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# Family carers: A role in addressing chronic disease risk behaviours for people with a mental illness?

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#### ABSTRACT

People with a mental illness experience greater chronic disease morbidity and mortality compared to those without mental illness. Family carers have the potential to promote the health behaviours of those they care for however factors which may influence the extent to which they do so have not been reported. An exploratory study was conducted to investigate carers': 1) promotion of fruit and vegetable consumption, physical activity, quitting smoking, and reducing alcohol consumption; 2) perceptions of their role and ability to promote such behaviours; 3) and the association between carer perceptions and the promotion of such behaviours. A cross-sectional survey was conducted with mental health carers (N = 144, 37.6% response rate) in New South Wales, Australia in 2013. Associations between current promotion of health behaviours and carer perceptions were explored through multivariate regression analysis in 2016. A majority of respondents promoted fruit and vegetable consumption (63.8%), physical activity (60.3%), quitting smoking (56.3%), and reducing alcohol consumption (56.2%) to the person they cared for. A perception that it was 'very important' to have a positive influence on these behaviours was positively related with promotion of each of the four behaviours, with those holding such a view being more likely to promote such behaviours, than those who did not (odds ratio: 9.47-24.13, p < 0.001). The majority (56.2%-63.8%) of carers reported promoting the health behaviours of those they cared for, demonstrating a need and opportunity to build the capacity of carers to contribute to reducing the health risk behaviours among people with a mental illness.

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#### 1. Introduction

In high income countries, people with a mental illness experience higher rates of preventable morbidity, mortality, and a life expectancy of 10 to 20 years less than those without such an illness; (Chang et al., 2011; Laursen et al., 2013; Wahlbeck et al., 2011; Lawrence et al., 2013; Brown et al., 2010) disparities largely attributable to a higher prevalence of chronic disease (Lawrence et al., 2013; Brown et al., 2010; Callaghan et al., 2014). Tobacco smoking, inadequate nutrition, harmful alcohol consumption and inadequate physical activity are the leading behavioural causes of the preventable chronic disease burden generally; (AIHW and O'Brien, 2005; Australian Bureau of Statistics, 2012; Australian Institute of Health and Welfare, 2014) with the prevalence of such behaviours being consistently higher among people with a mental illness

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(Cook et al., 2015; Hahn et al., 2014; Kilbourne et al., 2009; Kilian et al., 2006; Morgan et al., 2014; Prochaska et al., 2014; Ussher et al., 2011: Bartlem et al., 2015).

Family carers play a critical role in the lives of the people they care for (Wood et al., 2013; Office of the Chief Psychiatrist, 2007; Aschbrenner et al., 2014) and are increasingly acknowledged as key partners in mental health service provision in clinical and practice guidelines (Office of the Chief Psychiatrist, 2007; NICE, 2010; Rooney and Worthington, 2015; Wilson et al., 2015; Bland and Foster, 2012; New South Wales Government, 2014; NSW Department of Health, 2007; National Mental Health Commission, 2014). A large proportion of people in high income countries have a caring role for a relative with a mental illness: (Collings, 2009; Sinha, 2013) approximately 9 million people in the United States (AARP, 2015), and 2.4 million people in Australia (15% of the population) (Pirkis et al., 2010). A potential exists for carers to promote health behaviours for those they care for, and hence reinforce public health and mental health programs promoting such behaviours (National Mental Health Commission, 2014).

A review of the literature identified two qualitative studies of the role of family carers of adults with a mental illness in promoting health

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behaviours of those they care for. Carers (N=13) in the United States of older adults with serious mental illness reported actively assisting in weight loss through meal preparation, grocery shopping, and encouraging exercise (Aschbrenner et al., 2014). Similarly, an Australian study found that carers (N=12) monitored and managed the smoking behaviours of the person with a mental illness. The study found some dissonance between carers' concerns for the negative impacts of smoking on physical health and their 'complicity' in the purchase of cigarettes (Lawn et al., 2015). One factor that may influence the care provided by carers with respect to such risk behaviours may be their own risk status: whilst not yet explored among carers, the health behaviour status of clinicians has been shown to be inversely associated with their provision of preventive care (Johnson et al., 2009).

The limited body of research suggests that family carers may require information and support from health services to better support the person they care for in changing their health behaviours (Aschbrenner et al., 2014; Sono et al., 2008; Missen et al., 2013). The United States qualitative study mentioned above found participants desired guidance from primary care clinicians in the form of strategies to support weight loss (Aschbrenner et al., 2014). A qualitative study in New Zealand (N=6) found that family members reported receiving inadequate information from mental health services regarding the harms of tobacco, the benefits of available cessation treatments, and the impact of cessation on client mental distress (Missen et al., 2013). In a quantitative study of 152 Japanese family carers, 77% desired additional support from community services to help them promote the physical health of the person they cared for (Sono et al., 2008).

Given the limited research exploring the role of family carers in promoting health behaviours for adults with a mental illness, an exploratory study was undertaken to investigate:

- The extent of carers' involvement in promoting: fruit and vegetable consumption; physical activity; quitting smoking; and decreasing alcohol consumption of the person they cared for
- Carer health behaviours, attitudes and perceptions of their role and ability in addressing the health risk behaviours of the person they care for, and
- 3. Whether such carer health behaviours, attitudes and perceptions were associated with the promotion of such behaviours.

#### 2. Methods

#### 2.1. Design and setting

A cross sectional survey of 144 family carers of adults with a mental illness was undertaken in one non metropolitan region of New South Wales, Australia from July to November 2013. The study was approved by the Hunter New England Human Research Ethics Committee (No. 13/06/19/5.11) and the University of Newcastle's Human Research Ethics Committee (No. H-2013-0343).

#### 2.2. Participants and recruitment

Participants were sourced through their membership of a non-government carer support organisation that provided free support services to carers and families of people with a mental illness (Schizophrenia Fellowship of NSW Inc., 2008). Participants were eligible if they were 18 years or older and identified themselves as a carer for someone with any mental illness who was over 18 years of age.

Participants were identified by the organisation based on previous consent to participate in research; and mailed an information statement, survey instrument and reply-paid envelope, and a web link for online completion if preferred. After one month, participants who had not responded were mailed a one page reminder letter. The request did not specify a date for survey completion and no questionnaires were excluded from analysis. Most surveys were returned within one month; the remainder were received over a four month period.

Additional participants were approached by members of the research team through attendance at carer support group meetings organised by or affiliated with the carer support organisation.

#### 2.3. Data collection procedures

Socio-demographic, clinical and risk behaviour items were adapted from previous research (Bartlem et al., 2013). Other items detailing the carer's current practice and perceptions regarding promotion of health behaviours were developed with input from mental health staff and carers. Participants could complete the questionnaire online or in paper form.

#### 2.4. Measures

#### 2.4.1. Socio-demographic and clinical characteristics

Six items addressed age, gender, employment status, marital status, highest level of education achieved, and Aboriginal or Torres Strait Islander status for both the carer and the person they cared for. Participants were asked their postcode of residence to determine geographic remoteness (major cities, regional, rural) (Department of Health and Aged Care, 2001) of the area they resided in and the socio economic index (disadvantaged, average/advantaged) (Australian Bureau of Statistics, 2011).

Participants were asked: the primary psychiatric diagnosis of the person they cared for (schizophrenia, depression, anxiety disorder, panic disorder, bipolar disorder, post-traumatic stress disorder, eating disorder, personality disorder, dementia, unsure, other); how many years they had been in a caring role (years: less than one year, 1 to 2, 3 to 10, 11 to 20, >20); if they lived in the same residence (yes, no, sometimes); and what their relationship was to that person (parent, partner, child, sibling, neighbour, friend, other).

#### 2.4.2. Chronic disease risk behaviour status

Carers were asked 5–7 items adopted from previous research (Bartlem et al., 2013) assessing their: fruit and vegetable consumption; physical activity; tobacco smoking; and alcohol consumption.<sup>1</sup>

#### *2.4.3. Current promotion of health behaviours*

Participants were asked to what extent they currently sought to influence each behaviour (I don't try, I try sometimes, I try most of the time, I try all of the time, unsure, not applicable).

2.4.4. Carer perceptions of their role and ability in promoting health behaviours of the person they care for

Carers were asked for each behaviour: how important it was for them to have a positive influence for that behaviour for the person they cared for (not at all, a little, somewhat, very, unsure); if the person they cared for found it acceptable for them to talk about the health behaviour (strongly agree, agree, unsure, disagree, and strongly disagree);

<sup>&</sup>lt;sup>1</sup> Items assessing behaviours were: the number of serves of fruit (0, 1, 2 or more, unsure) and vegetables (0, 1, 2, 3, 4, 5 or more, unsure) usually eaten each day; how many days a week they usually do at least 30 min of physical activity (0, 1, 2, 3, 4, 5, 6, 7, unsure); if they are a smoker of any tobacco products (yes-daily, yes-at least once a week, notrying to quit, no-quit longer than 4 months ago, no-never smoked); how often they have an alcoholic drink (never-not drinking alcohol, monthly or less, 2-4 times a month, 2-3 times a week, 4 or more times a week, unsure); how many standard drinks they have on a typical drinking day (1-2, 3-4, 5-6, 7-9, 10 or more, unsure); and how often they have 4 or more standard drinks on one occasion (never, less than monthly, monthly, weekly, daily or almost daily, unsure). Risk status was subsequently determined based on Australian National clinical guidelines with risk defined as: consuming less than five serves of vegetables or two serves of fruit each day; (National Health and Medical Research Council, 2013) engaging in <30 min of physical activity on at least 5 days per week; (Department of Health and Aged Care, 1999) consuming more than two standard alcoholic drinks on a regular day (chronic consumption) or more than four standard drinks on any one occasion (binge consumption); (National Health and Medical Research Council, 2009) and any tobacco consumption (Ministerial Council on Drug Strategy, 2011).

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