
Available from: http://dx.doi.org/10.1080/15504263.2016.1267829

This is an Accepted Manuscript of an article published by Taylor & Francis in the Journal of Dual Diagnosis on 7 January 2017, available online: https://www.tandfonline.com/doi/full/10.1080/15504263.2016.1267829.

Accessed from: http://hdl.handle.net/1959.13/1353582
Family carers, mental health and smoking cessation

ORIGINAL RESEARCH

Exploring the potential for family carers to support people with mental illness to stop smoking

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Abstract

Cigarette smoking poses significant health burdens for people with mental illness. They die sooner than they should, and smoking is a major contributor to their high rates of morbid chronic physical health conditions and early mortality, compared to the general population. Family carers provide important support to people with mental illness. However, family carers’ perspectives of smoking by their family members with mental illness are largely absent from the research literature and from practice, despite smoking rates remaining high and quit rates remaining low for this population. We know little about how family carers are, or could be involved in supporting people with mental illness who smoke to stop smoking. This paper aims to provide a discussion of the opportunities for family carers to support their family member’s smoking cessation and a discussion of our preliminary research on this topic. From the available literature, it appears that family carers are well placed to support smoking cessation for this population; however, they struggled physically, philosophically and emotionally with perceived responsibilities involving their family member’s smoking and the caring role. They felt isolated and asserted that there was limited support from service providers to assist them. We concluded that family carers are important agents within the person’s immediate environment who could
help them to improve their smoking cessation success. This suggests also that mental health services and other health service providers could benefit from including family carers in their efforts to support smoking cessation for people with mental illness who smoke.

Keywords

Family carers; smoking; mental illness; smoking cessation
Background

Smoking is a significant public health problem, particularly among people with a mental illness who continue to smoke at disproportionately higher rates than the general population without mental illness, and despite existing population health efforts. One fifth of Australians aged 16-85 (3.2 mil) have experienced a mental illness in the past 12 months (Australian Institute of Health and Welfare (AIHW), 2014) and tobacco smoking is the most common substance addiction among this population (Scollo & Winstanley, 2015).

National research in three countries has established that a third of all cigarettes smoked are smoked by people with mental illness (Access Economics, 2007; Gfroerer et al., 2013; McManus, Metzler & Campion, 2010). Analysis of Australian national longitudinal data has established that the prevalence of smoking among people with a mental illness has not decreased in line with the reduction in smoking prevalence in the general population (Morgan et al., 2012; Prochaska, 2012). In 1997-98, 68.9% of Australians with a psychotic illness smoked and this figure was 67.2% in 2010; whereas, over this same time period, people who smoked with no history of mental illness smoked at a rate of 26% in 1998 and 20% in 2010 (Morgan et al., 2012; Scollo & Winstanley, 2015). This is despite many people with mental illness who smoke wanting to quit smoking (Stockings et al., 2013; Ashton et al., 2010).

International research has also established that people with a mental illness have a 13-30 years shorter life expectancy than the general population, with the primary cause of this differential being greater mortality from chronic diseases such as cardiac, diabetes and respiratory disease (De Hert et al., 2011; Galletly et al., 2012). Tobacco smoking is the major contributor to the
poorer physical health of people with a mental illness (Royal College of Physicians & Royal
College of Psychiatrists (RCP/RCPs, 2013; AIHW, 2012). As a consequence, development and
implementation of strategies that seek to reduce the prevalence of smoking among people with a
mental illness is a current priority area in Australia’s national health policy (Australian
Government Intergovernmental Committee on Drugs, 2012), and has also received significant
attention in other countries (RCP/RCPs, 2013; Gfroerer et al., 2013).

Is there a role for Mental Health Family Carers?

Informal family carers provide unpaid care and support to a family member or friend. The
National Mental Health Commission (2014) has stressed that a holistic care deliver approach that
includes a range of stakeholders in the care network, including family and friends, is central to
provision of quality care for people with mental illness. Family carers are a critical national
health care resource for many people with mental illness (Pirkis et al., 2010), including their
potential to support the person to address their smoking and support the achievement of national
health policy goals. Yet we know little about their views and experiences in relation to the cared
for person’s smoking. This paper therefore aims to discuss the current evidence and arguments
for exploring the role of family carers in supporting smoking cessation for people with mental
illness. Australia has over 2.8 million informal carers (almost 10% of all Australians), with 83%
of such carers residing in the same home as the cared for person (Australian Bureau of Statistics
(ABS), 2013; Access Economics, 2015). The annual replacement cost of care provided by unpaid
carers in Australia in 2015 was estimated to be $60.3 billion or 3.8% of Gross Domestic Product,
and equivalent to 1.9 billion hours of unpaid care (Access Economics, 2015).
Pirkis et al. (2010), in a study utilising data from the 2007 National Mental Health and Wellbeing Survey, estimate that 15% of Australia’s adult population may be caring for a person with mental illness. Caring may include help and support in any of the daily activities of the person being cared for, including physical and personal assistance and the provision of health, behavioral, emotional, social or financial support (ABS, 2013). Despite the recognised importance of carers in supporting family members with a mental illness, carers are provided little or no formal training or support for this role (Froggatt et al., 2007). To strengthen the role of carers, the National Carer Strategy and Roadmap for National Mental Health Reform call for strategies to build their awareness, self-agency, literacy, skills and capacity to provide care (Department of Families, Housing, Community and Indigenous Affairs (DFHCIA, 2011; Council of Australian Governments (COAG), 2012). Enhancing carers’ capacity to fulfil their role is an acknowledged central component of national and state policies regarding the community-based delivery of mental health services (COAG, 2012; NSW Mental Health Commission, 2014; National Mental Health Commission (NHMC), 2014).

The existing evidence confirms that family carers are an effective means of supporting positive health risk behavior change in the people to whom they provide care. The World Health Organization (WHO) has long recognised the family as a primary social agent in the promotion of health and well-being. Its focus on family and community empowerment and capacity building has underpinned all WHO statements on health. Australian national mental health policies and mental health services recognise carers as having a central role as a partner in providing holistic person-centred care (COAG, 2012; NSW Mental Health Commission, 2014). Carers are important role models in a unique position to influence ongoing recovery and well-
being of the person because of their close kinship ties with the person and personal insights into the person’s needs and preferences, and also their awareness of and capacity for early response to risks, distress and signs of relapse, and their ability to encourage the person to seek support from services (DFHCIA, 2011; McCrae, 2010; Spittal et al, 2015). The NSW Health guideline on Physical Health Care of Mental Health Consumers (NSW Health, 2009) recognises that carers have a critical role in improving health outcomes for people with mental illness by providing vital support to address physical health issues. Specifically, the guideline highlights the support provided by carers to encourage healthy lifestyle changes such as smoking cessation. However, little research has been conducted to investigate the acceptability of mental health carer support in health risk behavior change, or how to include their role effectively into collaborative practice with the range of healthcare service providers that may also be involved in delivering support, treatment and care.

Randomized control trials with carers generally have shown significant improvements for a number of physical health and mental health outcomes as a result of supportive family input. These include trials showing improved adherence to hypertension treatments, cardiac rehabilitation, and when family carers’ role is recognised and integrated into interventions (Campbell 2003). A systematic review by Chelsa (2010, p.363) concluded that, “family treatment approaches improved mortality over usual medical care across all studies where the patient suffered from a physical illness…that the family context is a potent factor influencing illness course in chronic conditions.” Campbell’s systematic review (2003) concluded that families have a powerful influence on physical health, beyond their biological influence, via their influence on health behaviors such as smoking, and their influence on cognitions and emotions.
that result in physiological responses by the family member; with emotional support being the most important and influential type of support provided by families. Orford et al. (2010) reviewed two decades of research on family experiences of alcohol addiction and suggested several potential concerns for families. Moriaty et al. (2011) explored resilience in families living with addiction and found that families play important roles in attracting and engaging the person into treatment and fostering supportive environmental change. Park, Tudiver and Campbell’s (2002) Cochrane systematic review found that partner support was important for smoking cessation but that how to increase and capitalise on that support was not well understood. However, these studies do not apply directly to people with mental illness who smoke.

The importance of carers’ role in providing smoking cessation support for people with mental illness who smoke is implied through their role in providing social and emotional support, or is stated without evidence in many smoking cessation guidelines. For example, the National Tobacco Strategy (2012) recognises the important role of family in prompting family members who smoke to make a quit attempt. A national study of mass media campaigns drew similar conclusions (Wakefield, Loken & Hornik, 2010). Social Support is noted as a key recommendation in the US tobacco treatment guidelines (Fiore et al., 2008). However, we know little about family carers’ attitudes toward smoking by those for whom they provide care. Being a carer involves having to manage a complex array of a persons’ needs and behaviors that may conflict with or differ from those of the carer (Lawn et al., 2013). To meet or to seek to modify these behaviors may present a significant challenge to the carer in the context of carers having a sense of duty to the person they care for, of familial responsibility, and/or concern for the
persons’ well-being (McCrae, 2010). The suggestion that carers have the potential to assist those they care for to stop smoking may therefore present significant challenges to the carer and to their caring relationship. In addition, exposure to secondhand smoke in the home through caring for someone who smokes poses a direct threat to the physical health of the carers (US Department of Health and Human Services, 2006). Carers have been reported to perceive tobacco dependence as a less significant problem compared with dependence on other substances (Boyd & Sigglekow, 2011).

We also have little understanding of the views of people with a mental illness about receiving smoking cessation support from their family carers. A small number of studies investigating smoking and quitting, from the perspective of people with mental illness who smoke, have confirmed the important role that family can play in supporting the person’s quit attempts; though these studies do not explicitly refer to family members as ‘carers’. Christakis and Fowler (2008) looked at the dynamics of smoking in a social network analysis of 12,067 people over 32 years and found that the role of family was an important influence, especially spousal influence on smoking continuance and quitting. Campbell (2003) called for more qualitative study to understand relationship dynamics within families and their influence on health behavior change. A US study by Dickerson et al. (2011) involving interviews with 78 people with severe mental illness who had successfully quit smoking found the main method cited by more than half of participants as enabling them to quit was support from family and friends. A further US focus group study with 36 smokers with severe mental illness from African American, Latino and White backgrounds (Nawaz et al., 2012) found racial and cultural differences in their attitudes, beliefs and behaviors towards seeking advice to quit smoking. The first two groups preferred to
seek advice from family members who had quit. Another US study by Aschbrenner et al. (2015) comparing two smoking cessation treatment support systems for 124 people with severe mental illness found that, "over and above demographic and personal factors, implicit social influences (others’ approval of treatment) significantly predicted use of smoking cessation medication, while explicit social influences (smoking with others) significantly predicted use of cessation group therapy" (p.169). Finally, a recent Australian study involving a survey with 754 smokers admitted to psychiatric facilities asked them about their recent quitting behavior and motivation to quit smoking. The majority of participants believed that their partner (71%) and family (82%) would be supportive of their quitting smoking. Of interest, 93% of this sample was daily smokers, and 44% lived with other smokers.

We cannot assume that all smokers with mental illness will see family carer smoking cessation support as acceptable. They may be highly dependent on carers’ practical and emotional support, and may struggle to maintain a sense of autonomy and choice within the carer-caree relationship, outside of that support. This complex situation may also limit their capacity to express their preferences, or to feel listened to by family carers or service providers. One Australian study also suggests that many people with mental illness who smoke feel unable to stop smoking, are fearful of becoming unwell if they try to stop smoking, like smoking, or feel that it gives them a sense of control in their lives when other aspects of their lives feel less within their control (Lawn, Pols & Barber, 2002). Existing research does, however, confirm 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 et al., 2015). Much of this literature has significant
limitations. It includes small samples drawn from specific settings, use of non-rigorous methods, and may be out of step with current attitudes. There is no existing research that examines directly what people with mental illness who smoke think about the role of carers in supporting their quit efforts; though the above studies that identify a positive role for family members is promising (Dickerson et al., 2011; Nawaz et al., 2012; Aschbrenner et al., 2015; Metse et al., 2016).

It is also unclear if and how services and service providers currently support family carers to provide support for smoking cessation for their family members with mental illness. We know that a strong culture of acceptance of cigarette smoking has existed across mental health services for many decades (Lawn, 2004; Lawn & Pols, 2005; Prochaska, 2011). Research has linked cigarette smoking to mental health service institutional culture, and described an enculturation of smoking that involves using cigarettes as a form of currency for economic and social exchange, to mediate power relationships between mental health patients and service providers, and used by health professionals to support clinical care (Lawn, Pols & Barber, 2002; Lawn, 2005, Lawn & Pols, 2005, Wye et al., 2010a, 2010b). How that culture has impacted on health professionals’ attitudes and actions towards the role of carers in addressing smoking has not been researched.

Research has also shown that, when people are more aware of the harms of smoking, they are more in favour of tighter tobacco control initiatives, smoke-free policy and smoking cessation (Morris et al, 2009; Stocking et al., 2013). Smoke-free policy in mental health services is recognised internationally as an important means of addressing the high rates of smoking for mental health populations (RCP/RCPh, 2013). However, the potential role and views of family carers have been largely overlooked within the establishment and evaluation of such initiatives.
(n, Branelly & Newton-Howes, 2013). This evidence base, and recommendations arising from it, do not include an understanding of what family carers experience in their day-to-day care of people with mental illness who smoke, what they think about smoking, what they do or the role they might play in either maintaining the person’s smoking behavior or in facilitating cessation, or how services might support carers of people with mental illness who have quit smoking whilst in hospital and wish to remain quit once discharged from hospital.

The existing research applies predominantly to clinical treatment settings, not where people with a mental illness spend most of their lives, at home and in the community (Lawrence et al., 2011). Prior to our work in this area, an extensive literature search located only one study from New Zealand of Maori peoples that described family carers’ views of smoke-free policy in mental health services (Missen, Branelly & Newton-Howes, 2013). This qualitative study explored family perspectives of smoking in two focus groups with a total of six participants. The researchers identified several beliefs held by participants about smoking and mental illness: the role of smoking for people with mental ill who smoke is different to that for others who smoke; it is difficult for people with a mental illness to stop smoking when so many others around them also smoke; people with mental ill who smoke are more vulnerable to stress than others and therefore need to smoke to cope with that stress (Missen, Branelly & Newton-Howes, 2013).

In the community, General Practitioners (GPs) are also a potentially important contact for mental health carers to seek advice about the cared for person’s smoking, particularly as they may accompany them to these appointments. Existing research confirms that people with mental illness seek GP consultations significantly more often than members of the general population,
but that GPs rarely offer them holistic lifestyle advice (Lord, Malone & Mitchell, 2010). These patients receive lower levels of preventative care and when there are co-morbidities, receive less treatment and at a later stage of the disease process (Bartlem et al., 2014; Lord, Malone & Mitchell, 2010; Qun et al., 2010). Clinical guidelines for GPs to respond to this issue focus on nicotine replacement and other treatments and make no mention of the person’s interpersonal context, the potential role of family carers or how GPs might work in partnership with carers on this issue (Royal Australian College of General Practitioners, 2011). Likewise, no research has explored the views of GPs on this topic.

To begin addressing this evidence gap, the authors recently conducted two studies, in collaboration with Australian carer organisations (Bailey et al., accepted; Lawn, McNaughton & Fuller, 2015). First, a cross-sectional survey was conducted in partnership with Carer Assist New South Wales, with 144 carers (Bailey et al, accepted). Most carers considered that mental health hospitals, community mental health services, GPs, and non-government organisations should provide smoking cessation care to people with mental illness (71.4%, 78.0%, 82.7%, and 56.6% respectively) and 50.4% expected all four service types to provide smoking cessation support to people with mental illness. Of those carers providing care for a person who smokes (69%), approximately three quarters (76%) considered that it was very important to support the person’s smoking cessation efforts; however, 53% expressed concern that attempting to do so might harm their relationship with the person (Bailey et al., accepted). The survey found little difference in views, irrespective of carers’ smoking status. It did find that residing with the person was associated with lower family expectation of smoking cessation care from service providers. Proposed reasons for this were that cohabiting family carers might perceive less need for
services, or that greater input from services might negatively impact their role as primary caregivers (Harris et al, 2015). Cohabiting carers might also be so bound by the daily process of monitoring and restricting support that smoking cessation is less of a priority (Lawn, McNaughton & Fuller, 2015). This study was limited in its ability to examine potential reasons for its findings, due to the survey methods used, and more detailed qualitative exploration is therefore needed.

The second study, conducted in South Australia, involved in-depth interviews with twelve carers (Lawn, McNaughton & Fuller, 2015) exploring their experiences of smoking by family members with mental illness. Carers described how they managed the family member’s smoking behaviors within their other caring responsibilities, often prioritising the person’s smoking dependence and ensuring supply of tobacco (as stated above); they appeared to do everything involved in smoking except smoking the cigarettes. However, their comments revealed clear ambivalence about their actions towards the person’s smoking. They perceived little or no support from service providers to address the person’s smoking. They felt isolated and demoralised in dealing with it, and resigned to continue with their current responses to the person and their smoking.

This pilot discovered new and potentially significant complexities in the caring role in relation to smoking, the nature and causes of which need to be understood in more detail. This complexity relates specifically and paradoxically to these family carers’ clear awareness of the physical health consequences of smoking. The study was hampered by a small sample, drawn from one state in Australia, using a single interview which then limited the exploration of what shaped their responses to the person who smoked, or other variables such as whether there might be urban and rural differences or differences according to the make-up of carer/caree relationship.
As a way forward, more theoretical exploration may offer a way to deepen our understanding of this issue, by focusing on exploring interpersonal interactions between carers, care recipients and other key support providers. Examining social factors contained within environments where people with mental illness who smoke live and interact would help us to understand how socially accepted norms are established and maintained. A range of sociological models should be considered as part of a conceptualization grounded in critical, narrative, realist and interactionist sociological traditions (Maxwell, 2012; Polkinghorne, 1995). These could include a close and critical examination of theories of carer burden (Hoenig & Hamilton, 1966; Schene, 1990) and role theory (Styker & Statham, 1985; Schumacher, 1995), informed by ecosystems theory (Bronfenbrenner, 1977). Research on carer burden and roles has been largely descriptive and does not inform us clearly about how, in particular, relationships between carer and care recipient are negotiated, or how conflicts are managed; for example, potential conflicts about the cost and supply of tobacco, and about smoking behavior and its harms to health. We also have little understanding of how these relationships may vary when the carer is also a smoker. Recent research (Metse et al., 2016) suggests the presence of significant others who smoke within the physical environment in which smokers with mental illness live has an important influence of their motivation to quit. Support for mental health family carers to quit smoking has not been investigated.

Research has also not looked at the influence of social structures and paradoxical actions of family members (such as ensuring supply of tobacco to their family member despite understanding the harms of smoking and being opposed to the person’s smoking, as suggested from our study) (Lawn, McNaughton & Fuller, 2015). The theory of ambivalence (Connidis &
McMullin, 2002) is likely relevant here also, given that our investigations suggest many carers are torn between condoning smoking and contributing to ensuring its supply, and acknowledging its devastating effects on the cared for person’s health and wellbeing (Lawn, McNaughton & Fuller, 2015). Ambivalence involves simultaneously held opposing feelings or emotions arising from countervailing expectations about how individuals should act. It might help us to understand how carers attempt to meet their own, their family’s and society’s expectations (Connidis & McMullin, 2002). It suggests the need for a phenomenological approach that is exploratory, descriptive and reflexive, exploring how participants make sense of their world by focusing on their subjective experiences (Rubin & Rubin, 2005). Applied to family carers of people with mental illness who smoke (and the influence of other key stakeholder experiences and views of what family carers’ role is, could and should be), these concepts would provide a deeper understanding of their views and experiences. They could also be useful in guiding education and support programs and resources for family carers who wish to provide smoking cessation support to their family member with mental illness who smokes.

Conclusion

Understanding the views and experiences of family carers is important to advance knowledge of how to support people with mental illness with smoking cessation, to respond more holistically to this issue, and to improve future policy and practice responses to address the high rates of smoking in this population. It will help improve the lives of mental health family carers and those to whom they provide care. It will also inform how family carers, people with mental
illness who smoke and service providers might work together, to better coordinate and respond to the needs of people with mental illness who smoke.

Acknowledgements

We wish to thank the many mental health family carers who participants in the original studies by the authors that are discussed in this paper. We also wish to thank the co-authors of the papers where the full discussion of results of those original studies is reported.

Disclosures

The authors’ reports no financial relationships with commercial interests.

Funding

The original South Australian study discussed here was supported by a Faculty research support grant from the first author’s University. The original New South Wales study discussed here was supported by a Faculty research support grant from the co-authors’ University. No financial support was received for the writing of the current paper, other than institutional support within the authors’ existing academic roles.
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