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What carers of family members with mental illness say, think and do about their relative's smoking and the implications for health promotion and service delivery: a qualitative study

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Abstract

Introduction: Few researchers have explored family carers' perspectives of smoking by their family members with mental illness, despite smoking rates remaining high for people with mental illness.

Methods: In-depth qualitative interviews with twelve South Australian family carers explored their experiences and views of providing care for people with mental illness who smoke.   Data were analysed thematically.

Results: Around the central theme of the caring role within the context of mental illness and smoking, were three interrelated themes: 1) responsibility; 2) accommodation; and, 3) dissonance. Carers struggled physically, philosophically and emotionally with perceived responsibilities involving their family member's smoking. They felt isolated and asserted there was limited support from service providers to assist them.

Conclusions: Carers are important agents within the person's immediate environment who could potentially help them to improve their smoking cessation success. Community services aiming to support smoking cessation support for this population need to incorporate the role of family carers.

Keywords: family carers, mental health promotion, responsibility, smoking, tobacco

1. Introduction

Tobacco smoking does considerable harm to those who smoke and the community (US Department of Health and Human Services, 2010). Over the past 40 years, smoking cessation strategies have assisted in halving Australia's overall smoking rates to 15.1% (Australian Institute of Health and Welfare, 2011). Despite this success, smoking remains a significant cause of death and disability in Australia.

People with mental illness smoke a third of all cigarettes sold and collectively account for more than a third of all smokers (Access Economics, 2007; Gfroerer, Dube, King, Garrett, Babb & McAfee, 2013; McManus, Meltzer & Campion, 2010). Since 1999, smoking rates have remained high at 66 per cent for people with psychotic disorders (Cooper, Mancoso, Borland, Slade, Galletly & Castle, 2010; Morgan, et al., 2012). People with mental illness die 13-30 years earlier than people without mental illness and smoking is an important contributor (de Hert, et al., 2011; Galetly, et al., 2012). Smoking is an increasing cause of health inequalities among disadvantaged groups (NICE, 2013). Research has shown that people with mental illness who smoke can spend a quarter to over a third of their income on cigarettes (Lawn, 2001). The question of whether these statistics mean that people with mental illness constitute a 'hardened' population who will increasingly continue to smoke, continues to be debated (Gartner, Scollo, Marquart, Mathews & Hall, 2012). Existing research confirms that people with mental illness prefer lifestyle health promotion information sources that they consider reliable and accessible, from people they already know, such as health care providers, family and friends who offer support and encouragement (Kemp, Fisher, Lawn, Battersby & Isaac, 2014). However, several assumptions (by workers and smokers with mental illness, and anecdotally by carers) about smoking and mental illness have contributed to a lack of effective smoking cessation support for people with

mental illness. These include the belief that: 1) smoking is necessary for self-medication of mental illness, 2) these smokers are uninterested in quitting, 3) they cannot quit, 4) recovery from mental illness is impeded by removing smoking as an important coping mechanism, 5) smoking is the least of their worries, 6) supporting smoking cessation is not the role of mental health workers, and 7) attempts to quit will lead to illness relapse and increased risk of aggression towards others (NICE, 2013; Lawn & Campion, 2013; McNally, et al., 2006; Prochaska, 2011). However, there is strong evidence that people with mental illness who smoke want to quit smoking and can quit with adequate supports (Ashton, Miller, Bowden & Bertossa, 2010; Solway, 2011). There is also now clear evidence that their mental health improves once they have quit smoking (Morris, Waxmonsky, May, Tinkelman, Dickinson, Giese, 2011; Shahab & West, 2009) and does not increase aggression towards others (NICE, 2013).

What role might family carers play in supporting smoking cessation for this population?

Family carers make up a significant population of people who provide regular and unpaid support to family members or friends who need help with daily activities because of illness, disability or frailty (Australian Bureau of Statistics, 2008a). In Australia, about 2.7 million people identify as family carers (12% of all Australians)(ABS, 2013), though the number of mental health carers is unknown. Given that 20% of the population will experience a mental illness, it is likely that mental health carers represent a significant proportion of the carer population. It is estimated that mental health carers spend, on average, 104 hours per week providing care (ABS, 2008a).

Many researchers have examined smoking behaviours within mental health settings from the perspectives of health professionals (Ashton, Lawn & Hosking, 2010;

Lawn & Campion, 2010, Lawn & Pols, 2005; Wye, et a., 2010a; Wye, et al., 2010b) and patients (Ashton, et al., 2010; Solway, 2011). However, people with a mental illness spend most of their lives, at home and in their community and many either do not access clinical mental health services or only access them intermittently (Lawrence, Lawn, Kisely, Bates, Mitrou & Zubrich, 2011).Therefore, the family interpersonal social environment of smoking for this population needs to be better understood. More broadly, Moriaty, Stubbs, Bradford, Tapper and Lim (2011) explored resilience in families living with addiction and found that they play important roles in attracting and engaging the person into treatment and fostering supportive environmental change, but that they lack awareness of available resources and fear social stigma and therefore tend to adapt negatively, under adversity, to the person's drug use.

To date, there has been little attempt to understand how mental health family carers understand, experience and respond to the smoking behaviours of those they support. Furthermore, the potential for them to support smoking cessation has not been examined previously. Carers are important agents within the person's immediate environment who could potentially help them to reduce their smoking and improve their smoking cessation success. Understanding their experiences, perceptions and capacity could also inform community and public health approaches to smoking cessation support practices for this population.

A comprehensive search of databases (Scopus, Proquest Central, Sage Journals, PsycINFO, PubMed, Expanded Academic Index ASAP, Informit, Web of Sociological Abstracts), grey literature, government websites and Google Scholar Keywords included 'mental illness', 'mental health', 'smoking cessation', 'tobacco', 'carers', 'family carers' and 'caregivers'. Identified abstracts were further scrutinized for more

keywords to ensure that no relevant literature was excluded. Searches included literature published 1980-2013, and written in English.

The literature search revealed only one small qualitative focus group study from New Zealand (Missen, Branelly & Newton-Howes, 2012) which explored family/*whanau* (Maori extended family) perspectives of smoke-free mental health and addiction services. The study included six participants in one geographical region of New Zealand. Seven themes were identified, including barriers such as lack of coordination and consistency with implementation of smoke-free policy, limited consultation with family/*whanau,* and inconsistency between mental health and general health smoke-free policy. Smoking was seen as a way of coping with stress and anxiety; though participants also identified a need for other activities and strategies to replace smoking in the lives of people with mental illness. The study recommended providing information to family/*whanau* and those with mental illness to help dispel assumptions and stigma associated with smoking and mental illness, as well as involving families in smoke-free initiatives. Its acknowledged small sample size was a significant limitation. It confirmed families' lack of inclusion by services (Mental Health Council of Australia, 2009; National Mental Health Commission, 2013). However, the researchers did not examine family carers' everyday experiences and responses to smoking and mental illness.

Following this review, our study's aim was to seek a better understanding of family carers' experiences and views, and the meanings that underwrite these; what they know, think and do about smoking.

2. Method

2.1 Participants and Recruitment

All participants lived in metropolitan or regional South Australia and were recruited via advertisements in electronic and hardcopy newsletters distributed through carer organisations, flyers placed on public notice boards at shopping centres, libraries and community centres, or by snowball sampling methods to ensure a cross-section of family carer types were recruited. These combined measures served to encourage twelve people to volunteer to be interviewed. Those being cared for were all current smokers according the nationally agreed definition: having smoked at least 100 cigarettes in their lifetime (ABS, 2008b), with participants estimating smoking ranged from 15-50+ cigarettes per day. All participants were Anglo-Australian family carers, aged from 30-82 years. Seven participants were caring for an adult child, three were caring for a spouse, and two were caring for a parent with mental illness. Nine participants were female. Length of caring role was 5-60 years. Three of the families included in the study were caring for two family members who smoked. Two participants were a married couple who shared the caring role for their child; they were interviewed separately. All participants had regular face-to-face contact with the cared for person.

Family members being cared for included nine males and five females aged from their late 20s to early 60s; eight were carers' children, two was a carer's husband, one was a carer's wife, one was the carer's mother and one was the carer's father. Diagnoses included schizophrenia, bipolar disorder and depression. Of the fourteen smokers being cared for, , nine lived in the family home, one lived in an adjoining unit to his parents, one moved between his parents' homes, one lived in supported residential accommodation and two lived independently.

2.2 Interview Content

We chose a qualitative methodology and used face-to-face, in-depth semi-structured interviews. This approach left room for participants to describe and reflect on their views and practices, raise new issues and take the interview in new directions that were meaningful to them. According to the literature, carers often feel disempowered in their roles (Low, 2007), so this style of interviewing was chosen because it has been used successfully and ethically with similar groups, can be cathartic for participants and aid the development of trust and rapport during the interview (Liamputtong, 2009). Open-ended questions were developed from the literature to address the exploratory nature of the project and the aims outlined above. Interview questions included the following:

Background/ Context Questions:

- Who do you care for?

- How did the caring role come about?

- How long have you been caring?

- How does your caring week unfold?

- What did you do before this role?

Family Carer/Smoking History, Experiences and Knowledge Questions:

- Tell me about your smoking history

- How do you view your own smoking behaviour (if relevant)?

- What experiences have you had in stopping smoking (if relevant)?

- What is your attitude to others smoking?

- What do you know about the risks of smoking?

- What do you think about people with mental illness smoking?

Cared for Person/ Smokers History Questions:

- How long have they been smoking?

- What was the reason they started smoking?

- Why do you think they continue to smoke?

- Have they attempted to quit smoking and if so what was the outcome?

- What do you believe are the barriers to quitting for the person you care for?

- What would assist them in quitting?

2.3 Data Collection Procedures

Interviews were undertaken in places convenient to participants—usually their homes—and lasted for between one and two hours. Reflective field-notes were made directly after each interview, capturing additional contextual information including non-verbal behaviours (Emmerson 1995; Liamputtong, 2009). All the interviews were audio-recorded, transcribed and returned to participants who checked for accuracy and contextual meaning, providing them with an opportunity for further reflective comments. The first seven interviews were undertaken by LF and the final five interviews were undertaken by SL.

Ethics approval 6074 was provided by the Flinders University Ethics Committee. An information sheet was provided, and signed voluntary consent was gained from all participants. A small honorarium was provided to all participants. Details of free carer support services were provided as part of interview debriefing.

2.4 Data analysis

Thematic analysis was used to report patterns within the data, using Braun and Clarke's (2006) six phase process: familiarising oneself with the data, generating initial codes, searching for themes, reviewing themes, refining and naming themes and producing the

report. Interviews were audio-taped and transcribed verbatim to ensure immersion in the data. Each of the first seven transcripts was read and re-read independently by each researcher, who then independently manually open-coded them to identify data features that seemed interesting and meaningful. Examples of open codes were: 'smoking is their choice' and 'carer concerns'. Codes evolved, following critical review and discussions between the researchers. SL then coded the remaining five interviews based on the research team's agreement on the preliminary coding structure.

Mind maps (a graphical technique for visualizing connections between ideas – Liamputtong, 2009) were used to assist the researchers to understand relationships and patterns in the data, as well as providing an overall conception of the results. Interview notes and reflections were incorporated into all stages to improve reflexivity and interpretive rigour. We were also acutely aware that all three authors are or were carers of family members with mental illness. This influenced the design by our recognition that the study topic might be a sensitive issue for family carers and, therefore, interpersonal methods (interviews) would be a suitable method for eliciting their experiences and views of smoking and mental illness. As mental health carers, we were cognisant of the need to be highly reflexive during data analysis and in drawing conclusions. To achieve this, we met routinely to discuss and debate the meaning of the data, presented the preliminary findings to a South Australian community carer forum (April, 2014), and presented our preliminary results at a national scientific conference (August, 2014) where feedback confirmed the strength of the themes. Final analysis involved the researchers meeting to determine and write-up a coherent logical story that incorporated meaningful extracts of participants' words to demonstrate each idea within the themes. Data saturation was perceived to be clearly reached once seven interviews had been conducted, as agreed upon by all research team members. To help verify this,

and due to concerns about the sample being biased towards female carers caring for adult children with mental illness, participants representing further types of family carers (spouse carers, child carers of parents) were sought. This did not substantially change the final coding structure; rather, it reinforced and gave further strength to the final themes.

3. Results

The most significant theme that underwrote the participants' responses and perceptions was the nature and scale of the caring role within the context of mental illness and smoking. We also identified three inter-connected sub-themes in carers' reflections on the smoking practices of their family members; namely: 1. Responsibility; 2. Accommodation and; 3. Dissonance. These are explored in more detail below.

3.1 Main Theme: The Nature and Scale of the Caring Role within the Context of Mental Illness and Smoking

In order to understand how participants experienced and responded to the cared for person's smoking, it is necessary to understand how this occurred within the broader context of their caring role. Participants described this role as providing constant and ongoing support for their family members. They identified the episodic nature of mental illness, the stigma and discrimination that surround mental illness and responses of mental health services as clear stressors. While participants gave examples of excellent and supportive relationships with service providers, most talked of experiencing disappointing and frustrating relationships, and of being perceived by some service providers as part of the problem. This made them feel isolated and alienated. Most participants said services were limited or non-existent or not useful for them or their family member, leaving them solely responsible for managing the family member's

mental health needs – including smoking cessation.

Some participants spoke about the caring role as a 'roller coaster ride', negotiating the changeable nature of mental illness. They spoke of having to be constantly vigilant to signs of declining health of their family member even during periods of wellness. As such, stress levels remained high, often resulting in emotional exhaustion. It was within this context that participants described how they had developed skills and strategies to respond to their family member's needs (including smoking), experiencing times of confidence but also times of self-doubt, inadequacy, uncertainty and ambivalence. All participants spoke of the ongoing responsibilities of caring, which entailed managing the competing emotional, physical and psychological needs of their family member with other aspects of everyday life such as family, finances and their own wellbeing. Notably, all participants managed their family member's smoking behaviours in similar ways to their other caring responsibilities. They commonly described three main strategies: establishing routines, short term planning and maintaining balance in daily lives.

3.1.1 Routines

Participants expected that smoking by their family member would continue. As a result they developed organised routines around smoking and smoking resources, which provided stability in a potentially changeable setting. This was how participants could demonstrate being 'responsible' carers; a key perceived aspect of their caring role.

3.1.2 Significance of Time

Participants managed tasks by not looking too far ahead. This was most likely due to the fluctuating wellness of the family member and constancy of caring. They spoke about the absence of energy required for future planning and the need to focus on 'one

day at a time', on what actions could be undertaken 'now and today', such as short timespan tobacco distribution routines that helped get from one point of stability to the next.

3.1.3 Maintaining normalcy

Most participants strived for balance in the everyday lives of their families, which they referred to as creating 'normal lives. However this aspiration was hindered at times by the stigma and discrimination associated with mental illness that they experienced and played a major role in impeding relationships with other family members and friends as well as connections to and engagement within the general community. Consequently, participants often spoke of actively monitoring their family members' behaviours to ensure they appeared 'normal' to others. For example, despite being aware of the harms, some participants purchased tobacco to stop their family member's picking up cigarette butts from the streets or out of garbage bins.

3.2 Theme 1: Responsibility - Carers

Many participants spoke of being solely responsible for all their family member's needs. This appeared to establish a clear context of isolation from outside supports in which they also felt solely responsible for responding to and managing the cared for person's smoking behaviours. Jennifer spoke clearly and strongly about how, with her husband, she cared for her two adult children, 'both of whom still depend solely on my husband and myself for their daily support'. Participants spoke strongly and with emotion, describing how they managed the stresses and demands of caring with minimal and sometimes no other supports. For example:

You don't get any support when they live at home. You get even less now, like case workers or support [...] I think they think they live at home and they [the family carers] can look after them (Nicole).

I seem to be taking her to doctors and getting tests for this and that, for cardiac and respiratory scans. And the doctors say it's the smoking but none of them seem to offer any ideas for helping her to stop the smoking other than telling her, and even then, I think some of them see the diagnosis of mental illness and don't even bother doing that (Ted).

All participants spoke of constantly juggling their caring roles and responsibilities which included organising appointments, controlling finances, undertaking domestic duties, providing transport and always being available as emotional support. Managing smoking activities were an extra, often demanding and complicating addition to participants' already considerable caring responsibilities.

3.2.1 Routines and smoking

Routines were seen as a very important strategy for establishing structure and order to the day. This practice was also used with smoking. Participants actively regulated, monitored and managed the habit and routine of smoking, while at the same time juggling their many other caring roles. For example, Beau described how she organised and regulated the cigarette supply on an hourly basis for her son as follows: 'He'll walk in the door, he'll give me his packet of cigarettes and I will give him one every hour'. Ruth described a similar rationing routine, one that was reinforced by mental health staff while her son was in hospital:

We used to help him ration his smokes because you'd get to 3 days before payday and he would run out of money and there'd be no smokes left and it was awful. And we used to say 'Why don't you smoke less and have just some each day?' and we used to actually count them out for him…He did really well with that for a

while and then he went back into hospital and, one time, he had a really good nurse who would bag up his packet of tobacco and give him an allowance each day.

3.2.2 Control resisted

Most participants' spoke of difficulties, stress and constant pressure associated with controlling and regulating smoking behaviours. Beau explained how her family member 'pushed against' the routine, making it 'hard' to maintain and 'time consuming'. She said:

> [It's] distributing them but in the short term, that's hard and it's time consuming, drives you mad, so my son's pushing the envelope, pushing the envelope to get back to half an hour. He's really pushing. I say, 'Excuse me, no son, it's been half an hour [for his next cigarette]; it's not an hour yet.

Importantly, all participants said that being 'the responsible person' for imposing or trying to impose routines that regulated tobacco use had resulted in family relationships tensions. Nicole spoke about being frustrated and upset when she had endeavoured to limit her family member's cigarette intake, with the family member undermining her efforts:

> I try to keep the relationship without yelling and sometimes I lose it and yell and scream, but it doesn't do any good. And I've thrown packets of cigarettes in the bin, but she can just go and buy another packet.

3.2.3 Capacity

All participants said their family members did not always have capacity to make responsible decisions. As a result of this framing, they felt the need to step in and take responsibility. Nicole judged her family member as vulnerable and lacking capacity because she did not think about the consequences of her smoking: 'I think a person with a mental illness doesn't register what it is actually doing or how bad it is ... Mental

illness doesn't make people realise the consequences of some things'. Brett described

his aging father as no longer having the capacity to smoke safely as well as the inherent

fire risks associated with this:

> Dad has lost touch with a lot of people and prefers to just stay at home now. I have
> to make sure that he doesn't smoke in his room. We have a spot out the back where
> he sits and I usually sit with him to make sure he doesn't drop his smokes on his
> clothes or fall asleep with a lit cigarette in his hand.

3.3 Theme 2: Accommodation

Participants described the duality of their caring role, as a meaningful activity that gave

them a sense of self-worth on the one hand, while also viewing it as work that involved

managing and balancing responsibilities and tasks on the other. This involved making

continuous adjustments or accommodations in response to the requests, expectations, or

demands placed upon them by their family members. Participants spoke about

weighing up and prioritising responsibilities which included managing the person's

mental health, tobacco use, and other health conditions; every day matters such as

cleaning, shopping and family events; maintaining 'normalcy' and the continuing

impacts on other family members. Addressing the person's smoking was but one part of

a larger set of issues and tasks that participants needed to consider, strategise and

juggle.

All participants accommodated smoking behaviour into their caring

responsibilities by prioritising the family member's smoking, focusing on day-to-day (in

some cases hour-to-hour) routines that ensured supply and distribution of tobacco to

their family member, over actions that could have reduced and/or stopped the smoking

behaviours. Some of these routines were also aimed at maintaining a certain level of

smoking as a ways to ensure this did not increase (cigarettes ever hour as opposed to

ever ½ hour). These accommodations reached into almost every aspect of their lives and impacted on finances, quality of quiet times, living spaces within the home and the participant's own energy levels and self-worth and relationship with the family member they cared for. Yet, they continued to maintain habitual and often elaborate routines that supported smoking: As Beau explained:

> I'll leave eight cigarettes and then I'll put the packet somewhere and if he runs out,
> he has to ring me and I have to tell him where the packet is, if I feel like it,
> depending how soon I'm going to get home.

3.3.1 Prioritising 'normalcy'

Participants devoted significant energy and time to striving to maintain 'normal' smoking behaviours such as limiting the amount of cigarettes the cared for person smoked and ensuring that their cigarette butts went in the bin. Jennifer set up a smoking reduction method to stop her son from chain smoking a hundred cigarettes a day. She explains:

> At one point with the younger son I actually was desperate and I got a box and I
> filled it with cigarettes and I wrote a time on the envelopes ... his cognitive
> impairment is quite severe and on the front of the envelope I wrote the time he had
> to have that cigarette and I put one cigarette in each envelope and it was every half
> an hour.

3.3.2 Unquestioning actions, making allowances

While participants were concerned about smoking and understood the risks, they spoke unquestioningly about how they accommodated smoking. Anne regularly cleaned her son's home, but did not question his smoking in the same space as she carried out housework: '... like our son smoking when we're in his place cleaning; it's his house, he keeps on doing what he wants to do'.

3.4 Theme 3: Dissonance

3.4.1 Knowledge of harms of smoking to health

When participants were asked what they knew about the health effects of smoking, all directly linked smoking with developing cancers, respiratory and heart conditions. They provided many examples of family members who had smoked and developed health conditions and suggested that it was a foregone conclusion that their family member who smoked would also develop health problems. As Jennifer explained:

My grandfathers died; one of lung cancer and one of a lung disorder, and ... my father although he didn't have cancer he developed emphysema ... so I'd be very surprised, especially if the oldest son didn't develop a cancer related disorder

Dissonance refers to the discord between knowledge and action. In this study, participants appeared to know the health risks of smoking, but maintained their habitual routines of purchasing, distributing and enforcing rules and limits around the smoking behaviours of their family member despite this knowledge. Ruth described how she and her husband helped their son to smoke, perceiving that he needed their assistance:

> When he came out of hospital one time, my husband used to roll his rollies for him because his hands were too shaky with the medication and I thought that was pretty incredible, not that we agreed with smoking, because neither of us have ever smoked.

However, participants simultaneously expressed feelings of despair, frustration and anger about this and the person's smoking. They appeared to be 'torn' by these dissonant feelings and yet unable to do anything to change their situation.   Susan described her husband's smoking situation as follows: 'I feel completely powerless to do anything. I just stand by and watch him slowly killing himself. I worry about it all

the time and the physical health things now'.

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3.4.2 Autonomy and the right to choose to smoke

Another standout response from all participants was their assertion that a person has a right to choose, to smoke, cease or not smoke at all. This speaks to a strong cultural trope in Australian society that recognises and celebrates the autonomy of the individual and a particular kind of egalitarianism commonly seen in notions of equity, the 'fair go', and in contemporary Australian nationalism (Kapferer, 1988). This response can also be read in other ways. It is possible that highlighting the right to choose was a way of explaining and possibly justifying carers' roles in supporting the continuation of smoking and, for some, in asserting quitting smoking was up to the individual and as such, not part of the carer's responsibilities. For example, Anne explained how she managed her family member's finances to ensure an ongoing supply of tobacco but clearly saw quitting smoking as the responsibility of her son: 'I really feel it's up to him. He has to do it himself. He has to make the decision, like with anything else'.

Dissonance was also evident in participants' descriptions and justifications of their actions through the idiom of respecting their family member's right to choose; in this case, to choose tobacco smoking. Smoking was seen as a personal or lifestyle choice and it was the person's responsibility to decide whether to smoke or not. The language of drug dependence was less evident in interviewees' responses. This emphasis on choice appeared to involve a desire to prioritise or respect the person's autonomy. Interestingly, this sat alongside participants describing at length, how they regulated, surveilled and controlled most other aspects of the person's life, including in many cases their smoking or access to tobacco. One the one hand there was the

importance of normality, autonomy and choice; on the other, carers described practices that suggested family members did not have full capacity to make informed judgements for themselves and these were taken up by their carers. Also of note, participants commonly perceived assistance with quitting smoking as the health services' responsibility, particularly mental health services. As Jenny explained:

> The only way there's going to be ever a reduction even in the amount they smoke, is for them to have another activity to do during the day, and so to me that is what mental health services have to handle. They have to work out ways to overcome this idea that they are difficult to engage and try to overcome those barriers, to engage them in things, so that they can't smoke all day, can't smoke as much as they do.

On the issue of choice, Ruth stated, 'Yes of course they choose to smoke'. However, her further comments demonstrate that she was not completely committed to this stance and that service providers also had an important role to play:

> Some good education would be good…and not just one a year from the quit smoking service people would be good, but also from people in the inpatient units and in the community health; to be something that was part of what they [mental health services] have to do…And this, 'It's got to be their choice' all the time; and it makes you sick. And we'd say 'Why don't you ask him about his cigarettes?' and they'd say 'Well he's got to ask' and we knew he never would ask them.

Of special note, all of the carers described lives that were highly stressful and severely overburdened and it is possible that comments such as these speak to a need and an expectation for greater support with regards to smoking and smoking cessation from health providers and services. In addition, some participants took the advice of health professionals who viewed smoking as a 'lesser evil' than other addictions or issues faced by their family member. As Anne explained:

His psychiatrist says also that he's talking about cutting back drinking and taking drugs and I think he's saying put smoking on the back burner so his psychiatrist is saying it's not as important as the other things, we'll deal with that later.

Here the health professionals are focusing on what they perceive to be the bigger issues and this is not unlike the carers in this study, many of whom suggest getting through the day is in itself an achievement.

3.4.3 Smoking is what I do

Common reasons and justifications participants gave for the person's smoking were that it relieved loneliness, was something for them to do every day, and filled a vacuum created by a poor quality of life. Consequences of mental illness combined with lack of meaningful activities highlighted to carer participants 'how little is available in the way of work or other meaningful activities' and 'how society has let these people down'. Consequently, Jennifer spoke about how her son saw smoking as his job: 'You know he might meet someone who says, 'what do you do?' And he'll just stand there and look and he's actually said, 'I smoke' '. With little else available to occupy his time or stimulate him, Jennifer's son provides considerable insights into his life when he observes that what he does, his 'work', if you like, is to smoke.

4. Discussion

This study is the first in Australia to explore family carers' experiences and perceptions about smoking by family members with mental illness. Taking a qualitative approach, it explores family carers' experiences and perceptions, in order to gain insights into what they know, think and do about smoking, and to understand their capacity to potentially assist their family members to give up smoking. The study goes well beyond Missen et al's (2012) findings, to describe the dilemmas family carers face when supporting a

person with mental illness who smokes which involves responding to competing needs, obligations and tensions within the caring role. These dilemmas included balancing the family member's autonomy and right to choose, and the carers' desire to respect them as a person ('individual'), with their perceived responsibility of caring for the person's health and well-being on a daily basis as well as expectations about health services.

The overwhelming response from all participants was that they 'could do no more' to stop the person's smoking despite knowing the harms of smoking to the person's health. Participants spoke of relentless, ongoing and competing demands, pressures and expectations of care. This left them with little energy or time to focus on planning ahead, to deliberate about the health consequences of their actions which maintained smoking behaviours or to think about their own needs. Participants appeared to be overwhelmed and wholly consumed by the caring role, which in every case included accommodating the management of tobacco supply. This resulted in participants being 'pulled' into the 'habit' of smoking where they often did everything involved in smoking apart from actually smoking the cigarettes. They also expressed feeling overburdened with the responsibility of tobacco management and the tensions this often created between them and the smoker. Within this context, and in the notably absence of health service support to address the person's smoking, participants felt demoralised and isolated and were resigned to continue maintaining current routines and strategies which also supported and reinforced the person's smoking.

Care work is a complicated role, undertaken in the privacy of homes among people who are related by marriage or descent. In their study of managing chronic illness at home, Corbin and Strauss (1988) described the unending work of care, using the term 'accommodation' to describe the day-to-day struggle to keep a sense of balance and meaning to the caring role; balancing one need over another. In this study,

accommodation was clearly evident in the way participants responded to the person's

smoking, while also balancing the stress and strain of the caring role and the impact that

smoking had on family relationships. Participants spoke of wanting a break from the

stress of managing smoking behaviours and yet, at the same time, feeling the weight of

responsibility and commitment to help meet the person's immediate needs. The

complexity of the role is increased further when one considers that those cared for are

adults, not children. This raises issues for mental health recovery such as the importance

of striving for independence, autonomy and dignity versus the need for support (Borg &

Davison, 2008). Our participants were torn in their values, knowledge and actions,

which appeared to then impact on their sense of burden and feelings of powerlessness to

effect health promotion for the person they cared for. In this context also, Moore and

Gillepsie's study (2014) provides interesting insights into what they call 'the caregiver

bind'; that, 'caregivers try to protect the care-receiver's identity by concealing the

extent of informal care provision, with the unintended consequence of undermining the

prospects of the caregiver receiving positive social recognition for the challenging work

of caregiving' (p.102). This was demonstrated by our participants as part of ensuring

cigarette supply to avoid other more adverse consequences for the person, like public

begging or picking up butts in the community, or financial support to ensure their

community tenure (for example, paying utility bills on time).

Orford, Velleman, Copello, Templeton & Ibanga's (2010) extensive research on

experiences of family members living with a relative with drug and/or alcohol addiction

offers clear parallels with experiences recounted by this study's participants. These

include the experience of hopes and dreams that had been invested in an important

relationship 'going wrong', uncertainty and worry about their family member, the

family member not actively taking part in family life and conflict over money. Orford et

al.'s (2010) stress–strain–coping–support model provides a useful framework to explain participants' responses. Like the participants in Orford et al.'s (2010) research, our participants coped by accepting smoking and maintaining tobacco use; 'putting up with' smoking through resignation and accommodation of it into their daily life (see also Orford, Velleman, Natera, Templeton & Copello, 2013).

Participants appeared to be 'torn' by their dissonant feelings and yet unable to do anything further to change their situations. Clarke (2005) argues that many of today's government policies aim to produce the ideal citizens; that is, people that are, 'moralised, choice making, self-directing citizens' (p. 451). Under this form of government, the ideal person is a responsible citizen who makes reasonable, rational choices. Therefore, bad choices result from wilful and irresponsible people rather than the distribution of resources, capacities and opportunities that influence health.[24] Mol, Moser and Pols (2010) similarly argue that today's society is characterised increasingly by the importance of the individual, autonomy, responsibility and choice; the idea that individuals should be responsible for their own health. Critics of this conservative stance (Bell, McNaughton & Salmon, 2011; Petersen, 1996; Petersen, 1997) point out that emphasis on individual responsibility for health not only blames people for ill-health, it effectively renders invisible the political and economic conditions that produce 'risk' behaviours and ill-health in the first place (e.g. poverty, bad housing conditions, industrial pollution, racism, lack of services). It lets governments 'off the hook' regarding their responsibility for providing adequate services and health promotion for the population in general (Bell, et al., 2011). This moralistic emphasis on individual responsibility is played out in the community with the lack of adequate provision of health promotion services and support to those with the greatest needs, such as people with mental illness who smoke and those who care for them.

These results demonstrate that, when structural supports are absent and when society and services are not playing their part in 'taking responsibility', people resort to coping in a variety of ways. Schultz, Finegan, Nykiforuk & Kvern (2011) state that responsibility becomes distorted when smoking is viewed as a morally interpreted behaviour, a 'lifestyle choice,' rather than an addiction that requires support. Many researchers have stated that if smoking is framed as an addiction, then service providers may be more inclined to become involved and provide treatment for withdrawal symptoms (Bell, et al., 2011; Lawn & Pols, 2005; NICE, 2013; Prochaska, 2011). Had participants chosen to view smoking as an addiction, coupled with the absence of adequate support services, there would be risks in adding the responsibility for providing smoking cessation support to already over-burdened carers.

Several studies of carer burden suggest that support programs should focus on the well-being of family carers, carer strengths and empowering approaches to encourage carers to redefine their lives beyond their caring roles. Jones and McCrae (2007) argue that carers are best supported by routine contact and trusting relations with service providers so that they do not feel isolated and solely responsible ultimately for care. Providing information, involvement in care planning, and acknowledgement of family carers' roles and expertise would assist in reducing these perceptions.

5. Conclusions and Implications

Study findings have clear implications for how services could respond, how family carers might be engaged and supported to be involved collaboratively with services providers attempting to offer smoking cessation support, and directions for tobacco control policies and smoking cessation support generally.

The need for health services, particularly mental health services, to do more to address smoking for people with mental illness and adopt a smoke-free policy within their care environments is now an internationally recognised imperative (NICE, 2013; RCP, 2013).This includes the need for consistent diagnosis, documentation and treatment of nicotine dependence to conform to established clinical practice guidelines (Wye, et al., 2010c). This response needs to occur across the full spectrum of community and inpatient care environments to ensure consistent support and to comprehensively address the cultural reinforement of smoking within this sector (Lawn & Campion, 2010). The results of this study demonstrate that this response must acknowledge and support the important role that family carers can play, and must support the carers themselves.

Orford et al. (2010) propose five steps that service providers could take to assist family members. Here we have applied these to carers of smokers with mental illness:

(1) Give carers the opportunity to talk about the problem and vent feelings;

(2) Provide relevant information about smoking and related issues;

(3) Explore how the carer responds or copes with the situation, what they may be able to do differently, and the advantages and disadvantages of each option;

(4) Explore current social support and what they may be able to do to enhance opportunities for positive and supportive social support; and

(5) Ongoing work, or referring on for further help, if needed.

More broadly, Dahlgren and Whitehead (1991) and Baum (2013) suggest distinct levels of intervention for health policy. Population focused interventions and health promotion policies have been successful in reducing smoking rates, with social policies such as smoking in public places, increased tobacco prices, advertising restrictions and media campaigns all playing an important role in smoking reduction.

Although debate exists about whether smokers with mental illness constitute a 'hardened' group of smokers and therefore warrant intensive individual-level smoking cessation support (Gartner, et al., 2012), the results of our study suggest it is time to consider interventions designed for disadvantaged groups, such as smokers with mental illness and their family carers. These interventions would need to consider how to support family carers, how to empower carers to provide or back up external support for smoking cessation by family members, and a realistic consideration of what supports family need in order to provide that support over and above their existing caring roles. This study has shown that providing family carers with education is important, but that it is only one of a number of considerations. They cannot be expected to undertake the role alone of supporting smoking cessation by their family member.

This research has explored the experiences and perceptions of family carers of family members with mental ill who smoke. It has highlighted the complexities and challenges inherent in the carer's role. The responsibility to provide care and support rather than operate from a punitive position in relation to smoking addiction poses major dilemmas for carers, and this was clearly evidenced in this study. Further research will contribute to developing a better understanding of carers' needs, expectations, concerns and capacities, and how to best deliver support to them. What is clear is that a stronger focus is needed on supporting carers to respond to smoking. This includes exploring how carers and service providers can work collaboratively, in equal partnership, to assist smokers with mental illness to address their smoking.

6. Limitations

The study design was limited to family carers from one jurisdiction. Inclusion of other family members, carers who were indigenous or from different cultural backgrounds in other regions or countries may have provided different results. Male carers, young

carers and those caring for a parent with mental illness were under-represented. We sampled for depth not for representativeness as is common in qualitative studies, so a larger sample size may have provided a more comprehensive picture of the family carer context in relation to smoking... While the recruitment process was modified to include a flyer, consideration of different recruitment methods is needed to improve participant numbers for future studies.

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