

The Family and Friend Support Program: A Pilot Study Examining Usability, Acceptability, and Feasibility

Stephanie Kershaw, Jessica Deng, Madeleine Keaveny, Bronte Speirs, Anna Grager, Dara Sampson, Kate Ross, Nicola Newton, Maree Teeson, Frances Kay-Lambkin, Cath Chapman

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Abstract

Background: Despite the known psychosocial challenges associated with supporting a loved one using alcohol and other drugs (AOD), there is a scarcity of mental health and wellbeing interventions for affected family members and friends (AFFMs).

Objective: This pilot study examines the usability, acceptability, and feasibility of the Family and Friend Support Program (FFSP; ffsp.com.au), a world-first, evidence-based online resilience and wellbeing program designed with and for people caring for someone using AOD.

Methods: In 2021 (November-December), participants across Australia completed a baseline online cross-sectional survey that assessed impact of caring for a loved one using AOD (adapted Short Questionnaire for Family Members (Affected by Addiction)), and distress levels (Kessler-10 Psychological Distress Scale). Following baseline, participants were invited to interact with FFSP over 10 weeks. Post program and follow up surveys (10 and 14 weeks post-baseline, respectively) and semi-structured interviews assessed usability and acceptability of the program as well as help-seeking barriers.

Results: Baseline surveys were completed by 131 AFFMs, with 37% completing the post-program survey and 24% completing the follow-up survey. On average, K-10 scores fell in the moderate to severe range at baseline. Overall, participants found FFSP easy to use and provided them with relevant, helpful, and validating information. Limitations included low program engagement and high attrition.

Conclusions: Overall, FFSP appears to be a promising mental health intervention for AFFMs. This study builds on existing research finding high levels of distress among AFFMs, whilst highlighting the ongoing barriers to help-seeking. Limitations and future directions for refinements and efficacy evaluation of FFSP are discussed.

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Original Manuscript

The Family and Friend Support Program: A Pilot Study Examining Usability, Acceptability, and Feasibility

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Abstract

Introduction

Despite the known psychosocial challenges associated with supporting a loved one using alcohol and other drugs (AOD), there is a scarcity of mental health and wellbeing interventions for affected family members and friends (AFFMs). This pilot study examines the usability, acceptability, and feasibility of the Family and Friend Support Program (FFSP; ffsp.com.au), a world-first, evidence-based online resilience and wellbeing program designed with and for people caring for someone using AOD.

Methods

In 2021 (November-December), participants across Australia completed a baseline online cross-sectional survey that assessed impact of caring for a loved one using AOD (adapted Short Questionnaire for Family Members (Affected by Addiction)), and distress levels (Kessler-10 Psychological Distress Scale). Following baseline, participants were invited to interact with FFSP over 10 weeks. Post program and follow up surveys (10 and 14 weeks post-baseline, respectively) and semi-structured interviews assessed usability and acceptability of the program as well as help-seeking barriers.

Results

Baseline surveys were completed by 131 AFFMs, with 37% completing the post-program survey and 24% completing the follow-up survey. On average, K-10 scores fell in the moderate to severe range at baseline. Overall, participants found FFSP easy to use and provided them with relevant, helpful, and validating information. Limitations included low program engagement and high attrition.

Conclusions

Overall, FFSP appears to be a promising mental health intervention for AFFMs. This study builds on existing research finding high levels of distress among AFFMs, whilst highlighting the ongoing barriers to help-seeking. Limitations and future directions for refinements and efficacy evaluation of FFSP are discussed.

Key words

Affected Friends and Family Members, Substance Use, Help-Seeking, Online Intervention, Pilot Trial



Introduction

The use of alcohol and other drugs (AOD) not only affects the person using the substance, but also impacts their family, friends, and community, often in adverse ways (Kourgiantakis et al., 2021; Orford, Velleman, et al., 2010). The 2022 – 2023 National Drug Strategy Household Survey (NDSHS) found that around one in three Australians (31% or 6.6 million) reported drinking alcohol above guideline recommendations (NHMRC, 2020), and around one in five (18% or 3.9 million) people had used an illicit drug in the previous 12 months (Australian Institute of Health and Welfare, 2024). Additionally, the Australian Burden of Disease Study reported that AOD use was estimated to be responsible for 7.5% of the total burden of disease and injury (Australian Institute of Health and Welfare, 2021). Considering the high rates of AOD use and associated burden in Australia, the number of family members and friends who are supporting someone using AOD, or are affected by someone's use, is likely to be high (Orford et al., 2013).

The term Affected Friends and Family Members (AFFMs), used in this paper, represents a heterogeneous group which includes parents, children, significant others, relatives, friends, and caregivers of someone using AOD. AFFMs often have the responsibility of advocating and caring for their loved one, whilst also managing their loved one's changes in behaviour, increased relationship strain and conflict, and financial insecurity (Kourgiantakis et al., 2021; McCann et al., 2017; Merkouris et al., 2022; Sampson et al., 2023). Taking on this support role in these circumstances can be difficult and unpredictable and it has been found that AFFMs experience a substantially poorer quality of life compared to the general population, including poorer physical and mental health (Birkeland et al., 2018; Ólafsdóttir et al., 2020; Ray et al., 2009; Vederhus et al., 2019). AFFMs may be at higher risk of developing AOD use, depression, and anxiety disorders themselves (Di Sarno et al., 2021; Orford et al., 2013). As AOD use and dependence can be a lifelong issue, there is a need to support AFFMs to develop effective long-term coping strategies and access support for their own needs and wellbeing (Copello et al., 2010a).

AFFMs also face significant stigma and social isolation which can further exacerbate stress and their ability to cope and seek support (McCann & Lubman, 2018c; McDonagh et al., 2019). As well as public and self-stigma associated with substance use, AFFMs may be subject to stigma by association or ‘courtesy stigma’ which involves public disapproval and negative social interactions invoked by narratives of blame, shame, and contamination around those supporting a loved one using AOD (Corrigan et al., 2006; Goffman, 2009). Both public stigma and stigma by association have been found to be a significant barrier to help-seeking. AFFMs may be deterred from seeking help due to shame, fear of judgment and concerns around privacy for both themselves and their loved one (McCann & Lubman, 2018b). However, help-seeking, both informally and formally, has been identified as an important strategy for helping AFFMs manage and cope adaptively with stressors and reduce levels of impact and burden (Duggan, 2007; McCann & Lubman, 2018a; Merkouris et al., 2022). Thus, addressing barriers of stigma and shame associated with seeking help are critical when developing and promoting effective forms of support and interventions for AFFMs.

Previous research suggests that the experiences and impact of supporting a loved one may depend on characteristics such as the AFFM’s gender and relationship with their loved one, as well as on socio-cultural differences (Arcidiacono et al., 2010; Dussaillant & Fernandez, 2015; Velleman et al., 2011). For example, female partners, parents, and those who live in the same household as their loved one are more likely to experience a greater cumulative burden compared to other family members and friends (Orford, 2017; Orford et al., 2017). Differences have also been found based on country and geographical location, suggesting cultural variations in impact and coping among AFFMs (Ahuja et al., 2003; Arcidiacono et al., 2010; Dussaillant & Fernandez, 2015; Orford et al., 2019). Therefore, it is important to consider potential differences in impact and coping based on demographic factors to appropriately capture the different needs of this diverse population.

Research now conceptualises AFFMs as an independent population who are uniquely impacted by the significant uncertainty, stress, and strain that may arise around a loved one’s AOD use.

Historically, AFFMs have been seen as ‘part of the problem’ or only as an adjunct to treatment of the individual affected by AOD use rather than as help-seekers in and of themselves (McDonagh et al., 2019; Orr et al., 2014; Velleman et al., 2005). In response to this, Orford and colleagues (Orford, Copello, et al., 2010) developed the Stress-Strain-Coping-Support Model which is a non-pathological model that recognizes the chronic stress of living with or supporting an individual experiencing drug dependence and the way this stress leads to strain which is mediated by their coping style and quality of social support. The 5-Step Method puts this model into practice with an emphasis on empowering family members, reducing distress, providing information, and enhancing coping and support (Copello et al., 2010b). This model has been shown to be effective in reducing the strain experienced by family members with some positive knock-on effects for the person they are supporting (Copello et al., 2010a). This finding is consistent with previous research suggesting that family members and family function play a key role in preventing and minimizing the risks and harms associated with a loved one’s AOD use, as well as promoting resilience and more positive and longer-lasting treatment outcomes (Copello et al., 2006; Roozen et al., 2010; Velleman et al., 2005; Xia et al., 2022). Specifically, family-focused approaches to intervention and recovery improve family functioning, reduce relapse, and help both affected family and their loved one improve their quality of life (Copello et al., 2006). This signifies the importance of fostering help-seeking among AFFMs, and the need for effective, targeted interventions for this population.

To date, there are few interventions available to AFFMs that do not require the involvement of the person using AOD and the interventions that do exist are rarely evaluated (Merkouris et al., 2022). Two recent online group programs developed specifically for AFFMs have shown promising results in terms of self-reported outcomes and feasibility (Peart et al., 2024; Rushton et al., 2024). Peart and colleagues’ peer-led online support program found significant improvements in self-efficacy and overall satisfaction with the program (Peart et al., 2024), and Rushton and colleagues’ found that the SMART Family and Friends, a mutual-support group targeting families delivered via video-

conferencing, was associated with significant improvements in psychological distress, family impact, family strain symptoms, and total family burden (Rushton et al., 2024). These programs demonstrate the need for support and interventions specifically developed to address the unique challenges faced by AFFMs, such as online groups and peer-based support.

While online peer support groups offer a valuable avenue of accessing help, it is important to consider the ongoing barriers to help-seeking including stigma, gaps in help-seeking knowledge, concern for their own and their loved one's privacy, and practical concerns (e.g., cost, location, time) which can deter AFFMs from accessing support even when it exists (Alcohol and Drug Foundation, 2024; Degenhardt et al., 2019; McCann & Lubman, 2018c). Additionally, AFFMs often face multiple competing stressors on top of and related to caring for a loved one using AOD and this can lead to carer burnout, introducing an additional barrier to participating in structured, group-based interventions (McCann et al., 2019; McCann et al., 2021). These barriers and the isolating impacts of stigma highlight the need for interventions to be privately accessible anywhere at any time for AFFMs.

To address this gap, the Family and Friend Support Program (FFSP) (www.ffsp.com.au) was developed in 2019 (Kay-Lambkin, 2020). FFSP is a world-first, evidence-based, online intervention designed with, and for, family members and friends supporting loved ones using AOD. Development of FFSP was based on the Stress-Strain-Coping-Support Model and the 5-step method (Copello et al., 2010a) and included consultation and collaboration with AFFMs, capturing their concerns and needs through online surveys and interviews. The program provides tailored support for AFFMs that is free, confidential, and accessible online anywhere at any time across Australia. This allows vulnerable and burdened family members and friends to access support without anxieties around compromising their own or their loved one's privacy. It also ensures that at-risk groups and marginalized communities have access to the program including women (who often bear the greater caregiver burden), low socio-economic communities (who experience greater financial stress), and

reach those living in rural/regional/remote areas with limited resources (Degenhardt et al., 2019; Kourgiantakis et al., 2021; Laslett et al., 2023). In this way, FFSP is positioned as a low-barrier early-intervention option for AFFMS learning to manage their role as a carer and advocate for their loved one using AOD. FFSP features a package of modules informed by principles of Cognitive Behavioural Therapy including psychoeducation, interactive activities, real stories from families and friends, and information on online resources and services (Kay-Lambkin, 2020). (See Appendix 2 for program screenshots)

This pilot study aimed to assess usability, acceptability, and feasibility of FFSP. A secondary aim was to capture a cross-sectional snapshot of a diverse sample of AFFM's experiences of caring for a loved one using AOD.

Method

Study Design

The study involved online surveys completed at three timepoints: 1) baseline; 2) post-program (10 weeks post baseline); and 3) one month follow-up (14 weeks post baseline) (See Appendix 1 for study flow) Following baseline surveys, participants were invited to interact with FFSP (ffsp.com.au/aod) and complete 11 evidence-informed modules, including four core modules and seven mini modules, over a 10-week period. The post-program survey was offered, 10 weeks post-baseline, to all AFFMs who completed baseline, regardless of whether they had accessed all, part, or none of FFSP. The same sample was offered a follow-up survey four weeks later. Participants were offered the opportunity to volunteer for an in-depth phone interview at both post-program and follow-up timepoints. All participants provided informed consent.

Ethics approval was obtained from the University of Newcastle (H-2017-0040) Human Research Ethics Committee.

Participants and Recruitment

Between November and December 2021, Australian residents aged 18 years or over were recruited

via social media (Facebook, Twitter) along with e-newsletters. Recruitment ads targeted AFFMS (e.g., *“Have you been affected by someone else’s use of drugs/alcohol? Researchers at the University of Newcastle and the University of Sydney have developed an online program and information website to help families/friends.”*). All three surveys were administered online via RedCap (Harris et al., 2019; Harris et al., 2009), an online data capture tool. Inclusion criteria were being an Australian resident, over the age of 18 years, and having a close family member or friend whose AOD use was causing them concern. Participants who completed the post-program and follow-up surveys were reimbursed with a \$50 gift card for each survey.

Measures

Demographics

Demographic information included age (in years), gender (“How do you identify?”), residential postcode, geographic region (metropolitan, regional, or rural/remote), and cultural heritage. (Australian Bureau of Statistics, 2021) Participants were also asked how they typically accessed the internet (smartphone, PC, tablet, tablet), and questions about their family member or friend who uses AOD including demographics, substance of concern, length of use, and the participant’s relationship to that person (e.g., partner, friend).

Psychological Distress

Psychological distress was measured using the Kessler Psychological Distress Scale (K-10) (Kessler et al., 2002). The K-10 is a well validated and widely recommended simple screening measure of psychological distress (Wojujutari & Idemudia, 2024). Participants responded to 10 items about their emotional states in the past 4 weeks on a 5-point Likert scale (where 1 = none of the time and 5 = all of the time). Scores were then summed with the maximum score of 50 indicating severe distress, and the minimum score of 10 indicating no distress.

Stress, Coping, and Social Support

Stress, coping and social support were measured via the adapted Short Questionnaire for Family

Members (Affected by Addiction) (SQFM-AA) (Orford et al., 2005) . The SQFM-AA has shown satisfactory to good internal reliability and validity (Orford et al., 2017). The SQFM (AA) consists of 33 questions about a loved one's AOD-related behaviours in the preceding three months and participants rated how often they have engaged in certain responses using a 4-point Likert scale (1 = never, 2 = once or twice, 3 = sometimes, 4 = often). The SQFM-AA includes sub-scales measuring impact (worry and disturbance), symptoms (physical and psychological), coping (engaged emotional, engaged assertive, tolerant, and withdrawal), social support (helpful formal, helpful informal and unhelpful informal), and total family burden. Total family burden scores include the cumulative score of impact, symptoms, and coping with scores ranging from 0 – 48 and higher scores indicating higher degree of burden experienced by the family member.

Help-Seeking Experiences

At post-program and follow-up, participants were also asked about their previous help-seeking experiences: “Over the past month, did you seek help to help cope with or manage your role supporting your loved one (e.g. mental health support)? Yes/No” and if they answered “Yes”, they were prompted to select all that applied to them from a list of services including “Online”, “GP”, “Counsellor/psychologist” and “Friend or family member”. Participants were then asked, “Did you receive the help that you needed?” (Yes/No), followed by “Please comment on the help you did or did not receive” (free-text box). All participants were asked about barriers to help-seeking. Barriers to help-seeking was assessed using the barriers to help-seeking scale, adapted from the widely used, reliable and valid Perceived Need for Care Questionnaire administered in the Australian National Survey of Mental Health and Wellbeing (Kershaw et al., 2024; Meadows et al., 2000). Participants were asked “Were there any barriers that have stopped you from seeking help (Select all that apply)?” and then asked to select from 11 pre-defined statements. Additionally, there was an option to select “Other” followed by the prompt “Please specify other barriers that have stopped you from seeking help?” and a free-text box.

Usability, Acceptability, and Perceived Usefulness of the Program

Program usability was assessed via the System Usability Scale (SUS) (Sauro, 2011). The SUS reliably measures usability and consists of 10 items including several facets such as ease of website use and website complexity. These 10 items were scored on a 5-point Likert scale ranging from 0 (strongly disagree) to 5 (strongly agree). Higher scores indicate better usability and range from 0 to 100. Scores of 80 or above indicate a strong performance, with the average SUS score being 68 as based on more than 500 studies (Sauro, 2011).

Additionally, participants answered the Likert scale (e.g., “How easy was it to find the information you wanted? (Select an option: Very easy, moderately easy, somewhat easy, not very easy, not easy at all, unsure)”) and open-ended questions (e.g., “Was there anything missing from FFSP that you expected or wanted to be included?”) about the acceptability and usefulness of FFSP in terms of structure and content. Participants also answered open-ended questions about perceived barriers to accessing the program (“What barriers stopped you from accessing FFSP (specify)?”), likelihood of recommending to someone else (“On a scale of 1 (wouldn’t recommend at all) to 10 (extremely likely to recommend), how likely would you be to recommend FFSP to a person supporting a loved one using alcohol and/or other drugs?”), and feedback on ways to improve the program (“Was there anything missing from FFSP that you expected or wanted to be included? If yes, then, what was missing (specify)?”).

In-Depth Phone Interviews. Further, optional in-depth semi-structured phone interviews were conducted by a clinical psychologist or social worker experienced in interviewing. Confidentiality was explained to the interviewee before obtaining consent to audio record the interview which was later transcribed by a member of the research team. Participants who completed the interview were reimbursed with a \$25 digital gift card.

Data Analysis

Data were analyzed using the IBM SPSS Statistics version 25. Independent samples t-tests and one-

way ANOVAs were conducted to assess differences in baseline K-10 and SQFM-AA Total Family Burden scores based on demographic factors (age, gender, geographical location, and relationship to loved one using AOD). To assess attrition, independent samples t-tests were conducted to compare participants who completed only baseline vs both baseline and post-program, as well as participants who accessed vs. did not access the program at post-program. Repeated measures ANOVAs were conducted to compare endorsement of coping styles and social support. Although analysis of changes in outcomes across timepoints was intended, it was not conducted due to the small sample size ($n = 11$) of those who reported accessing the program and completed all three timepoints. This paper therefore reports findings from the quantitative data collected at baseline as well as the qualitative data from post program and follow up.

Results

Demographics and Sample Characteristics

A total of 131 participants completed baseline measures (refer to Table 1 for characteristics). Mean age was 50.9 years ($SD = 12.7$) and 80.2% identified as female. Just over half of participants were from metropolitan areas (51.9%), with the majority born in Australia (81.7%) and not identifying with a particular cultural group or heritage (82.4%). The most common relationship of the loved one was a child (38.2%) and the most reported substance of concern was ice/crystal methamphetamine (48.9%).

A total of 49 participants went on to complete the post-program survey (37%) and 32 participants completed the follow-up survey (24%). At the post-program timepoint, 17 participants (13% of the baseline sample) reported accessing FFSP, whilst at the follow-up survey, 14 (11% of the baseline sample) participants had accessed FFSP since post-program. Five participants took part in individual semi-structured interviews.

Table 1

Demographic Characteristics of the Sample

N = 131

Percentage of Total Sample

Age (Years)

Mean (SD)	50.9 (12.7)
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Gender

Woman or female	105	80.15
Man or male	25	19.1
Non-binary	1	0.8

Country of Birth

Australia	107	81.7
Other*	24	18.3

Geographical Area

Metropolitan	68	51.9
Regional	42	32.1
Rural/Remote	21	16.0

Loved one using AOD

Child**	50	38.2
Partner***	29	22.1
Sibling	11	8.4
Friend	10	7.6
Parent	10	7.7
Other****	21	16.0

AOD of Concern

Crystal Methamphetamine	64	48.9
Alcohol	40	30.5
Cannabis	12	9.2
Heroin	4	3.1
Prescription Opiates	4	3.1
Other	7	5.4

*Other includes Afghanistan, Canada, Indonesia, Iran, Malaysia, Netherlands, New Zealand, Scotland, Singapore, South Africa, UK, USA.

**Child includes son, daughter, step-son, step-daughter.

***Partner includes husband, wife, spouse, partner.

****Other includes ex-partner, sibling-in-law, nephew, roommate, neighbour.

Analysis of Dropout and Attrition

As attrition (62.6% drop out) between baseline and post program timepoint was high, analysis was undertaken to explore if there were any demographic differences between those who completed only the baseline survey and those who completed both the baseline and post-program survey. Age, gender, geographical location, and relationship to the affected loved one were not significantly

associated with drop out from baseline to post program. There were also no significant differences in basic demographic factors between those who did and did not access the program.

Psychological Distress at Baseline

Mean K-10 score at baseline among the total sample was 28.4 (SD = 8.6), which falls in the moderate to severe range of psychological distress (see Appendix 3). There were no significant differences in K-10 scores based on age, gender, relationship to affected loved one, or geographical location. However, participants who accessed FFSP had significantly higher baseline K-10 scores (M=31.6, SD=10.3) compared to those who did not access FFSP (M=24.2, SD=7.6), $t(47) = 2.86$, $P = .006$.

Stress, Coping, and Social Support

Stress, Strain, and Total Family Burden

Mean total family burden scores at baseline was 44.96 (SD = 9.46), indicating a high degree of burden experienced by participants associated with their loved one's AOD use. Total family burden did not differ significantly based on demographics such as age, gender, relationship to loved one, or geographical location.

In terms of the impact of their loved one's AOD use over the previous 3 months, the majority of participants reported that their loved one's AOD use at least sometimes; affected the family's finances (n = 89, 68%), got in the way of their social life (n = 99, 75.6%), led to worry about their loved one's neglect of self-care (n = 104, 79.4%), led to fights or arguments (n = 96, 73.3%), or upset family or social occasions (n = 81, 61.9%). More than half reported that their loved one has threatened them at least once or twice (n = 71, 54.2%). The majority (n = 93, 71%) of participants reported often worrying about their loved one's AOD use. Almost half the participants reported sometimes having difficulty concentrating (n = 77, 48.9%) and feeling weak in parts of their body (n = 64, 48.9%).

Coping Styles

One third ($n = 39$, 29.8%) of participants endorsed often watching their loved ones' every move and 15% ($n = 19$) had often started an argument with their loved one about their AOD use and 30% ($n = 37$) often got moody and emotional with their loved one. One third of participants endorsed often talking frankly about their AOD use and making clear to their loved one their expectations of what how they should contribute to the family. Over a third ($n = 45$, 35%) endorsed often putting themselves out for their loved one, for example getting them to bed or clearing up mess after they had been drinking or taking drugs.

Social Support

A majority of participants ($n = 88$, 64.1%) endorsed that friends/relations sometimes or often listened to them when they have talked about their feelings, that their friends/relations sometimes or often have been there for them ($n = 83$, 63.3%), and that friends/relations have sometimes or often talked to them about their loved one and listened to what they had to say ($n = 82$, 62.6%). Over half the participants endorsed that they never; had health/social care workers give them helpful information about problem drinking or drug taking ($n = 76$, 58%); had health/social care workers make themselves available to them ($n = 77$, 58.8%), or confided in their health/social care worker about their situation ($n = 70$, 53.4%) (see Appendix 4 for full breakdown of SQFM-AA scores).

Help-Seeking Experiences

Among the participants who completed the post-program survey ($n = 49$), the majority ($n = 27$, 55.1%) reported that they did not seek help to cope with or manage their role supporting their loved one. Of the 22 (44.9%) participants who reported that did they seek help, the most common form of support accessed was a counsellor/psychologist ($n = 13$, 26.5%). Participants provided a mix of positive and negative comments on their previous help-seeking experiences. Examples of positive comments include, "My psychologist has been a great listener and has been very understanding and supportive" and another commented, "NA (Narcotics Anonymous) has been useful in that we now have a small group of people who understand our situation and are supportive. Otherwise, NA and 12

steps in particular don't feel relevant or useful to me.” Examples of negative comments include, “{health workers) Judgement or jumping to conclusions” and “too long of wait lists”. These sentiments were also reflected in interviews, for example, one interviewee highlighted that stigma is an ongoing barrier to asking for help, *“One barrier that I think I could identify there is that it’s very common, in my experience, that people, family and friends of people who’ve got a substance abuse problem...feel almost embarrassed to admit that this is something that’s completely out of their control, and participating in programs can often be a very challenging thing for them to do, because they fear that they’re going to be held accountable”*. Barriers to help-seeking are summarized in Table 2.

Table**2.***Barriers to Help-Seeking Endorsed by Participants at Post-Program.*

Barrier to Help-Seeking	N = 49	%
I couldn't afford the money	14	28.6
I didn't need help	11	22.4
I preferred to manage myself	11	22.4
I didn't think anything could help	9	18.4
I was afraid of legal implications	9	18.4
I previously asked but didn't get help	9	18.4
I couldn't afford the time off work	8	16.3
I previously asked for help but had a negative or bad experience	6	12.2
I was afraid of what others would think of me	4	8.2
I didn't know where to seek help	4	8.2
I was afraid to seek help	2	4.1
Other* (service unhelpful, not needing support, general stigma, other support)	6	12.2

Note. Participants were able to select multiple responses.

*Free text box.

Usability, Acceptability, and Perceived Usefulness of the Program

The average System Usability Scale score for FFSP was 70 ($SD = 18$, $n = 17$), which is slightly above average score of 68 from 500 studies (Sauro, 2011). Among the participants who completed the post-program survey, the majority ($n=36$, 65.3%) of participants reported that it was easy to find the information that they wanted, and most ($n= 35$, 71.4%) reported that the information was easy to understand. Further, over half ($n=26$, 53.1%) felt that the activities were somewhat, moderately, or very helpful. After interacting with FFSP, 1 in 3 ($n=17$, 34.7%) felt very or moderately confident when faced with AOD related issues. The majority ($n=35$, 71.5%) of participants rated that they would be likely to recommend FFSP to a person supporting a loved one using alcohol and/or other drugs.

All interviewees in the semi-structured interviews (n=5) identified the need for programs such as FFSP to address the lack of accessible support for AFFMs, to validate and normalise AFFMs experiences, and to combat misinformation and stigma surrounding AOD use. For example, one interviewee found the vignettes of lived experience stories validating, *"It's extremely comforting.... to find that there is somebody else who is just like you."* Another interviewee spoke about the important role of online support in overcoming shame, *"There is a big role for online support to play because it helps people not feel so bad because I think...half the problem is, people don't tell anyone because it's so shameful, particularly once they're an adult."* Another interviewee highlighted the need for online, 24/7 access particularly when living in a small town, *"being in a smaller town where everyone seems to know everyone's business makes it a bit harder to front up to those sort of things (ask for help). So when you can do stuff online it can be obviously done in your own time."*

Some interviewees described the length and amount of content as a barrier to completion. For example, one participant found that *"FFSP felt quite complex and needed considerable time commitment"* and another participant noted that *"There was just so much information, it required considerable time to work through."* In terms of ways to improve the content of FFSP, participants suggested including more practical strategies and skills for supporting their loved one, more content focused on lived experiences and follow up with in-person community groups and resources. For example, when asked what they would like to include, one interviewee said, *"more stories of what being a friend or family support person might involve"*. Another interviewee wanted more content addressing stigma and shame in the carer role, *"I think it would be very helpful if you could give to people going through the program, tips to enable them (a) to understand this is not your fault, (b) to come to the realisation that you don't have to be angry at the person who's in substance abuse."* Finally, another interviewee said that they would like the online format to be complemented by in-person services and resources, *"It needs direct references into live communities of belonging, not just web resources."*

Reasons for not accessing the program between the survey timepoints included time restrictions, other stressors (e.g., their own sickness, work stress, carer burnout), and perceived lack of need (e.g., receiving other formal or informal support, loved one doing well/in recovery). Several participants also noted technical difficulties (e.g., links not working, forgetting passwords).

Discussion

This pilot study investigated the usability, acceptability, and feasibility of the Family and Friends Support program (FFSP), a world-first, evidence-based online intervention developed to support the wellbeing of family members and friends with a loved one using AOD.

Overall, FFSP demonstrated good usability and acceptability among AFFMs and was found to be useful in validating user's experiences and addressing stigma around seeking help. Most participants reported that FFSP was easy to use, and it was easy to find and understand the content. Participants reported that the lived experience vignettes on FFSP were validating and normalized their own experiences. This feedback is reflective of broader research highlighting the value of sharing lived experiences to reduce stigma and discrimination around mental health and substance use for both individuals and the general public (Jorm, 2020; Morgan et al., 2021; Treloar et al., 2019). Similar to peer support programs, the sharing of lived experience stories plays an important role in empowering AFFMs by validating their unique difficulties supporting a loved one with AOD use whilst also normalizing seeking and accessing support for themselves (Tari-Keresztes et al., 2023). Participants highlighted that they would like to see even more emphasis on stories and voices of lived experience in FFSP.

The findings indicate that FFSP was feasible to administer as an online, self-paced program which users are able to access at their discretion. The private and confidential format helps to address participant's concerns around stigma and fear of judgement. Further, the program being free, self-paced, and available 24/7 helps overcome other help-seeking barriers that participants endorsed of financial strain, time restrictions, and other life stressors.

This study also examined AFFMs experiences of caring for a loved one using AOD in relation to their levels of distress as well as their experiences of stress and strain, coping and social support. On average, AFFMs in this study reported moderate to severe levels of psychological distress. This is in line with previous research highlighting AFFMs as a population may be vulnerable to increased risks of psychological distress and mental health difficulties (Di Sarno et al., 2021; Ólafsdóttir et al., 2020; Orford, Velleman, et al., 2010). Distress levels were similar across demographic variables including age, gender, geographical location (metropolitan, regional or remote areas), and relationship to their loved one. Similarly, there were no significant differences in SQFM-AA scores across these participant characteristics. For example, scores measuring the degree of burden falling on an AFFM due to the effects of their loved one's AOD use did not differ based on relationship to the loved one. This finding is interesting as previous studies have found significant differences in symptoms of stress and level of harm based on gender, cultural factors, and relationship to the family member (Orford, 2017). For example, a previous study in Brazil found that wives and mothers reported higher levels of burden compared to other family members including fathers (Orford, 2017). A smaller sample size in the present study as well as uneven distribution across types of relationships and cultural background may partially explain this different finding. Although the present study did not focus on this, it would be important for future studies to explore the differences amongst social and cultural factors in order to inform the development of services that are culturally sensitive and responsive (Marel et al., 2022; Rickwood, 2006). Finally, the majority of participants did not access or receive helpful support from formal services, consistent with previous findings of low rates of help-seeking among AFFMs which may also reflect to a lack of accessible or appropriate formal support available (McCann & Lubman, 2018c).

Finally, higher levels of psychological distress were significantly associated with accessing the program. This is in line with this study's finding that the most common reason for participants not accessing the program was a perceived lack of need. Almost one third of the reasons given for not

accessing the program were related to the participant's loved one being in recovery or generally doing well. This may reflect the fact that recovery is a lifelong dynamic process dependent on individual, social, and contextual factors (Laudet, 2008; Laudet et al., 2002; Scott et al., 2005; Vaillant, 2003). Knowing that AFFMs are greatly impacted by their loved one's AOD use, AFFM's own mental health and support needs are also likely to change over time depending on both their loved one and their own life events. This points to the importance of ensuring programs such as FFSP are a known option for AFFMs to access when they need it. This might include liaising with clinicians and health workers who are likely to be in contact with people during periods of difficulty who may then be able to refer individuals to FFSP, positioning the program as a complementary tool in their broader recovery journey.

Strengths, Limitations, and Future Directions

A key limitation of this study was the low rate of program uptake and high attrition which hindered the study's aim to assess the program's effectiveness. This may be partly due to the impact of the pandemic and natural disasters occurring over the course of recruitment, however, poor adherence to online interventions is a universal problem (Forbes et al., 2023; Shams et al., 2023). Further, AFFMs are a particularly vulnerable and hard to reach population facing ongoing barriers of stigma and carer burnout (McCann & Lubman, 2018c). Previous research has found that integrating therapist or facilitator elements into online interventions tends to be associated with higher rates of engagement compared to self-guided interventions (Baumeister et al., 2014; Borghouts et al., 2021). Thus, future strategies to promote engagement and retention of FFSP might include non-clinician facilitation such as email reminders, online technical or administrative support, 'gamification' (progress and completion rewards), or clinician guidance such as complementing brief psychosocial support from a trained therapist. Further, enhancing usability and accessibility through optimizing user experience particularly for mobile may increase engagement and adherence as most people accessed the internet on their smartphone (Jakob et al., 2022). Finally, future content improvements could include more

lived experience stories, prioritizing clarity and conciseness of information per page, and additional resources and links to in-person services to provide follow-up and encourage people to build a network of support options. These learnings will guide a future large-scale trial evaluating the efficacy and outcomes of FFSP.

This study also had a number of strengths. Firstly, an intention-to-treat approach was followed which aimed to minimise the risk of bias related to adherence and attrition in regard to assessing the acceptability of FFSP. This allowed us to capture more diverse perspectives and account for potential differences between those who do and do not access the program and those who do and do not complete the post program and follow up surveys.

Secondly, as reflected in the broader literature, AFFMs are a particularly hard to reach population in research and healthcare considering the unpredictability of their carer roles, concurrent burdens they face as well as ongoing impacts of stigma and social isolation. The present study was successful in recruiting a relatively representative sample of AFFMs which included a range of genders, ages, geographical locations, and relationships to the loved one using AOD. The flexibility of FFSP allows family members and friends to access the program 24/7 when they have the time, privacy, and space to access support. This flexibility is key to reaching at-risk groups including women (who often bear the greater caregiver burden), low socio-economic communities (who experience greater financial stress), and reach those living in rural/regional/remote areas with limited resources (Degenhardt et al., 2019; Kourgiantakis et al., 2021; Laslett et al., 2023). As reflected in the quantitative and qualitative feedback on the program, participants provided positive feedback on the ease, convenience, and need for online programs.

Conclusion

This study adds to the growing body of literature demonstrating high levels of distress and strain among people caring for a loved one using AOD, whilst highlighting the ongoing barriers to help-seeking among this population as well as the opportunities for early intervention and support. This

pilot study found that FFSP is feasible to administer, acceptable, and has the potential to fill an important gap in services specific to family and friends supporting a loved one using AOD. This study also identified areas for improvement of the program and highlighted important learnings prior to conducting an evaluation of program efficacy. Whilst FFSP is a promising intervention for AFFMs, there is ongoing need for increased research and investment into reducing stigma and other barriers to help-seeking as well as developing and evaluating early intervention and support for both people caring for a loved one using AOD as well as the loved one themselves.

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Supplementary Files

Multimedia Appendixes

Study procedure.

URL: <http://asset.jmir.pub/assets/191e7997f9351a9360dbafc2ec290d87.docx>

Screenshots from the program.

URL: <http://asset.jmir.pub/assets/fe0bcdd1de01ca4abc02c6a9167912cd.docx>

K-10 and SQFM-AA descriptive statistics.

URL: <http://asset.jmir.pub/assets/33dbe7c0889e87651e2ca5be10584619.docx>

SQFM-AA individual item endorsement.

URL: <http://asset.jmir.pub/assets/7def30f4e7b3480c1a1a8401725cc59d.docx>