Quit Because You Care: Evaluation Report

Final Report

September 2018

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Acknowledgements

This report was developed in collaboration with the project coordinator, Louise Ross, and reflects the work of the “Quit Because You Care” staff and project Steering Committee. Special thanks to One Door Organisation, Sydney Local Health District Drug Health Services and Mental Health Services, Transcultural Mental Health and Canterbury Mental Health. We are especially grateful to the carers, carer advocates, peer support workers and mental health consumers how reviewed and provided valuable feedback on project resources throughout the life of the project.

1. Executive Summary

Mental health consumers have a high prevalence of smoking. Carers of mental health consumers may be potential advocates and supporters for smoking cessation for this group. This project aimed to: i) improve the evidence base of carers' knowledge regarding smoking and smoking cessation; ii) determine the prevalence of smoking among mental health carers and their exposure to environmental smoke; and iii) develop education and training resources for carers.

Smoking prevalence was higher among the carers of mental health consumers than among the general Australian population (18% vs 12%). Exposure to household environmental smoke was very high for carers compared to that for the general New South Wales population (41% vs 6%).

Commonly held misconceptions included a belief that smoking reduces stress for people with mental illness (47%) and that quitting smoking is too hard for people with mental illness (45%). Most (59%) did not believe that "smoking improves mental health symptoms so quitting may harm recovery".

Most carers were interested in improving their knowledge and skills in smoking cessation (69%), irrespective of their own smoking status and were willing to provide smoking cessation support for the person they provide care to (82%).

The resources developed for the project were reviewed favourably by tobacco cessation experts, carers and mental health consumers. Pilot testing of the education program revealed substantial changes in knowledge pre- and post-course across a range of domains.

Although the project has been unable to determine the long-term impact to the program a protocol considering this is currently being developed. Continuation and expansion of the program are key recommendations.

2. Background

Mental health consumers have a high prevalence of smoking and are twice as likely as the general population to report daily smoking (Australian Institute of Health and Welfare, 2017). They are also more likely to smoke more heavily and are more nicotine dependent (Bowden et al., 2011, Pateman et al., 2016). Physical health is also generally poorer among mental health consumers who live up to 16 years less than the general Australian population, with tobacco one of the likely contributors to this disparity (Lawrence et al., 2013, Prochaska et al., 2017). These data suggest that this population have not benefited from initiatives that have reduced smoking rates across the general population.

Recent research has identified family members and carers of mental health consumers as potential advocates and supporters for smoking cessation efforts in this population (Lawn et al., 2017). A survey of carers and families of mental health consumers found that the majority are supportive of smoking cessation and recommended that these should be provided by all health and community service providers who have contact with mental health consumers (Bailey et al., 2016). The limited data available also suggests carers and families of mental health consumers feel under-supported in smoking cessation efforts (Lawn et al., 2017).

These issues are compounded by widespread misconceptions that mental health consumers are unable to quit or benefit from smoking cessation support (Lawn and Campion, 2013, Prochaska et al., 2017). Addressing these misconceptions and providing support mechanisms for carers and families may help engage more staff, carers and consumers in smoking cessation efforts.

The Sydney Local Health District (SLHD) has supported smoking cessation for mental health consumers through expanded access to specialised tobacco treatment services and smoke-free inpatient services. However, currently there is a gap in evidence-based tobacco cessation resources for mental health carers.

This project aimed to address some of the issues around carers of mental health consumers' smoking cessation knowledge. Specifically, it aimed to: i) determine the prevalence of smoking among mental health carers and their exposure to environmental tobacco smoke; ii) build on the scant evidence base of carers' knowledge regarding smoking and smoking cessation; and iii) from the information obtained develop education and training resources to give carers the tools to more effectively assist mental health consumers cease smoking.

3. Evaluation overview

The 'Quit Because You Care' project was undertaken as a joint endeavour and included Sydney Local Health District (SLHD) Drug Health Services, SLHD Mental Health Services, One Door Mental Health and the University of Sydney. Members from each organisation were on the project Steering Committee and met regularly throughout the project. The project was led by SLHD Drug Health Services. SLHD Mental Health Services and One Door Mental Health, a non-government organisation which provides services and advocacy support for people living with mental illness and their families, including carers of mental health consumers, provided expertise into mental health issues and facilitated carer and consumer access. The University of Sydney provided input into survey design, evaluation and evaluation process.

The evaluation was comprised of three components: i) a survey of mental health consumer carers; ii) resource development and evaluation; and iii) train-the-trainer course evaluation.

Carers' Survey

The Carers' Survey was run to obtain background information about both carers' needs in terms of their own and the person they care for smoking status and their knowledge and skills in tobacco cessation. The survey was conducted from April 2017 to May 2018.

Resources

Resources were developed based on the needs identified through the Carers' Survey. Resource development was overseen by the project Steering Committee and included focus testing brochures with carers, consumers and a medical professional. Brochures were translated into Arabic, Greek and Vietnamese and translations were then checked for accuracy with Multicultural Health and community members.

The group education program, which also contained an educational video, was checked by the New South Wales (NSW) Tobacco Trainer, project Steering Committee and carer advocates who attended the Train-the-Trainer. Each of the six modules were further checked by a carer advocate and the group education program was also checked by an independent consultant with tobacco expertise, Dr Allison Salmon.

The group education program was pilot tested at two sites. Piloting testing at three sites was originally planned but this was not feasible within the project timeframe

Each module was piloted at the Train-the-Trainer event. It was evaluated to assess changes in training participants' knowledge around smoking, cessation and mental illness.

4. Carers' Survey

Methods

An online cross-sectional survey was developed to assess carers' i) knowledge around smoking cessation (or "quitting") for people with mental illness; ii) their attitude to consumers quitting; iii) misconceptions and needs to encourage and support smoking cessation for the person they care for. We also wanted to determine the prevalence of smoking among carers compared to consumers and their exposure to second-hand smoke.

The survey was developed by the project lead, a tobacco treatment specialist. It was based on the NSW Ministry of Health guidelines for Managing Nicotine Dependent patients and the Global Adult Tobacco Survey (Global Adult Tobacco Survey Collaborative Group, 2011) and the Heaviness of Smoking Index (Heatherton et al., 1989). The questionnaire was reviewed and approved by the project Steering Committee and was focus tested by carers and mental health peer support workers.

Surveys were translated into Vietnamese, Arabic and Greek as these groups were identified by the Cancer Institute as having the highest prevalence of smoking. The translated surveys were then reviewed by Multicultural Health and community representatives from each language group.

The online survey was distributed to over 600 carers via: One Door Mental Health, SLHD Mental Health Services, Mental Health, South East Sydney Local Health District, Mental Health Carers NSW, Carers NSW, Flourish and Headspace.

Two versions of the survey were completed between January 2017 to May 2018. The first version contained 42 questions regarding demographic information, smoking status of both carer respondents and the person they care for, information about the type of tobacco products used, nicotine dependence and related behaviours including prior quit attempts and smoking within the home. Information was also collected on attitudes and knowledge of smoking and smoking cessation and how it related to those with mental health issues. Carers' support needs were also assessed.

Following carer feedback that the survey was too long, it was abridged (Version 2) to contain 24 questions. All the above domains were included in the second version but with fewer questions.

Participation was voluntary, and all respondents could opt to be entered into a draw to win one of five $100 shopping vouchers by providing their name and contact information. The survey was approved by the SLHD RPA zone Human Research Ethics Committee.

All data was collected via an online data collection system and then transferred to SPSS for statistical analysis. Data from both surveys was merged. Only the variables included in both surveys are reported. Data were generally categorical and are presented as frequencies and the chi-square statistic was used to determine differences between groups with the probability level set at alpha 0.05. Proportions are reported based on the number of responses for each question (i.e. excluding missing data) unless otherwise stated. Some proportions may add up to greater than 100% due to rounding.

Results

Demographics

In total there were 133 respondents, 78 participants completed the survey in from January 2017 to April 2017 and a further 55 completed the survey in May 2018. Demographic data was missing from three respondents.

The survey was completed by 133 carers with a median age of 57 years (range 19 to 83 years) and 72% were aged over 50 years. Most (70%) were born in Australia and spoke English at home (80%). Five respondents identified as Aboriginal or Torres Strait Islander (3.5%).

Forty percent of the respondents had completed tertiary studies (university or trade). Fewer than half the respondents were in paid employment (44%), one-fifth received a government pension or benefit and a further 22% received income from a retirement or superannuation fund. Most (78%) respondents were living with others.

Eight-three respondents reported living with their spouse/partner and/or children (62%) nineteen lived alone (14%) and a further 21 lived with other relatives (16%). Respondents typically lived in privately owned (69%) or rented dwellings (32%). One respondent reported no usual residence.

Smoking status

Respondents answered questions about their own smoking status and that of the person they care for. Responses were available for 119 respondents, 22 (18%) of whom reported being a smoker. Fifteen reported daily smoking and seven reporting occasional smoking. Of the 119 respondents who answered the question about their smoking status, 35 (29%) reported that they were an ex-smoker. One-hundred of the 119 respondents provided care for either a daily (76%) or occasional smoker (8%). Only seven (6%) respondents reported caring for someone who was a former smoker and 12 (10%) provided care for someone who had never smoked. Forty-five respondents reported (41%) exposure to smoking inside the home.

Twenty-eight respondents reported the tobacco products they used and 105 identified those used by the person they care for (105 respondents stated they were not a current smoker and 25 stated that the person they care for is not a current smoker). Cigarettes were the most commonly used form of tobacco for both respondents (79%) and the person they care for (89%; Figure 4.1). Only two respondents reported using “chop-chop” (illegally imported tobacco products) and only one reported the use of bumpers (cigarette butts off the street), although a small but somewhat larger proportion reported the person they cared for used these products (12% and 10%, respectively; Figure 4.1). Use of tobacco mixed with cannabis was reported by two respondents and 15 (14%) persons respondents cared for (Figure 4.1).

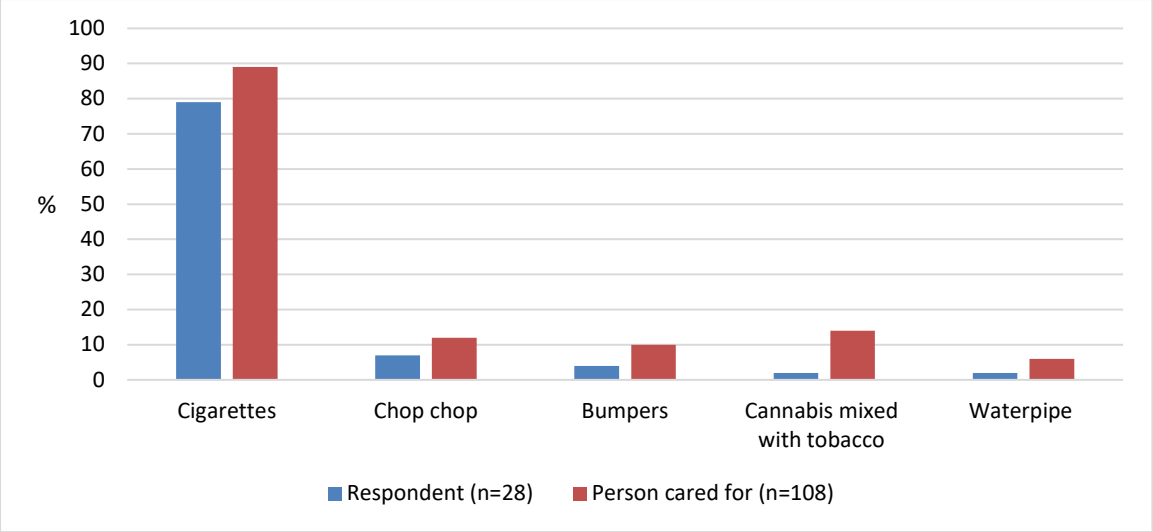

Figure 4.1: Tobacco products reported to be used by respondents and the person they care for

The number of cigarettes smoked per day was reported by 25 respondents, 105 responded that they did not smoke, and data was missing for five participants. Fifty-four respondents provided information on the number of cigarettes per day the person they cared for smoked.

Most participants smoked either 10 or fewer cigarettes per day (39%) or 21-30 cigarettes per day (57%). Only one respondent smoked more than 20 cigarettes per day and none reported smoking more than 30 cigarettes per day (Figure 4.2).

Similar proportions were reported for the person the respondent cared for (Figure 4.2), although a slightly larger proportion reported the person they cared for smoked 21-30 cigarettes per day (15%). None were reported to smoke more than 30 cigarettes per day.

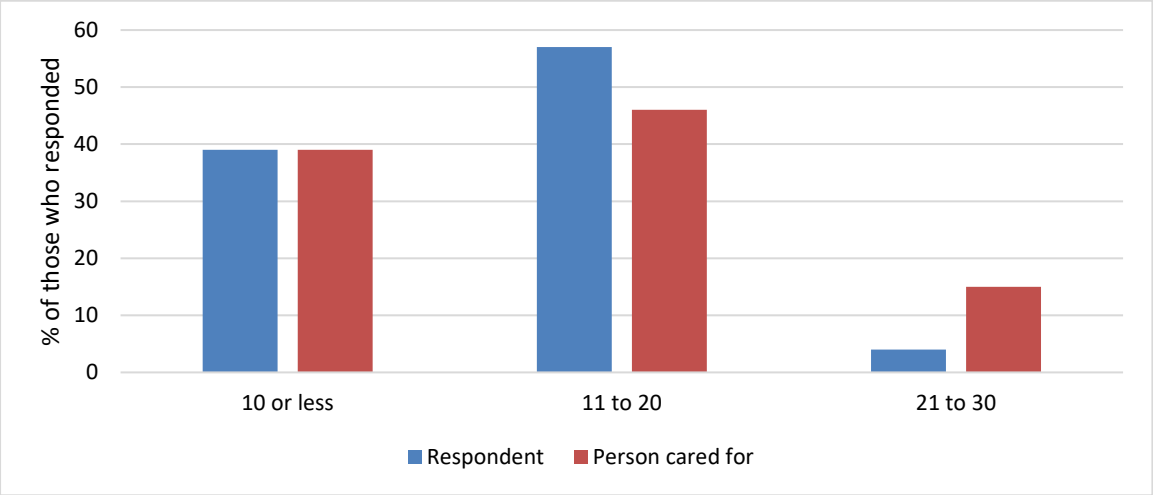

Figure 4.2: Number of cigarettes smoked daily by respondents and person they care for

The amount of time from waking until first cigarette (an indicator of nicotine dependence) was reported by 23 respondents who smoked. Ninety-five respondents provided information on the amount of time between waking and first cigarette for the person they cared for and a further 25 reported that the person they cared for was not a smoker (13 missing data).

Five of the 23 respondents (22%) for whom data was available reported smoking within five minutes of waking, eight (35%) reported smoking within 6-30 minutes of waking and 10 (43%) did so within more than 30 minutes. For the 95 people cared for by respondents 59% reported they smoked within five minutes of waking, 22% reported smoking within 6-30 minutes of waking and 17% did so within more than 30 minutes.

Smoking triggers

Respondents were asked about a range of smoking triggers for both themselves and the person they care for. For this question, 104 respondents stated that they were not a current smoker, so proportions were calculated based on 29 possible responses as missing data was unable to be determined. Twenty-three respondents stated that the person they care for is not a current smoker. Missing data were unable to be calculated so proportions were calculated based on 110 possible responses.

A range of smoking triggers were identified for both respondents and the people they care for (Figure 4.3). Anxiety (59% respondents and 65% person cared for) and spending time with smokers (48% respondents and 60% person cared for) were the most common triggers for both groups (Figure 4.3). Boredom (59%), stress (73%) and hearing voices 31%) were the common triggers for the people respondents care for (Figure 4.3).

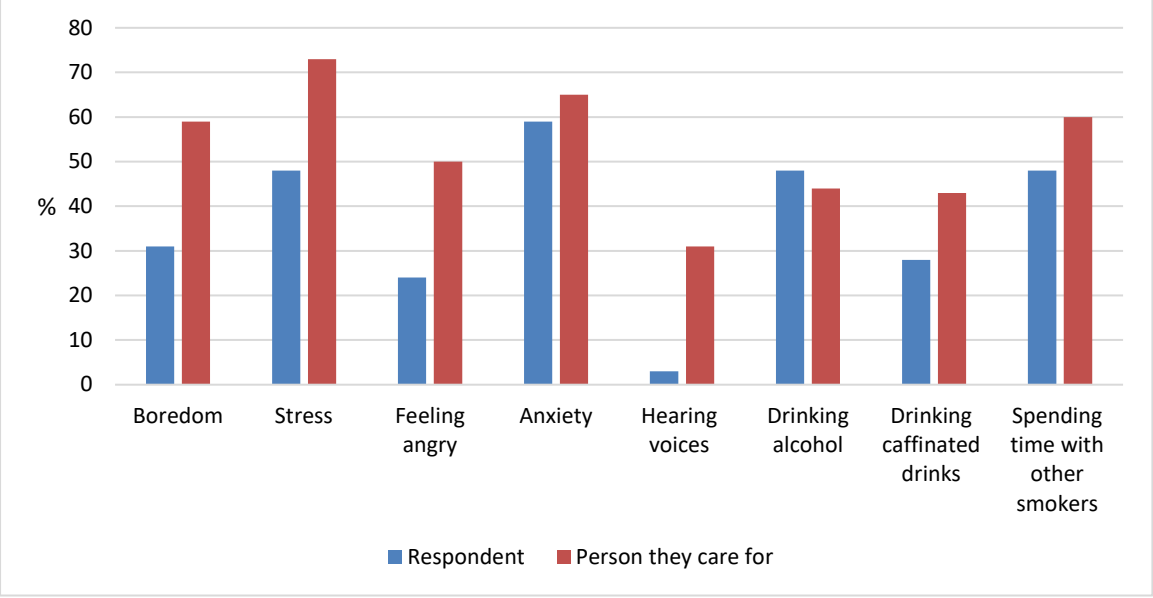

Figure 4.3: Smoking triggers for respondents and person they care for

Smoking cessation

Thirty-seven respondents reported a prior quit attempt. Of these, two (5%) reported an attempt lasting hours and a further two lasting days (5%). Four reported an attempt lasting weeks (11%) and 10 reported a quit attempt lasting months (27%). Nineteen of the 37 respondents who reported a quit attempt reported that they had quit for more than one year (51%).

Eighty respondents reported that the person they care for had made a quit attempt. Of these, seven (9%) reported an attempt lasting hours, 27 lasting days (34%), 18 (23%) lasting weeks and a further 18 (23%) lasting months. Only 10 (13%) were reported to have had a quit attempt lasting more than one year. Twenty-seven respondents reported that the person they care for had never had a quit attempt.

Respondents were asked about their own and the person they care for intention to quit smoking. Seventy-eight respondents reported that they were not a current smoker and a further 28 reported that they had given-up. Twenty-four respondents reported that the person they cared for was not a current smoker and a further six had given-up. Twenty-two respondents reported that the intention to quit status for the person they cared for was unknown.

Of the 19 carers who were current smokers and responded to the question concerning intentions to quit, most (64%) were planning to quit (6 within one month and 6 within the next three months). Seven (37%) respondents reported no plans to quit.

Intention to quit information was reported for 76 people for whom the respondent cared for. Two-thirds (n=50) of these were reported to have no plans to quit. Plans for quitting among the persons for whom respondents cared for were reported to be for five (7%) people within the next month, 12 (16%) within the next three months and nine (12%) within the next 12 months.

Twenty-six respondents reported that neither they nor the person they care for had accessed any quit smoking support and a further five were unable to respond (i.e. it was not unknown what, if any, support was accessed). The most commonly accessed support was general practitioners (GPs) Respondents reported accessing a range of services for smoking cessation support (Figure 4.4).

Nicotine replacement therapy was the most common medication used to assist with smoking cessation for both respondents (n=21) and the person they cared for (n=68). Varenicline had been used by 10 respondents and 19 respondents reported it had been used by the person they care for. Four respondents reported using bupropion and three respondents reported it had been used by the person they care for.

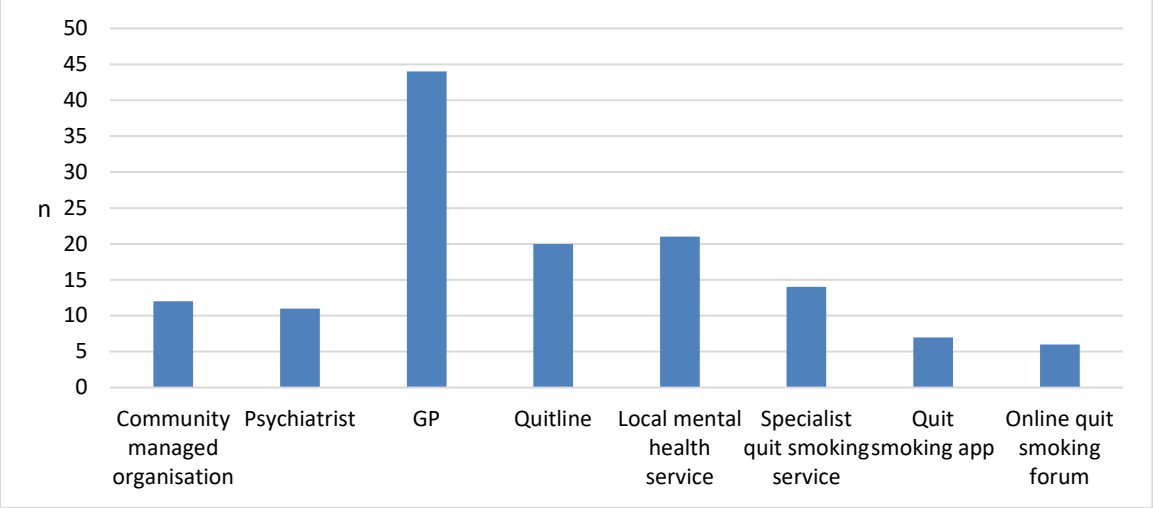

Figure 4.4: Support services accessed

Smoking and mental illness

Respondents were asked four questions about their views on smoking and mental health issues (Figure 4.5). Of the 113 respondents who answered, almost half (n=53) believed smoking reduces stress for people with mental illness. Responses were available from 49 survey respondents on smoking and mental health symptoms, the majority (n=29) did not support the statement "smoking improves mental health symptoms so quitting may harm recovery". Fifty of the 112 (45%) survey participants who responded believed that quitting smoking was too hard for people with mental health issues (Figure 4.5). Eighty-five responses were available regarding increased carer stress. Most of the respondents reported that they were either concerned (n=14) that they would suffer increased stress if the person they provided care for quit smoking or were unsure (n=15), and just less than half (n=19) were not concerned (Figure 4.5).

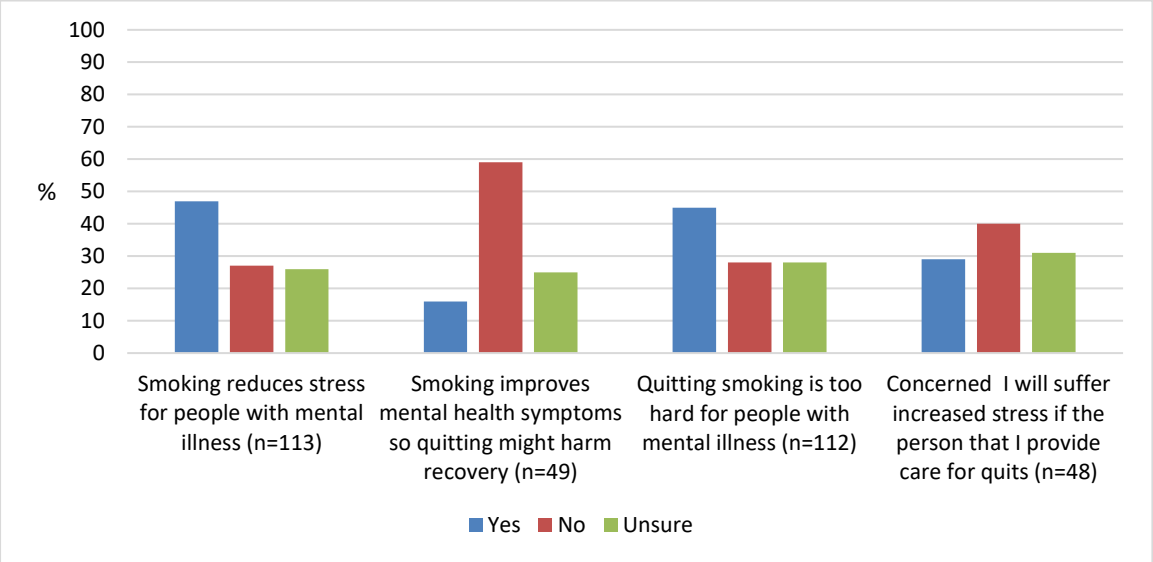

Figure 4.5: Views on smoking in those with mental illness

Of the 133 survey participants, 82 provided responses to two questions about providing quit smoking support. More than two-thirds (69%) of the 82 carers who responded reported that they were interested in improving skills and knowledge around effective quit smoking strategies, with a further eight (16%) either unsure or not interested. Fifty-one respondents answered the question "I am willing to provide quit smoking support to the person I provide care to", of whom, 42 (82%) were willing, six (12%) were unsure and three (6%) were unwilling.

There was no statistically discernible differences between carers who smoked and carers who did not in terms of their believes and views about smoking and mental illness and willingness to support the person they provide care for to stop smoking (Figure 4.6).

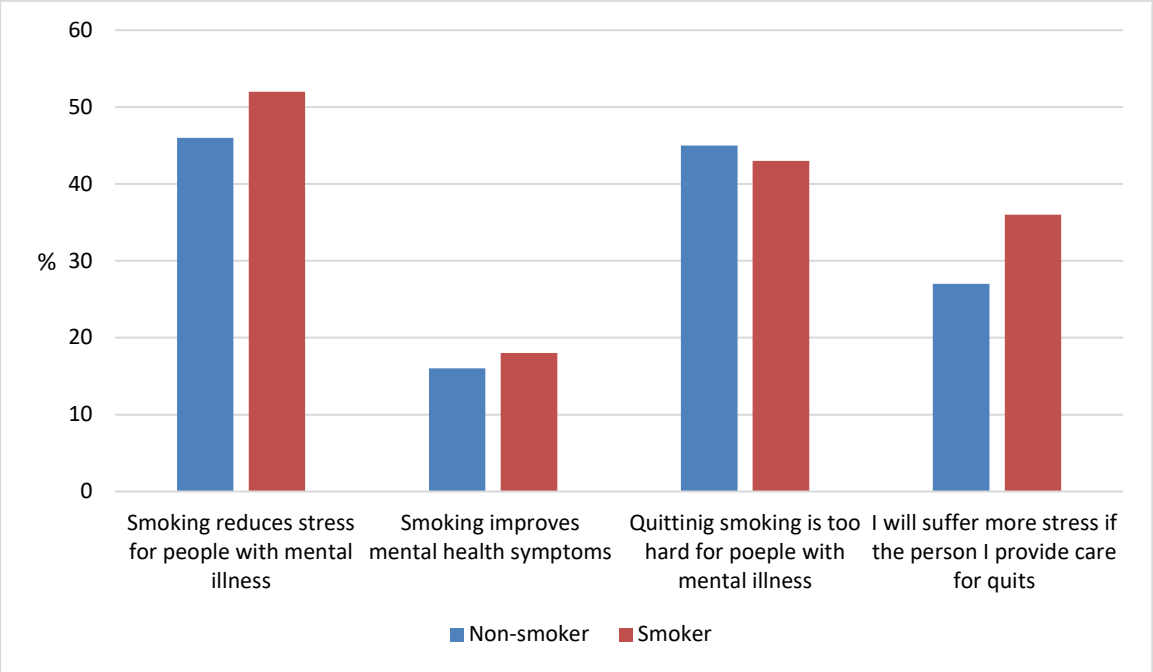

Figure 4.6: Smoker and non-smoker views on smoking in those with mental illness

Of the respondents who answered questions about improving smoking cessation skills and providing support, 39 were reported being non-smokers and 12 reported being smokers. Most non-smokers and smokers reported interest in improving their skills and knowledge around effective smoking cessation strategies (72% and 58%, respectively), with no statistically discernible difference. A high proportion of both non-smoking (85%) and smoking (75%) respondents reported willingness to provide smoking cessation support to the person they provide care to; the differences were not statistically discernible.

5. Resource development and focus-testing

Overview

A suite of resources was developed based on the survey outcomes. The resources comprised a brochure and group education program which included an educational video. All resources were focus-tested with content experts, carers and consumers. The resources were disseminated across NSW and uploaded to the One Door website and the SLHD Mental Health webpage to ensure access beyond the duration of the project.

All the resources were comprehensively reviewed by content experts, consumers, carers and graphic design experts. The graphic design for the brochure and group education program were undertaken by an external graphic design company, Juntos Marketing, which has expertise in the production of health resources. Juntos Marketing provided advice about the layout and images. SLHD Communications unit reviewed all resources before completion.

'Quit because you care' brochure

A storyboard was created for the brochure and approved by the Steering Committee. A Tobacco Treatment Specialist developed the initial draft of the brochure which was comprehensively reviewed and updated based on feedback from the project Steering Committee and external reviewers including tobacco treatment specialists across NSW, Sydney and South East Sydney Local Health District Mental Health staff, One Door Mental Health Carer Advocates, a SLHD addiction medicine specialist, SLHD Health Promotion Manager, the SLHD Consumer and Community Participation Manager and the SLHD Corporate Communications Manager. Twelve drafts were developed before the final draft was reviewed and approved by the project Steering Committee.

The brochure, including size and content, targeted older carers as this was the main age group of survey respondents. Attempts were made to engage younger carers and an image of a young carer was added to the brochure. However, the issues for younger carers tend to be different to that of older carers and include the power differentials. Space limitations impeded a more detailed section targeting younger carers. Following review, it was determined that a separate brochure should be developed for younger carers albeit beyond the scope of the current project.

The brochure was reviewed and approved by the project Steering Committee and the medical content approved by an addiction medicine specialist. It was then focus-tested with consumers and carers (details below). Translated resources were checked by two community members from each language group. The multicultural worker at the Cancer Institute was also invited to comment on the representation of the language groups represented in the images in the resources and provided positive feedback about the representation of several cultural groups.

Brochure readability testing was conducted by the SLHD Consumer and Community Participation Manager. Comprehensive feedback was provided to improve readability. Readability was varied from easy to difficult depending on the content. Definitions were added to address this. More generic terms were also identified and changed to improve readability (e.g. "particularly" changed to

"mainly", "successfully" changed to "well"). A table of contents was added and size (A4) and font styles (sans serif) amended based on this feedback.

Carer review

Four carer advocates were asked to review the 'Quit Because you Care' brochure, including showing it to carers and consumers to provide feedback. In addition to general feedback for each page of the brochure carer advocates were asked: i) if the page was easy to read; ii) if it makes sense; iii) if any changes should be made to the page; and iv) if they approved of the image on the page.

Overall the resources were reviewed favourably, with few changes recommended by carer advocates and consumers. Generally, only minor comments were made. Five of the 11 pages (pages 4, 6,7,9,11) were reviewed favourably and no comments were made. Comments on the other six pages were minor, three of which were minor comments specific to the images (page 1, 2, 10).

Images

There was one comment regarding the image on page 1, which suggested the person in the background be in camera focus. There was suggestion that a trigger should be placed on the table in the page 2 image, the image was liked by all reviewers. There was also only one comment on the page 10 image which suggested the person depicted in the image have a "tear". All photos were from standard photo library stock and as the comments were minor and raised by only one reviewer, no changes were made. One reviewer did comment that an image of a younger carer should be included which was then incorporated in page 2. All other images used in the brochure were generally well-received. The representation of a diverse range of cultural and ethnic groups was reviewed favourably.

Text

All comments were reviewed and assessed as to whether the comments warranted a change to the brochure. Comments on the text were made for pages 2, 3, 5 and 8. One reviewer commented that the "smoking trigger" as it appeared in the table of contents would be unfamiliar to some non-smokers. There was one suggestion that the explanations for the "truth" statements on page 3 could be shortened and a one suggestion that the text "Try asking these questions" could be emphasised on page 5. One reviewer commented on page 8 while all other reviewed these favourable. The one comment was concerning "Champix" (Varenicline) due to the "bad press" it has received and sought clarification that information was well-founded.

A further comment was made that many older carers potentially have difficulty downloading apps. Given the very minor nature of the comments and the lack of consensus regarding these comments, no changes were made to the brochure.

Consumer focus group

A focus group was conducted by the Tobacco Cessation Specialist with five consumers who attend a quit smoking group delivered by mental health peer support workers from Canterbury Mental Health, two of whom were smokers. Focus group participants reviewed the resource and gave feedback. Consumers were specifically asked what is important from a consumer perspective. Consumers reported that the most important messages to include in the resource to encourage carers to do were:

- Be supportive and patient;

- Say things like: “never quit quitting”;
- Be positive and encouraging;
- Give consumers space and show understanding and compassion if there is a slip or lapse;
- Not to be judgemental or criticise if the consumer has a slip.

These messages were subsequently threaded throughout the resource. Overall, consumers were positive about the resource and felt it addressed the issues that they raised.

Group Education Program

A six-session carer group education program was developed in consultation with the NSW Health Tobacco Trainer and in line with the survey and consumer focus group feedback. The program included a comprehensive facilitator manual and a participant manual. Six carer advocates were recruited to review a module each from the program and a consultant with expertise in tobacco edited the resource.

Carer advocate feedback was generally positive: “It looks great and I am so keen to deliver this to family and carers in my areas” (rural-based carer advocate); “[bilingual carer advocates] have learned a lot from you, and they will start having the conversations with their carers using the information you’ve provided” (CALD carer advocate). Practical suggestions regarding word changes to improve clarity was also received, for e.g. “If sleep disturbances continue” changes to “If sleep disturbances occur”.

The program was reviewed and approved by the project Steering Committee and participants who attended the Train-the-Trainer (see Section 6). The program was piloted at the Train-the-Trainer course and with Transcultural Mental Health carer advocates (see Section 6).

Video

The video development was added to the project following feedback from the project Steering Committee and the NSW Tobacco Trainer. The intention of the video was to provide another medium for conveying key project messages to carers. The video is intended for use in the training program but is available to view by carers through the One Door Mental Health site and SLHD Mental Health site.

The video included information from carers, consumers, health and medical professionals and mental health peer support workers. The script was developed by an award-winning video production company ‘The Perfect World’, experienced in developing videos on health issues. The script was reviewed and revised by the SLHD Audio Visual Department, who managed production.

The draft video was reviewed by video participants, carer advocates, consumers and the project Steering Committee. Formal feedback was provided to SLHD Audio Visual and the video was updated before the final version was developed.

6. Train-the-Trainer

Overview

A Train-the-Trainer course was developed as a vehicle for disseminating the project resources, to enable group facilitators from across NSW to deliver the Quit Because You Care group education program to carers. The Train-the-Trainer course served two important purposes: i) it provided an opportunity for each of the group education modules to be focus-tested with carer advocates from a range of services and culturally and linguistically diverse (CALD) community groups; and ii) facilitate scalability and sustainability of the project resources beyond the project completion date.

Invitations were sent to Local Health District Mental Health Services across NSW and partner organisations including One Door Mental Health, Carers NSW, Mental Health NSW, Flourish, the Lebanese Muslim Association, Transcultural Mental Health and Headspace. Participants were required to run groups for carers as part of their role. Participants received a comprehensive facilitator and participant manual and a video resource to accompany the group program. Participants also received a range of resources to equip them to deliver the group education program including a sample of nicotine replacement therapy products, Quitkits, posters, stress balls and a supply of the Quit Because You Care brochures in each language.

The NSW Tobacco Trainer co-facilitated the course with the Drug Health Tobacco Treatment Specialist. A mental health consumer was also invited to present at the course about his quit smoking journey, use of quitting medications, support needs and benefits of quitting on mental health, health and finances.

Two Train-the-Trainer sessions were run: one at the Royal Prince Alfred Hospital in May 2018 and ii) a shorter Train-the-Trainer course involving nine bilingual group leaders from Transcultural Mental Health in June 2018.

Flights and accommodation costs were covered for participants outside of Sydney attending the Train-the-Trainer course at RPAH. The RPAH Train-the-trainer course participants completed a brief survey regarding their knowledge and learning needs prior to the training session. Each participant also completed a post-course survey and evaluation form immediately following the training session.

The Lebanese Muslim Association sent a staff member to the course and have subsequently received funding from SLHD to deliver a specialist tobacco treatment service. A Vietnamese carer facilitator from Bankstown and an Indigenous Local Health District Carer facilitator from Southern Mental Health Local Health District also attended the course.

The second course was run because the service was unable to afford to send staff to the full course because carer advocates at Transcultural Mental Health only work part-time. The shorter training program was developed and delivered at their site in Parramatta. The language groups covered in this session included Arabic, Assyrian, Afghani (Dari-speaking), Chinese (Cantonese & Mandarin), Farsi, Khmer, Macedonian, Serbian, Spanish and Vietnamese. This Train-the-Trainer session was unable to be evaluated due to participants' time restraints, thus evaluation results refer only to the RPAH course.

Train-the-trainer evaluation (RPAH)

Twenty-six carer advocates completed the train-the-trainer course at RPAH. Twenty-five of the 26 participants completed the pre-course survey, 23 of whom were females and two were male. All twenty-six participants completed the post course survey. Two-thirds were born in Australia.

Two-thirds of the participants were either in a paid or voluntary position with a non-government organisation and nine (36%) were in a government position (paid or voluntary). Fifteen (60%) were carer advocates, three (12%) were counsellors, social workers or psychologists and two (8%) were nurses. Seven (28%) of the course participants were the carer of someone living with mental illness.

Seventeen (68%) of the course participants reported that they currently run education groups for carers and the same proportion reported that they had never attended a smoking cessation education; three (12%) were unsure. All but two of the participants had prior experience in delivering education to groups (92%). Half (52%) of the group described themselves as being extremely or very knowledgeable about group work skills and only two (8%) participants described themselves as not being knowledgeable about group work skills, with the remaining 40% reporting themselves as being either somewhat or moderately knowledgeable about group work skills.

Pre-course needs

Participants had variable knowledge of smoking cessation (Figure 1). None of the participants believed that smoking improves mental health symptoms, but eight of the 25 participants were unsure. However, 40% believed smoking reduces stress for people with mental illness and almost one-third (32%) believed quitting smoking was too hard for people with mental illness. Almost half the participants believed that quitting medications are harmful for people with mental illness (Figure 6.1).

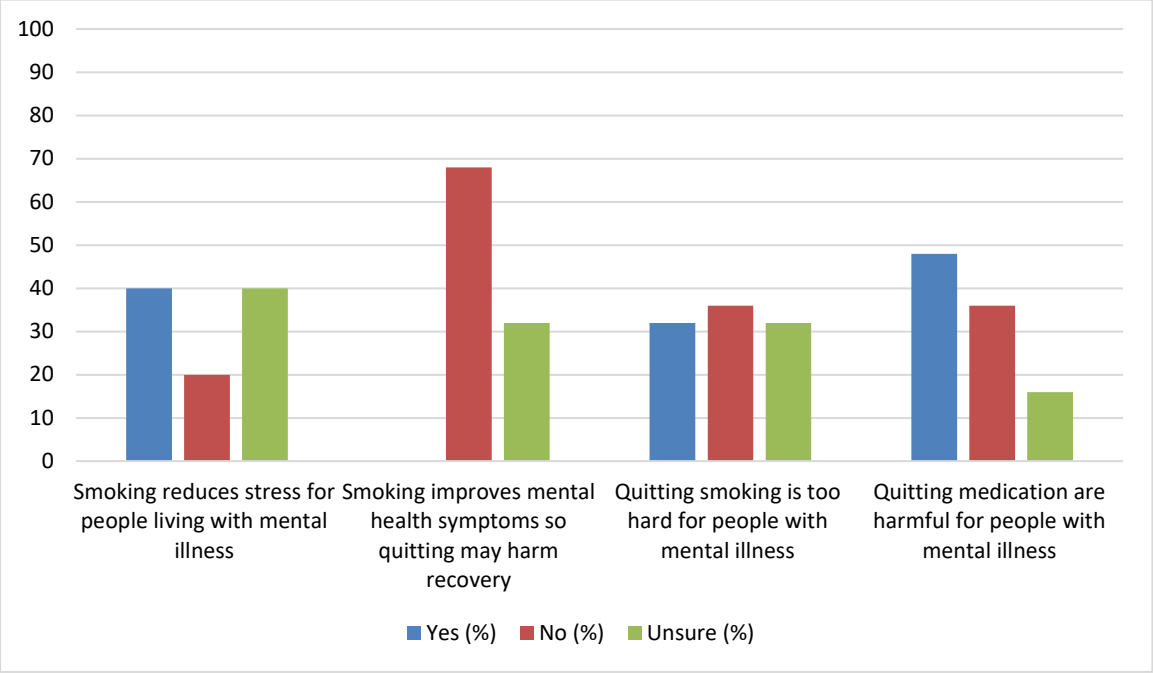

Figure 6.1: Course participants prior knowledge of smoking cessation and mental illness

Pre-course self-reported knowledge of smoking and barriers to smoking among mental health consumers was modest among course participants. None of the participants reported they were extremely knowledgeable about any of the domains (Figure 6.2). The majority rated themselves as somewhat or moderately knowledgeable about smoking harms and barriers for mental health clients, but few (4-16%) indicated that they were not knowledgeable (Figure 6.2).

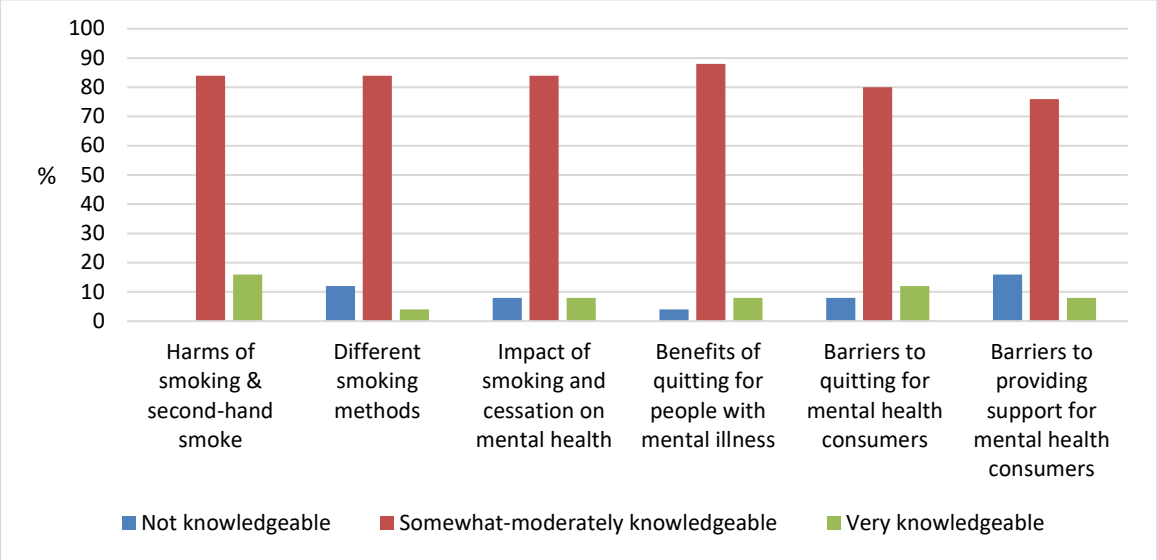

Figure 6.2: Participants' pre-course knowledge of smoking and barriers to quitting among mental health consumers

Pre-course self-reported knowledge of nicotine dependence and withdrawal and therapeutic approaches to smoking cessation also received mixed self-reported ratings of knowledge, although generally a higher proportion of participants reported not being knowledgeable across the domains (Figure 6.3). Seventy-six percent of the group rated themselves as having somewhat or moderate knowledge of nicotine dependence and withdrawal and one-person (4%) rated them self as extremely knowledgeable. Three (12%) participants rated themselves as not knowledgeable (Figure 6.3). There was more spread across participants' rating of their therapeutic skills including motivational skills, stages of change knowledge, strategies to manage common smoking triggers and provision of support (Figure 6.3). Knowledge of group skills, however, was generally rated highly, with only two (8%) participants reporting they were not knowledgeable, but 44% reporting they were very knowledgeable and a further two (8%) reporting they were extremely knowledgeable (Figure 6.3).

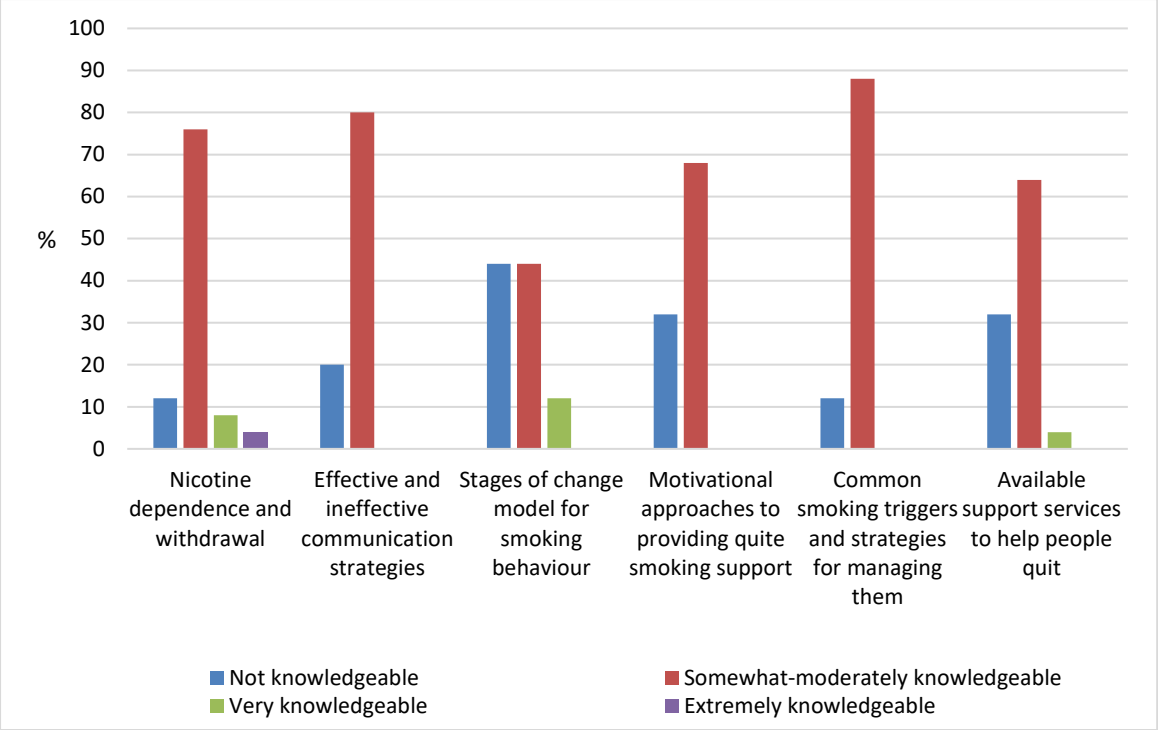

Figure 6.3: Participants' pre-course knowledge of nicotine dependence and therapeutic skills

Few participants reported they were 'very knowledgeable' about quit smoking and medications, including nicotine replacement therapy (Figure 6.4). Seventeen (68%) participants reported they were 'not knowledgeable' about medications not recommended for quitting smoking (Figure 6.3).

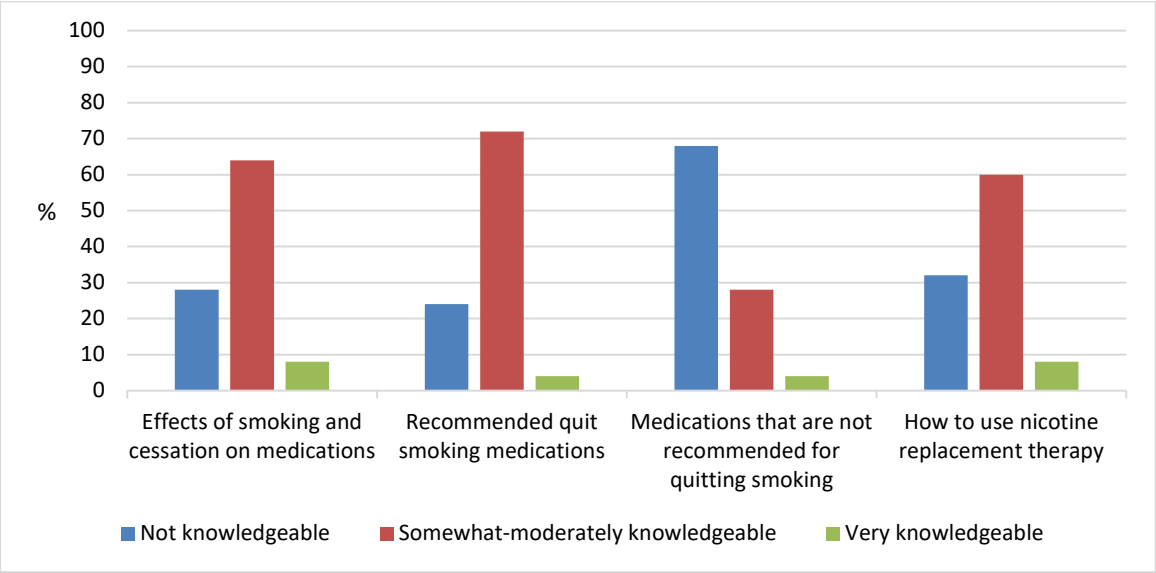

Figure 6.4: Participants' pre-course knowledge of smoking cessation and medication, including nicotine replacement therapy

Post-course evaluation

Participants knowledge improved substantially following the course. Self-reported knowledge across all domains improved, with more than 80% of participants reporting they were 'very' or 'extremely' knowledgeable across the domains (Figure 6.5-6.7).

The domain with the least self-reported knowledge post-course was harms of second-hand smoke, where one participant reported themselves to not be knowledgeable about this domain and a further one participant reported themselves as 'somewhat knowledgeable'. All other participants self-reported being 'moderately knowledgeable' (15%), 'very knowledgeable' (65%) or 'extremely knowledgeable' (12%).

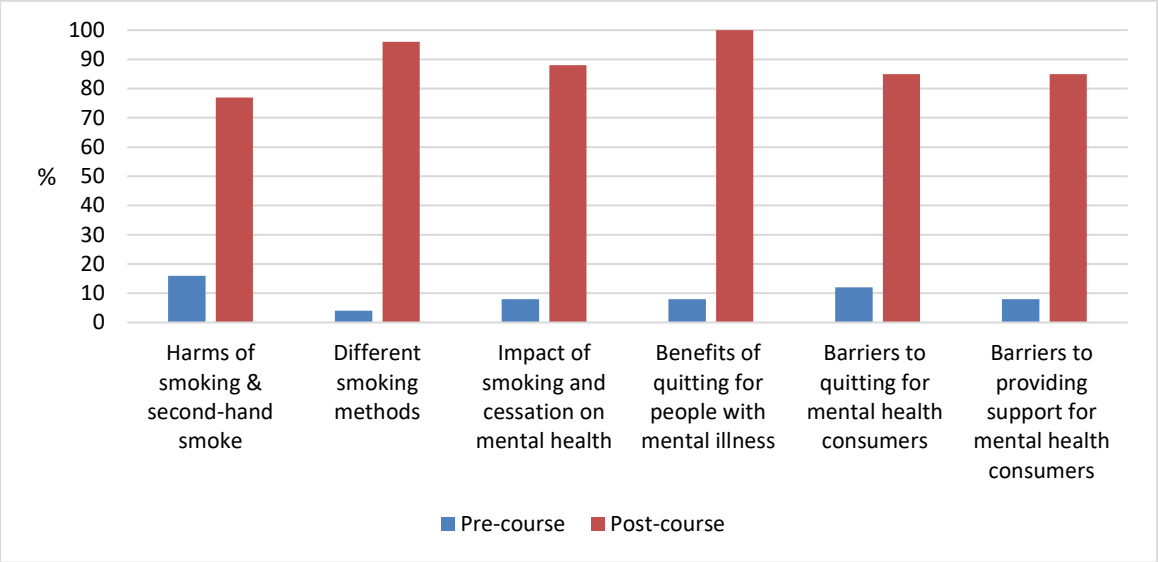

Figure 6.5: Participants' reporting themselves as very or extremely knowledgeable about smoking and barriers to quitting among mental health consumers pre- and post-course

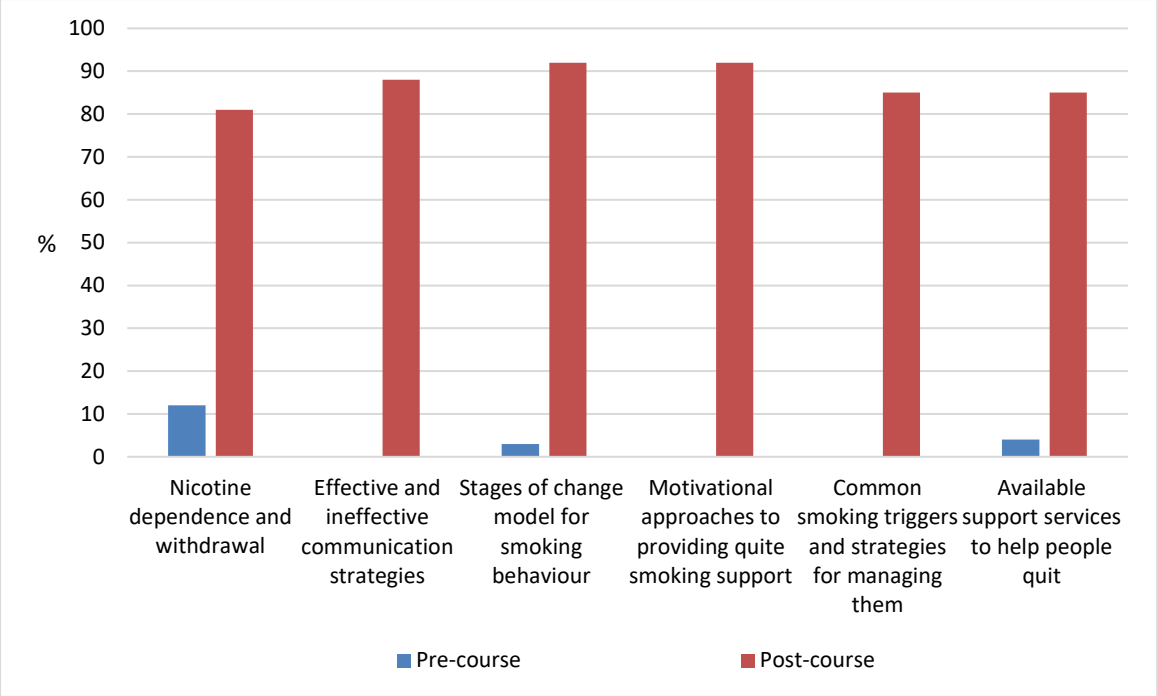

Figure 6.6: Participants' pre- and post-course self-report as being very or extremely knowledgeable about nicotine dependence and therapeutic skills

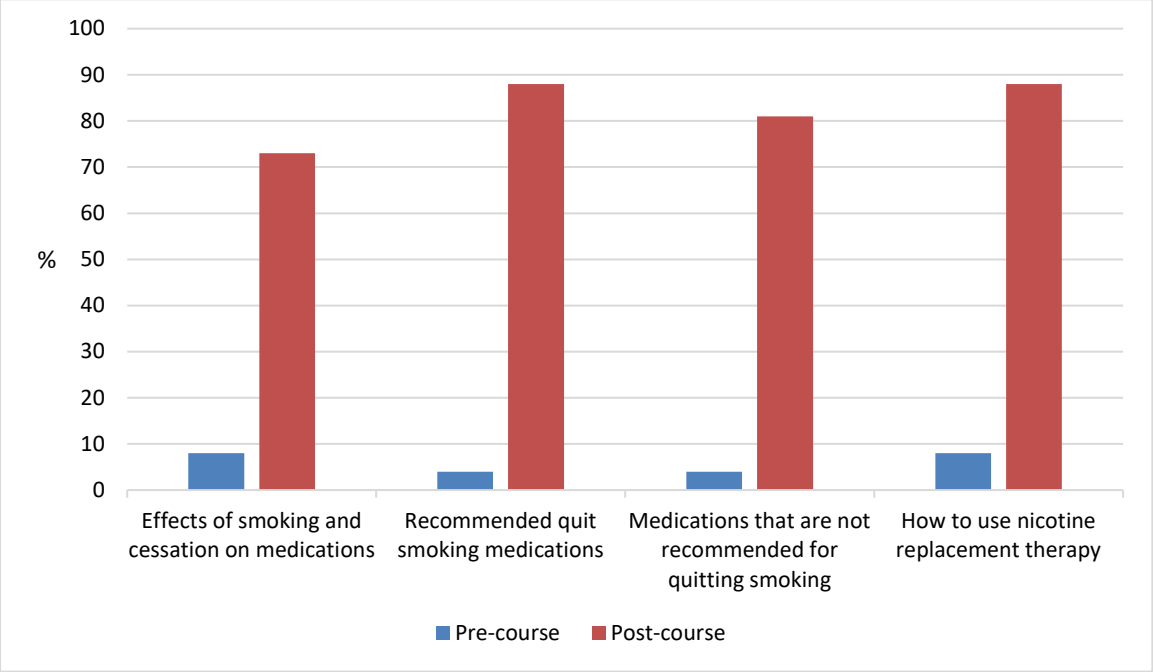

Figure 6.7: Participants' pre-course knowledge of smoking cessation and medication, including nicotine replacement therapy

7. Discussion

In this study, smoking prevalence was higher among the carers of mental health consumers than among the general Australian population, with 18% of survey respondents reporting being a smoker compared to 12% (Australian Institute of Health and Welfare, 2017). However, this was similar to the recent findings of Bailey et al. (2016) who reported 17% of the carers they surveyed smoked.

The prevalence of smoking among mental health consumers as reported by the carers in the Carers' Survey was very high at 69%, the same figure reported by Bailey et al. (2016). These figures are much higher than those reported in the national data, where 24% of those who report a mental health diagnosis or had received treatment for a mental health issues report smoking (Australian Institute of Health and Welfare, 2018). However, the available evidence suggests smoking prevalence increases with severity and can be up to 70% (Cooper et al., 2012). Our data is likely to reflect this groups with more severe mental illness.

Exposure to household environmental smoke was very high among survey respondents with 41% exposed to smoke inside the home. This figure is almost seven times the state average where 6% of households are reported to be smoke free (NSW Ministry of Health, 2018).

The survey also revealed some commonly held misconceptions about smoking and smoking cessation. More than half of the survey respondents believed smoking reduces stress for people with mental illness and almost half believed quitting smoking was too hard for people with mental illness. It was, however, encouraging that more than half of the carers who responded disagreed with the statement "smoking improves mental health symptoms so quitting may harm recovery". This is consistent with findings reported by Bailey et al. (2016) where the majority of the participants believed quitting smoking would have a positive impact on mental health for consumers.

The survey revealed that most carers, irrespective of their own smoking status, were interested in improving their knowledge and skills in smoking cessation. Most carers reported that they were either concerned that they would experience more stress or were unsure if they would experience more stress if the person they provide care for quit smoking. Yet, despite this, the majority of carers reported that they were willing to provide smoking cessation support for the person they provide care to.

The resources developed for the project were carefully reviewed by a range of experts including both carers and consumers and content experts. The resources were favourably reviewed and included several language groups, with subsequent expressions of interest to have the resources translated into numerous other language groups.

Pilot testing of the education program revealed very substantial changes in knowledge pre- and post-course. There were marked increases in participants' self-ratings of knowledge across a range of domains, including the benefits of and barriers to mental health consumers quitting.

Limitations

The Carers' survey suffered some limitations. Given the survey was online, it is not possible to determine an exact response rate. The survey was emailed to over 600 carers via One Door, but it cannot be determined how many carers received the invitation. Some questions were not fully answered resulting in several variables with missing data. Nevertheless, the sample size and findings are broadly in line with another recent survey of family members who care for mental health consumers (Bailey et al., 2016) and provided valuable information to inform the educational materials which was the core component of the project.

It was not possible to run multiple groups during the life of the project due to time restraints and some geographical issues. However, the has two more groups planned for September and November 2018 which will also be evaluated.

We have been unable to determine the long-term impact to the program and whether there has been further delivery of the group program by the trainers who participated in the train-the-trainer course. However, protocol development is currently underway which aims to assess the longer-term uptake and, if possible, the broader impact of the program.

Recommendations

The key recommendation to emerge from the program are:

1. The train-the-trainer program should be run regularly to ensure greatest reach and reinforce the messages and significance of smoking cessation for mental health consumers.
2. Groups and education sessions should be expanded to consumers and support workers as recommended by carer advocates who attended the group education programs.
3. More work is needed to engage young carers and different cultural groups including Aboriginal and Torres Strait Islander people and other culturally and linguistically diverse groups.
4. Resources should be developed to engage younger carers who are likely experience different issues to older carers.
5. Efforts should be made to engage people who both care for and who are mental health consumers.
6. The brochure should be translated into many other language groups as requested by Transcultural Mental Health staff.

8. References

AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE 2017. National Drug Strategy Household Survey 2016: detailed findings. Canberra: AIHW.

AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE 2018. Australia's Health 2018. *Australia's health series no. 16. AUS 221.* Canberra: AIHW.

BAILEY, J. M., WYE, P. M., STOCKINGS, E. A., BARTLEM, K. M., METSE, A. P., WIGGERS, J. H. & BOWMAN, J. A. 2016. Smoking cessation care for people with a mental illness: Family carer expectations of health and community services. *Journal of Smoking Cessation,* 12**,** 1-10.

BOWDEN, J. A., MILER, C. L. & HILLER, J. E. 2011. Smoking and mental illness: a population study in South Australia. *Australian and New Zealand Journal of Psychiatry,* 45**,** 325-331.

COOPER, J., MANCUSO, S. G., BORLAND, R., SLADE, T., GALLETLY, C. & CASTLE, D. 2012. Tobacco smoking among people living with a psychotic illness: The second Australian survey of psychosis. *Australian and New Zealand Journal of Psychiatry,* 46**,** 851-863.

GLOBAL ADULT TOBACCO SURVEY COLLABORATIVE GROUP 2011. Tobacco Questions for Surveys: A subset of key questions from the Global Adult Tobacco Survey (GATS). 2nd ed. Atlanta, GA.: Centers for Disease Control and Prevention.

HEATHERTON, T. F., KOZLOWSKI, L. T., FRECKER, R. C., RICKERT, W. & ROBINSON, J. 1989. Measuring the Heaviness of Smoking: Using self-reported time to the first cigarette of the day and number of cigarettes smoked per day. *British Journal of Addiction* 7**,** 791-799.

LAWN, S., BOWMAN, J., WYE, P. & WIGGERS, J. E. 2017. Exploring the potential for family carers to support people with mental illness to stop smoking. *Journal of Dual Diagnosis,* 13**,** 52-59.

LAWN, S. & CAMPION 2013. Achieving smoke-free mental health services: Lessons from the past decade of implementation research. *International Journal of Environmental Research and Public Health* 10**,** 4224-4244.

LAWRENCE, D., HANCOCK, K. J. & KISELY, S. 2013. The gap in life expectancy from preventable physical illness in psychiatric patients in Western Australia: Retrospective analysis of population based registers. *British Medical Journal,* 346.

NSW MINISTRY OF HEALTH. 2018. *Health Stats* [Online]. Available: http://www.healthstats.nsw.gov.au/Indicator/env_smohous_age/env_smohous_age [Accessed August 2018].

PATEMAN, K., FORD, P., FITZGERALD, L., MUTCH, A., YUKE, K., BONEVSKI, B. & GARTNER, C. 2016. Stuck in the catch 22: attitudes towards smoking cessation among populations vulnerable to social disadvantage. *Addiction,* 111**,** 1048–1056.

PROCHASKA, J. J., DAS, S. & YOUNG-WOLFF, K. 2017. Smoking, mental illness, and public health. *Annual Review of Public Health,* 38**,** 165-185.