seven in their 40s, 11 in their 50s, and seven in their 60s. We believe this offers a good range of perspectives. All participants were in heterosexual relationships, 26 were legally married, and two were in long-term de facto relationships. Length of relationship ranged from 3.5 years to 45 years. Vietnam veteran wives (n=8), in particular, tended to be in long-term relationships, often marrying their spouse just before the spouse went off to war, or just after they returned home. Length of caring role ranged from 2.5 to 45 years. For all except five participants, their caring role began after the relationship commenced. For these five, two Vietnam veteran wives commenced their caring role at the same time as their marriage commenced, and the other three spouse carers were aware of their partner's mental health issues when they first met them.

Introduction to the Themes

The overall sense gained from the interviews was that these spouse carers held an enduring commitment to their mentally ill spouse, based on the central premise that this was a relationship first and foremost. “Carer” was a term that did not sit readily with them. They saw themselves as wives, husbands and partners. Sentiments like, “He’s my husband, I’m not his carer”, were commonly expressed, regardless of the cared for person’s level of disability. They were a person, husband, wife, mother or father of children first and a person with mental illness second. There were roles expected of them, just like expectations held in any mutually respectful intimate relationship. This embodied the world that participants were trying to convey overtly or unconsciously to themselves, the person and others. In line with symbolic interactionism, within this “constructed” reality, there were both positive and negative consequences for participants. Many navigated across two realities: one where they got on with their day-to-day lives blending into their community and/or workplace; and the other where they lived entwined in the world of the person’s mental illness. At times, this made their lives seem surreal, leading to feelings of deep isolation and aloneness.

Within the context of this being “a relationship”, terms like “burden” did not seem to fit with participants’ experience, and resentment about their circumstances or envy toward other spouse relationships was not expressed by any participants (except fleetingly by one), or sensed by us during interviews. Participants appear to have resigned themselves to their circumstances as “just the way it was”. Many believed that they had stronger relationships with their spouses because of the mental illness, and stronger than what they saw in couples around them. Loyalty and love of the person were central to their life narratives, within this relationship that they were actively choosing. Within this context, being excluded from involvement in care decisions by service providers was perceived as extremely hurtful and demonstrated the failure of services to see “the relationship” beyond the tasks or role of being

a “carer”, or to see it at all. Each of these carers had accommodated to the mental illness and its impacts on their spousal relationship, with little or no support from services. These experiences are described in more detail in the following central theme and six subthemes.

A Real and Genuine Relationship - Love, Loyalty and Commitment (Central Theme)

Participants expressed an overwhelming sense of commitment to their spouse and upholding their marriage vows. Promises made were seen as important to keep, taking the good with the bad, in an open exchange in which they felt that the person would do the same for them given different circumstances. But more than this, they expressed overwhelming loyalty to the person who was variously respected for their achievements, admired for their courage in the face of illness, or merely adored because of the person they were. Within this realm, the term “carer” did not seem to sit comfortably within their perceived role within the relationship.

I made a promise to the man all those years ago (30 years) and I meant that promise, and I still love him.

I’m his carer but to the outside world he’s my husband I didn’t marry him to be his carer. I married him because this is a relationship. I chose him and he’s the person I adore.

He’s always loved me and always he’s been instrumental in helping me become the person I am. He’s certainly not a perfect person but neither am I. . . . There were a lot of years where I lived in fear, not knowing what was going to happen next but there’s never been any doubt that I haven’t been loved, and I certainly haven’t been bored.

Friends say to me “You should pack your bags and just leave.” Well, I just find that a non-event. . . . Why would I ever do that when the lady needs me more than ever?’ I think I can see through the smoke and see that she’s still the same person I married.

I can be myself around him. There’s an honesty that comes with the presence of mental illness. And it’s different to any other relationship I’ve had before. . . . It’s the complete comfort that I have with him as a person. It’s ironic that it’s the most real relationship you find yourself in.

All participants displayed stoic determination to maintain and protect the relationship, and safeguard their spouse’s quality of life. Few spoke about fear of their spouse when unwell, though a number of participants recounted situations that must have been truly terrifying. Two participants had experienced near death siege experiences in the context of their spouse being psychotic, and several Vietnam veteran wives recounted being on the receiving end of PTSD-related impacts. An example of this was being woken, being held in a head lock by their spouse who was experiencing combat flashbacks. Participants exchanged intimate communication with their spouse and were therefore privy to the full brunt of the person’s mental illness symptoms. This bond went beyond participants’ expressed empathy; it was enriching, engulfing, and sometimes traumatising.

It’s when they really feel exposed . . . it’s quite an honest thing on their part. At least it’s right there in front of you. There’s no escaping the strategies that they have. . . . It’s completely sitting in that fragility and at the same time overwhelmingly an act upon me as well. . . . In the act of not living the illness, and living the relationship instead, she supports me by having the relationship with me.

I've listened to his recounting of his past traumas so many times that I feel like I was there experiencing them too. They are a vivid part of my being, now part of my life history along with his. . . . Because you're inside that person's head and you've almost experienced, or you know the experience, through them. So you're very attuned to what impacts them.

All participants also expressed qualities in their relationships in ways that appeared to sound similar to any "ordinary" marital relationship, with its growth, partnership, trust, compromises, and challenges. Mental illness talk was absent largely from their comments.

It's that sense that we are fighting something together rather than fighting each other.

He stood up for me when things in my life were tough. No-one else ever did that.

We've had our ups and down, like anyone. . . . But, overall, we're still together, and I guess I've been depressed before. So we bounce off each other. I've come, through her, to understand my problems too. It's been a learning curve we've done together.

Only one participant appeared to be truly unhappy in her spousal relationship. However, she also seemed to weigh up her situation, not in illness but in relationship terms, as her and her husband growing apart as a couple. This weighing up of her situation was also evident in her response to then being asked what kept her and her husband together.

We're living life apart. The kids are the only thing that perhaps keeps us together. I suppose the love connection has changed. The caring part of me loves him, but he's not my friend anymore. . . . apart from the children, there's not a lot we have in

common. . . . you stay together because of the marriage commitment and because going out there looking again is so hard at any age once you've been married.

Subthemes:

Striving for the relationship - standing up to mental illness. Participants expressed dogged determination to nurture and protect the spousal relationship, in particular, to nurture their spouse's self-esteem in the face of often debilitating mental illness. They displayed this in a range of ways, through their determination to include the person in theirs and their children's lives. Others described their determination to see their spouse as a person, not as the illness, not to become "their therapist" or to "psychoanalyze" their problems, or think that they were solely responsible for fixing their spouse's problems.

I want this to be a relationship. This is what I signed on for. If I'm having a relationship then I've got to work the elements of the illness as well. . . . But if there's an edge of psychosis in it . . . I find I become stubborn, and unwilling to be sucked into the vortex. I'm kind of hanging onto the edge and going, "No, I won't go there".

There are times when you have to stand your ground and say, "This is what I need here" or, "this is the level that I'll put up with things, and one of us has got to make a stand". [During a paranoid psychotic episode] And I got to the point where I just said, "How dare you" and I gave him a piece of my mind and said, "One of us has got to stand up to these thoughts and tell them they are not right". It made him sit up pretty quick and think about not just succumbing to the thoughts. . . . It also let him know that we would fight this together, that he wasn't alone.

Participants also spoke about striving to maintain and nurture intimacy in their relationship with their spouse. Several participants did not raise the issue of their sexual relationship. This

might be because they did not see it as relevant, or because they were not asked about this directly. Some participants (particularly men) spoke about respecting their wife's needs, especially where their wife had experienced child sexual abuse. Others openly talked about this. In all comments, commitment to their spouse was prominent.

Because he's on medication, it's ruined those parts of our relationship to a degree and for us, my husband's a cuddly bear of a person so we find a way I suppose of being a couple; but there's no sex [laughs].

It's not so much the sex life that sustains our relationship, it's more of a friendship, companionship, being able to talk to one another about anything . . . that means the most I think in our relationship, and the fact that we enjoy each other's company.

Expectations, responsibility and navigating the boundaries of mental illness.

Many participants talked about making certain demands on the relationship with their spouse, as a relationship first and foremost, and navigating dependency and attachment issues with them to preserve what they could of the marriage relationship.

It's a balancing act, knowing when to just take it, and other times when you do sort of stand your ground . . . most of the time I can work out when he's just my husband and I can get away with nagging him, or putting a bomb under him to get him moving to help with jobs and join me and the kids in doing things. And other times when he seems to be struggling with his stress levels and that I can back off. But, there are things that I expect of him, because it's a relationship after all!

Attachment issues were very apparent, and participants recounted behaviours exhibited by their spouses that many of us can relate to within relationships of any kind. Some participants

used humor, such as one participant who said, “When I had my last child, my husband had the labour pains and the morning sickness”. All strived to create definitions of the impacts of the illness that were about relationships, not illness symptoms. This demonstrated their attempts to accommodate and to “live the relationship” in the face of circumstances where illness was seen to constantly try to overwhelm and envelope the relationship, as if they were railing against dependency by their spouse.

I’m careful not to do more than I absolutely have to because otherwise, it becomes that I don’t want to be the dominant one, and I don’t want him to be dependent either.

I think you do have expectations and when they’re not meeting them, and especially when they don’t want to seek treatment or those sorts of things, you can become quite resentful because you go, “Look, I expect you to be able to do certain things so therefore I expect you to do something about this and not stress me out”.

One downside of navigating relationship needs with the needs of the illness was that participants found they must always compromise in their relationship; that “one plus one equalled the spouse’s needs”. One participant found this process overwhelming, and they recognized how they had become “the one in charge”.

I got to a point in my life where I thought, “This is too hard. I can’t be his wife and his mother. I’ve got to be one or the other”. So I think I consciously dropped being the wife because it just complicates everything. I’ve let go of all of those expectations. . . . You can wish all you like but it’s going to be what it’s going to be.

Participants perceived themselves as the pivotal responsible person in the relationship, mediating the environment in which they and their spouse interacted with others, “shifting

life around the person” and believing that they were nurturing the relationship for both of them. This was expressed as an awkward position to be in, given the constantly moving nature of the relationship and illness. Their spouse’s attachment to them as “the anchor”, sometimes meant that their own identity and needs got lost in the needs of the spouse.

I feel that I’m carrying a higher load of responsibility in the elements that keep the relationship stable . . . but there’s a cost to me, to remain as the anchor. When I’m in that role, I’m in that role . . . if my mood swings and I’m sick, or if I’m physically sick, or not being the anchor and the rock, then that’s really disturbing to her.

If I get ill, he gets angry, upset and I end up wearing it anyway. I don’t get any support. I can’t get sick; that’s just not in the equation. . . . It’s like you’re inside them and they’re inside you . . . all I want is a bit of strength when I’m afraid. I have taken over the role of being, what do I say, in charge of taking care of everything.

Isolation – physical and emotional. Despite their commitment to their spouses, many participants described high levels of isolation and feelings of extreme aloneness, verging on dissociation and anomie that engulfed them, particularly when the person was more unwell; a deep distress as part of a central state of being. This created a sense of their lives being surreal. This was their intimate partner after all. They described continual emotional pressure that they carried with them through each day. No participants used the word “burden”. They discussed their circumstances and emotional wellbeing with candor and frankness, speaking openly of the emotional vacuum in which they found themselves, and the sacrifices they had made within and for the relationship with their spouse.

You have to carve out a life for yourself to some degree. . . . It's a lonely existence that takes a very strong juggling act to keep the dark side of it here beside us, and at the same time have a happy smiling face when you go out into the world.

It's like I'm a fly on the wall looking at life a lot of the time from a distance . . . when you're out and about, you can relate to people on the street but you don't have many people that are very close to you.

A small number of participants expressed dreams of an alternative life, though this was not described as resentment for the person. Rather, it was perceived as a desperate and distressed response to the pressure of extreme situations that they sometimes found themselves in when their spouse was unwell, and feeling powerless to help, with no way out.

At times, I just want to bloody run away.

There are times when things are so hard and so stressful with the barrage of his psychotic ideas and their impact on us all, and he's doing all the wrong things and self-sabotaging, that I just wished he didn't wake up. Watching him suffer is distressing, and I feel powerless to do anything.

Many participants also described a lack of emotional support from their spouse. These were tough, stoic people, often living solitary lives, who had developed an emotional sense of "going it alone". However, it did not mean they had come to terms with this emotional vacuum. On the contrary, it travelled with them through each day, surfacing as grief, anger, frustration and anomie at different points. Men participants, in particular, seemed to be adversely impacted and unable to seek comfort for their emotional needs from their spouse or

others. Participants also spoke about the altered spousal relationship once mental illness appeared. They described navigating a new path, but at the cost of also maintaining a sense of reserve which blocked their ability to share completely their hopes, fears and needs with their spouse. Ironically, this created a further sense of isolation and aloneness in the relationship, displayed as grief that could not be resolved because to do so would be to reject their spouse and what was positive in the relationship. This appeared to contribute to their surreal state.

I'd say that I live constantly with a sense of loss. . . . [When asked if his wife was aware of that] No. That's something that you have to keep in a very central place on your own. . . . [When asked if he shared that with his wife] I can't. If I shared that with her then that costs me a valuable part of the relationship.

How spouse carers cope and get their needs met. Participants provided many clues to how they cope and get on with their lives. Several participants used humor to make light of their situation, especially the women.

[Talking about the Vietnam veteran carers' group] For the DVA ladies who come along to our group, we get together and do a lot of swearing [laughs].

Men participants expressed coping styles that reflected the intensity of their emotional isolation. Compared with the women's narratives, the sense gained from hearing the men's narratives was that they were struggling, arguably more so than many women participants. They did not seem to have the networks of support from family or friends that many of the women had to draw on. They were very much alone with no-one to talk to about their experience, and did not seek others to talk to about their needs. Many men kept their experiences hidden from their peers and, in doing so, were even more isolated.

I just keep doing what I'm doing. I've learnt to shut down, to shelter a lot of things.

I love my work and I throw myself into it. . . . It's a way of getting out and just getting away and having something that's not thinking about this all the time.

Women, however, strived to find meaning and positive ways to get on with their lives; to self-nurture. They appeared to be more able to seek refuge within domestic tasks and routines and in their community; accommodating to their circumstances and not letting them subsume their individual identity or personal autonomy.

You have to value who you are, not as what you do. Some people I've met who are carers get so much down that track of losing themselves in the role that they are just living through that other person. . . .Like sometimes it's just nice to be able to do your washing or do your ironing. It sounds crazy but that puts a little bit of normality in your life, especially during times when he's not as well.

The implications for children. Twenty-one participants who reported having children were asked about their experiences of childrearing within the spousal relationship. They were not asked directly about the impact of mental illness on their children, because this was outside the study's scope. Many participants talked about feeling like both the mother and father for their children, especially when their spouse was unwell, and of being the emotional caretaker in the family, as shown by the first quote below. However, most of the time, they consciously strived for inclusiveness of their spouse in all aspects of family life. They expected their spouse to do what they could in the parental role, again standing up to the mental illness, as shown by the second quote below. They just got on with it, and perceived that their children did too. Participants described themselves as doing a constant balancing act between ensuring the welfare and care of children and the care of their spouse

and relationship. They did not raise any concerns about their children growing up in a household where mental illness was present. However, based on their self-report, almost one third of participants had children who went on to develop mental illness as adults.

[Describing her children] I often feel like I'm navigating a whole lot of their emotional development, and safety and security; making sure that they're emotionally well whilst navigating stressors . . . around the caring role, especially when my husband is delusional and psychotic; so looking after a whole lot of peoples' feelings.

Having a child made me more assertive . . . because the first time that he become unwell after we had our son I just turned to him and said, 'I'm not going through what I've been through previously. We have a child. You need to think about him'.

A different experience from carers of mentally ill adult children. Questioning participants about whether they saw their experience as the same or different from other mental health carers provided clues about how their experiences were unique. They had many varied views on this, but all saw it clearly as a different experience. Of note, this was an intimate chosen relationship, with expectations of emotional reciprocity within that intimacy that appeared to set their experience apart. It was also the difficulty of separating the "tasks" of caring that were perceived to be more straightforward with adult children or aging parents (such as help with cooking, shopping and budgeting), from the emotional expectations of being in an intimate relationship that set them apart from other types of mental health carers. This included the potentially greater manipulation of their feelings by their spouse, as shown by the final quote; whereas, they perceived that carers of adult children could draw more readily on using parental discipline and teaching their "child" to take more responsibility.

Absolute bottom line difference is that their roles, society and their personal obligations mean they almost have no choice in their caring role. I have a choice and I'm lucky. . . . There're lots of tasks to being a parent. Whereas, if it's a husband or wife you're less likely to have that distance that the task gives you because you have other things that you expect from them in the intimacy of the relationship.

Caring for an adult child who's actually functional enough to have a separate life means that they're at a distance from you. Whereas, if it's a wife or husband, because you're so much expecting and in an intimate relationship with them, what can you separate? To do so means loneliness in the relationship. I think if you started to pull away, then that would be the start of destruction of the relationship.

In summary, the spouse carers saw themselves as husbands and wives rather than as "carers". Their experience was situated within "a real and genuine relationship". First and foremost, they strived for the relationship with their spouse and accommodated mental illness into their lives to protect the relationship. Within this relationship, spouses often strived to keep the mental illness from dominating the relationship. This involved navigating complex and shifting expectations and responsibilities, continually creating spaces for nurture the relationship. Examples of this were creating normality for spouses through intimacy, childrearing expectations and routines. However, this striving also came with costs which meant spouse carers' lives often felt surreal, separating them from others as part of protecting the relationship. This stance was clearly different from experiences of carers of adult children with mental illness because to treat their experience as a caring "role" or "task" would undermine the legitimacy of the intimate relationship.

Discussion

This article provides an insight into how spouse carers make sense of their caring experience, within the context of their relationship with their mentally ill spouse, reflecting the complexity of their experiences and feelings. At times, they felt closer to the person cared for because they were standing up to the illness together; and, at other times, it left them in a surreal state. The complexity of this latter finding has not been articulated in previous carer research. These carers held an enduring commitment to their spouse, based on the central premise that this was a relationship first and foremost. Their actions were driven by their genuine commitment to the relationship rather than it being part of a role that they played as “carer”. Their views appear to be similar to those expressed by Erlingsson, et al. (2011) in their analysis of 31 Swedish articles on carers of people with chronic conditions. They reported that spouses perceive the caring role as emanating from their sense of love and duty towards their partner; to protect and nurture promises made within the relationship (p. 645).

However, the participants perceived clear differences between their experiences and those of other mental health carers. Jungmeyer et al. (2004) explored differences between caring for a spouse and for adult children, concluding that, “While the relationship between parents and grown-up children is often perceived as an indissoluble, lifelong connection, marriage or partnership is interpreted as a relationship” (p. 673). In our study, spousal relationships were subject to different conditions and expectations which, if not met, could be terminated. The participants were actively choosing the relationship with their spouse, and they had found ways to navigate the illness with the relationship, and this path had enriched the relationship. They accepted the limits within which the relationship existed, maximizing positive aspects and minimizing negative ones, using humor and making sacrifices for the relationship. Only a longitudinal study exploring the development of relationships over time, including the journey for spouses who leave their relationship, can truly tell us why some spouses stay and others leave. Our study provides clues for further investigation.

Another noteworthy finding is that, although male participants shared many of the positive and negative sentiments that female participants expressed, gender appeared to play a role in how spouses expressed their experiences. Men seemed less able to find support among peers, were more emotionally isolated, and many seemed to be ‘doing it tough’, with little support. They seemed less able to establish a dual existence to cope with their situation, and were often adrift as a result, finding it particularly difficult to juggle responsibilities at work and their caring role which they stated was not well understood at their work. This might be because of societal perceptions that caring is a woman’s role with men not expected to be carers (Treloar & Funk, 2011). Other researchers have found that gender differences do exist in how spousal carers feel and think about distress (Yee & Schulz, 2000) with women reporting more distress than men. However, our research suggests that men who are carers of a mentally ill female spouse might, in fact, struggle more with their caring role.

The participants spoke clearly of their expectations of their spouse. This was a relationship after all. Many participants expressed feeling that they had a stronger relationship with their spouse than that of other couples they saw around them. Loyalty and love of the person was central to their narratives, embodied within this relationship that they were actively choosing and in which their actions and beliefs were intentional (Liamputtong & Ezzy, 2005, p. 8). This was particularly apparent in their descriptions of striving against the illness. In their research involving spouses of people with schizophrenia, Jungmeyer et al. (2004) found that some participants interpreted mental illness as, “‘an emergency’ in which a mutual promise of solidarity was kept” (p. 672), as part of traditional views of marriage and commitment, and that the person cared for would do the same for them if the circumstances were reversed and the carer became unwell. Our participants reported similar beliefs.

In a study which looked at personal life strain, social relations, financial burden, and intrinsic rewards for spouse carers of people with chronic conditions, Baanders & Heijmans

(2007) found that impacts on the carer's life are profound. However, in another Netherlands study of spouse carers of people with schizophrenia, Angermeyer et al. (2006) found that psychological well-being and social relationships were negatively affected but overall quality of life was unaffected. Davis et al. (2011) found that loss of intimacy in the relationship had a significant negative impact on quality of life for those caring for a spouse with Alzheimer's or Parkinson' disease. Our article offers fresh insights into potential reasons why quality of life can remain unaffected despite the presence of severe mental illness, and that it is in fact enhanced for some spouse carers. The participants strived to nurture the positive parts of the relationship in spite of the illness and this likely contributed to creating a transformative process that brought couples closer together (Mahrer-Imhoff, et al., 2007). Eriksson & Svedland's (2006) study of four women with chronically ill spouses described a similar striving for normalization and the women's desire to be loved as a wife and not as a carer.

Feelings of burden and depression were not specifically identified by the participants. This might be because most described having high intimacy levels with their partners, in spite of mental illness and its negative consequences for their sexual relationships. Cormac and Tihanyi (2003) argued that professionals continue to ignore the topic of intimacy, sexual relationships and sexual health for carers. The participants' comments showed how intimacy, regardless of whether there was sex, was central to a successful spousal relationship.

Research on spouse caregivers of people with other chronic conditions offers interesting insights. Morris, et al. (1988) found that cares of people with dementia who experienced greater loss of intimacy had higher levels of depression (p. 231). This is important because, in our study, the participants' capacity to maintain and create high levels of intimacy with their partners seemed to protect their wellbeing. Williamson and Shaffer (2001) found that more depressed carers and those with less reciprocal relationships prior to arrival of illness were more likely to treat their spouse in potentially harmful ways and perceive their current

relationship as less rewarding. Tanji et al. (2008) found that greater mutuality between the spouse and their partner was associated with reduced carer burden, improved quality of life, and better mental health of both partners.

Eriksson & Svedland's (2006) reported negative impacts of caring being increased isolation, with positives being that illness brought couples closer together. We provide further clues to the nature of this experience, by clearly describing the surreal world that the participants created to maintain the relationship and stand up to illness. To understand this dichotomy (Wuest & Hodgins, 2011), we need to further understand the complex emotions that carers accommodate into their lives and how carers make sense of their carer experience, over time. Understanding this could also prepare spouses entering the caring role and inform better service provider support for mental health spouse carers. However, merely providing information and increasing carers' knowledge and skills in how to manage mental illness is likely to be inadequate in supporting spouse carers (Davis et al., 2011). The participants did not say they wanted more knowledge and skills to manage the tasks of caring. They said they wanted to be understood and acknowledged, and for the relationship to be acknowledged.

Limitations

Our research had several limitations that impact on the parsimony and completeness of the "relationship theory" proposed. Our research involved Australian carers. Snowball and convenience sampling mean that they could have been a relatively homogenous group not reflecting broader spouse mental health carers' views. The sample only included spouses in heterosexual relationships, even though it was open to spouses in homosexual relationships. Different recruitment methods might be necessary to capture their views. We addressed these concerns by ensuring that we captured views of carers of different ages, locations, length of time in the spousal relationship, and caring for spouses with varying types of mental illnesses. Another limitation is variation in length of relationship which might influence how spouse

carers perceived their situation. We also did not explore perceived quality of the relationship prior to mental illness (Davis, et al., 2011), nor did we explore cross cultural perspectives. Wong (2007) found that Chinese caregivers have a stronger tendency to maintain a longer-term commitment to caregiving than their Western counterparts.

Specific limitations were that fewer men than women participated. Further research with a larger sample of male carers, more purposefully recruited, would ensure saturation. We also missed the views of those not living with their spouse, whose spouse refused their participation, who might not have participated because of fear or for some other reason, or those who were an ex-spouse. Therefore, highly burdened spouses might have been excluded. These important aspects have not been researched and could provide further understanding about how to support spouse carers. Also, inclusion of veterans' wives might have skewed the sample because they have specific experiences influenced by their spouses' war experience, holding high levels of respect and loyalty toward their spouse because of that experience. We addressed this by limiting the number of veteran spouses in the sample.

Limitations with methods used were that we did not also include interviews with the person cared (Taylor & de Vocht, 2011). Another limitation was that spouse carers' experiences were collected via single interviews which, although long, meant only limited and single point in time reflections were collected. This was minimized by offering all participants the opportunity to check their interview transcript and correct or add further reflections (Liamputtong & Ezzy, 2005). A final limitation was the potential for us, as mental health spouse carers, to have biased the analysis. We addressed this through the rigor with which we continually reflected on the data during its analysis. These limitations have several implications for further research. Clearly, the views of spouses unable to remain in the relationship could be explored further, as could other subgroups of spouse carers identified above. In particular, further research with male spouse carers is indicated. Research with both

spouses and longitudinal research with spouses at different stages of their relationship is also warranted to help develop a more complete theory for understanding their experience.

Conclusions

This article has clearly described how caring for a spouse with severe mental illness, although challenging and complex, is viewed by spouse carers as belonging within a relationship rather than in a caring role, with love, loyalty and commitment as central emotions held by spouse carers. The central theme of “relationship” and subthemes provide theoretical beginnings for a more complete theory of their experience. Our findings have implications for how support could be tailored for spouse carers who might not identify with an “othering”, task-oriented focus of carers of mentally ill adult children. The centrality and intimacy of “the relationship” described here suggests that workers and services need to be mindful of the negative impacts of suggesting separations from mentally ill spouses, and of excluding spouses from decisions about the person’s care. These problems have been frequently reported by mental health carers generally (Mental Health Council of Australia, 2009).

Exclusion of spouse carers also has serious implications for how policy is developed and practiced, and for the health and wellbeing of spouse carers and their children. These implications include how spouse carers are identified, and whether their risk of developing chronic physical and mental health conditions is also identified and responded to. From our collective experiences we know that, for many people with mental illness, their relationships often fail as a consequence of the mental illness and the challenges it poses for their intimate relationships longer term. Staying in relationships often involves the spouse having extraordinary resilience, commitment and love for the person. Service providers have a role to play in being aware of the importance of the relationship for spouses and the cared for person. This can then inform how they might provide more effective information and support to families, especially to male spouse carers.

Acknowledgements

We thank the participants for their contributions to this study. We also thank our husbands for inspiring us to undertake this research.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and or publication of this article: This research was funded by a Flinders University Faculty of Health Science Seeding Grant.

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Bios

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