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Developing and testing the F-SIM, a measure of social inclusion for people with mental illness

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ABSTRACT

Social inclusion is an important contributor to good mental health and greater mental health outcomes for people with psychiatric disorders. A psychometrically-sound measure of social inclusion is required to facilitate progress in this area. The aim here was to report on preliminary findings from a novel, user-friendly measure of social inclusion that comprehensively assesses the construct. Preliminary testing of the Filia Social Inclusion Measure (F-SIM) was conducted with ninety participants (30 consumers; 30 family members/carers; 30 community members). Participants completed the self-report measure and a usability questionnaire. Preliminary findings demonstrated poorer social inclusion for people with mental illness compared to those without, with differences seen in each of five domains (housing and services, social functioning, occupational functioning, finances and health). Differences were also seen regarding family members or carers, with consistently poorer social inclusion than general community members observed. Participants reported the F-SIM as easy to use, and considered it to measure social inclusion well, indicating good face validity. The F-SIM demonstrates an ability to differentiate between groups. Implications for use and suggestions for future research are detailed. Following further psychometric assessment, the F-SIM will have wide applicability in clinical and research settings.

1. Introduction

People with severe mental illness are amongst the most vulnerable to social exclusion, commonly experiencing complex and inter-related forms of disadvantage (Social Exclusion Unit, 2004). The concept of *social inclusion* (existing on the other end of a fluid continuum from social exclusion) consists of a number of inter-connected factors including cohesive social networks, social and occupational participation (including education and training), housing, access to and utilisation of well-resourced services, community participation, good health and positive lifestyle factors (Filia et al., 2018).

Social exclusion can increase vulnerability to poor mental health outcomes, with a lack of supports, finances and other protective structures, such as good social capital, stable housing and steady employment. Conversely, social inclusion is beneficial and has protective elements, resulting in more positive mental health outcomes (Dunstan et al., 2017; Fenton et al., 2017; Saeri et al., 2018).

Social exclusion is also experienced by caregivers (Spoehr et al., 2007; Taket et al., 2009), with the burden of care placed on them resulting in reduced opportunities for social and occupational participation, a loss of finances, negatively impacted housing situations and reduced emphasis on self-care and leisure activities. Differences in social inclusion between consumers, caregivers and members of the general community are assumed, however have not yet been examined.

Understanding of the positive impacts of social inclusion on mental health outcomes is increasing. This has led to a similar increase in efforts to reduce, or reduce the impact of, social exclusion including psychological therapies and psychosocial programs and interventions (Riva and Eck, 2016). Despite increasing understanding of the concept, valid and reliable measures of social inclusion are lacking (Coombs et al., 2013; Cordier et al., 2017; Huxley et al., 2012). This lack of measurement means that it is difficult to: (i) identify populations in need or at risk of social exclusion; (ii) determine targets for intervention; and (iii) measure intervention effectiveness and/or efficacy.

Central to the lack of appropriate measurement tools, has been the absence of a clear, specific and/or operationalised definition of social inclusion (Huxley et al., 2012; Morgan et al., 2007; Vinson, 2009). While other constructs commonly encountered in mental health

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research possess similar definitional fuzziness (e.g., functioning, quality of life, recovery, wellbeing), social inclusion is an emergent concept. Without clear delineation of what social inclusion is, it is difficult to ensure that any measure developed thus far is accurately evaluating this concept (Coombs et al., 2013). In addition, the relativity of social inclusion means that for each population, different elements of social inclusion are of greater importance or relevance, with varying needs and challenges experienced in particular for at-risk groups (Filia et al., al.,2019). Measures developed specifically for people with mental illness (being a group most vulnerable to social exclusion) are therefore important, particularly with nuances specific to each population potentially impacting psychometric evaluations.

Several measures for use with people with mental health conditions have been proposed (e.g., Dorer et al., 2009; Huxley et al., 2012; Lloyd et al., 2008; Marino-Francis and Worrall-Davies, 2010; Mezey et al., 2013; Secker et al., 2009; Stickley and Shaw, 2006). However, these measures require either re-development to address limitations that restrict their ability to be applied, for example they had been developed with too much specificity, to measure the impact of a particular intervention or service (Dorer et al., 2009; Marino-Francis and Worrall-Davies, 2010; Secker et al., 2009; Stickley and Shaw, 2006), or require further psychometric testing (Huxley et al., 2012; Lloyd et al., 2008; Mezey et al., 2013). Therefore, there is currently no psychometrically sound measure of social inclusion.

In addressing these limitations, our team adopted a systematic approach to developing a measure of social inclusion for use with people with lived experience of mental illness. We conducted a thematic analysis of carefully selected literature relating to social inclusion (academic, peer-reviewed and grey literature) and identified what professionals working to improve social inclusion consider key contributors (Filia et al., 2018). We then conducted a consensus study with consumers of mental health services, carers and general community members to understand, from a personal angle, the importance and relevance of key contributors of social inclusion (Filia et al., 2019). Based on these studies, we have developed a social inclusion measure, named the Filia Social Inclusion Measure (F-SIM). It has been designed for use with people with lived experience of mental illness. Here we provide a preliminary analysis of the measure's validity, with a focus on how items discriminate between people with and without lived experience of mental illness.

2. Methods

2.1. Participants

Participants were from three groups: (i) consumers of mental health services (past or present, 'Consumers'); (ii) people with a close family member with mental illness or carers of a person with mental illness (past or present. 'Family/Carer'); and (iii) and general community members (no diagnosis of severe mental illness, not acting or having acted as a carer, and not identifying as being affected in a day-to-day manner by the presence of mental illness within their family, 'Community'). *A priori* power calculations indicated that a sample size of 30 or more in each group was required to provide sufficient power ($1 - \beta = 0.80$) to reliably detect group differences between three groups with a large effect size and $\alpha = 0.05$ (Cohen, 1992).

Recruitment ran from April to July 2013. The majority of participants in the Consumer and Family Member/Carer groups had participated in an earlier, related study where recruitment had largely focused on inviting consumers and carers through their advocacy roles at mental health outpatient services and support services (Filia et al., 2019). Remaining participants were selected via the techniques outlined in Table 1. Group membership was self-selecting.

Table 1
Number of participants approached to take part in the study using each recruitment strategy.

Recruitment Strategy	Consumers	Carers	Community Members
Previous research participants	31	37	9
Advertisements	2	1	1
Emails and phone calls	4	5	20
Referrals from existing participants	5	6	7
Totals	42	49	37

2.2. Instruments

2.2.1. The Filia Social Inclusion Measure (F-SIM)

The F-SIM was developed based on the team's previous work (Filia et al., 2018, 2019). The aim here was to create a user-friendly questionnaire that comprehensively measured the construct.

The F-SIM was designed as a self-report questionnaire, with additional information/instructions to assist participants in completing the assessment. The F-SIM comprised 126 items, divided into 55 questions. The majority of items pertain to the past month, unless indicated otherwise. Most items were measured on a dichotomous scale with *Yes/No* responses, some were ordinal, e.g., *I don't have a group of friends to call on to do anything socially (Not at all/A little bit/Very much so*) and others nominal. (e.g., *Where do you currently receive an income from?)*. A balance of items measuring social inclusion from an objective (e.g., *How much net income do you receive each week?)* and subjective perspective were included (*Do you receive enough income to cover your basic everyday costs?)*. Items merged logically into five domains: Housing, Neighbourhood and Services; Relationships, Activities and Setbacks; Employment and Education; Finances; and Health and Wellbeing. Age, gender and diagnosis (for the Consumer and Family/Carer groups) were also obtained.

2.2.2. The F-SIM Experience

The F-SIM Experience is a usability questionnaire developed to examine the utility, face validity and acceptability of the F-SIM. It comprises five questions reflecting participants' experiences of completing the questionnaire, including time taken to complete the F-SIM, perceptions of utility and face validity, and barriers impeding completion. Items were again measured using mixed-measurement, with ordinal (*Yes/No/Maybe a little),* dichotomous (*Yes/No),* and nominal data collected. Prompts were provided to determine which aspects of completing the questionnaire were considered difficult, and a free text response allowed for additional information.

2.3. Procedure

Ethics approval was granted by the Melbourne Health Human Research and Ethics Committee (HREC 2010.105). Participants were contacted via email, phone or mail, with a verbal and/or written description of the study. Most participants completed the questionnaire online using *surveymonkey.com*. One person requested a hard copy via mail. All participants were informed that consent was implied by completing the questionnaire; information regarding study information, privacy and confidentiality was provided. Measures were completed only once.

2.4. Data analysis

Data screening was conducted, and normality assessed for each continuous variable on the F-SIM, looking at skewness and kurtosis of distributions. As per Tabachnik and Fidell (2012), where the ratios of skewness and kurtosis to their respective standard errors were greater than 3, further investigations were conducted to determine where discrepancies lay. Transformations were applied where appropriate, but as

analyses did not yield different results, findings pertaining to untransformed variables are presented here.

The focus of the inferential analyses was on determining differences between the three groups: Consumers, Family/Carers, and Community. Descriptive statistics were used to summarise age, gender and diagnosis (for the Consumer and Family/Carer groups). Chi-square tests (χ^2) for independence and one-way analysis of variance (ANOVA) models were used to determine whether the three groups were matched with respect to gender and age, and to determine differences between groups regarding their responses on the F-SIM and F-SIM Experience. Where the assumption of variance was violated, the Brown-Forsythe test statistic was reported. In a number of cases groups were collapsed to increase cell size (>5 cases in greater than 20% of cells) to enable chi-square comparison tests to be performed. This was only done where the outcome was unaffected by collapsing groups.

Following the identification of statistically significant differences between the three groups, post-hoc comparisons were made within each domain using the Tukey HSD test for parametric variables. Column proportions were compared using Bonferroni adjusted p-values, where chi-square analyses indicated significant differences.

All statistical analyses were conducted using IBM® SPSS® Version 25.0.

3. Results

3.1. Participants

The final sample comprised ninety participants, with thirty participants in each group. Group demographic characteristics are outlined in Table 2, including test-statistics.

Overall, 71.1% of participants were female ($n = 64$) and 28.9% male ($n = 26$); there were no significant groups differences in terms of gender. Participants ranged in age from 24–81 years ($M = 40.76$ years, $SD = 12.15$). Differences in age were seen between groups, $F(2, 87) = 4.07$, $p = .020$: with post-hoc tests indicating that the differences were between the FMC group ($M = 45.27$ years, $SD = 14.64$) and the Community group ($M = 36.63$ years, $SD = 10.14$), $p = .015$. The mean age of participants in the Consumer groups was 40.37 ($SD = 9.87$).

Those in the Consumer and FMC groups most commonly experienced affective disorders such as depression, comorbid depression and anxiety, bipolar disorder and schizoaffective disorder.

Participants from the FMC group were most likely to be caring for a parent with mental illness (40.0%, $n = 12$). 30% of participants from this group reported multiple family members (up to five immediate family members) with mental illness ($n = 9$).

3.2. The F-SIM

Table 3 provides details regarding differences on individual items within the five domains of F-SIM, including group results, appropriate test-statistic for each item and significance values.

3.2.1. Housing, neighbourhood and services

There were significant differences ($p \leq .01$) between the three groups with respect to who they lived with, the amount per week spent on accommodation (rent or mortgage), whether they would prefer to be living in another location/area, having experienced neighborhood crime or violence and, using the internet for social interactions. Differences were also seen between groups regarding weekly contact with neighbours ($p = .035$).

Post-hoc comparisons indicated that Consumers were significantly more likely than the Community group to report: living alone, in a location other than where they would prefer, experiencing neighbourhood crime or violence, and using the internet to fill a social need not met elsewhere. With respect to housing costs, Consumers reported significantly lower costs than the Community group ($p = .004$). Members of the Community group reported significantly more weekly contact with their neighbours than those in the Family/Carer group ($p < .05$).

3.2.2. Relationships, activities and setbacks

Differences were observed between groups regarding the experience of setbacks or limitations that interfered in participants' ability to take part in social activities. Differences were seen with respect to: poor self-confidence or self-esteem, feeling unwelcome or like they don't belong, feeling excluded or not part of the group when taking part in new activities or joining new groups, and not knowing what to do to improve their circumstances ($p \leq .01$). Post-hoc comparisons indicated that these differences were all seen between the Consumer and Community groups ($p < .05$) with Consumers reporting more setbacks or limitations than Community members in all instances.

Groups also differed in how often participants spoke to a family member or friend on the phone $\chi^2(4, N = 90) = 10.02$, $p = .040$, but post-hoc comparisons failed to indicate where differences between groups lay.

3.2.3. Employment and education

A large proportion of the sample overall had been employed or enrolled in formal education over the past 12 months (92.2%, $n = 83$). A number of participants reported experiencing some limitations to employment with differences between groups ($p < .01$) noted

Table 2
Demographic characteristics of participants in each of the three groups.

Variable	Consumer	Family Member or Carers	General Community	Test statistic	*p*-value	
Gender: Female% (*n*)	73.3 (22)	80.0 (24)	60.0 (18)	χ^2 (2, N = 90) = 3.03	.220	
Age, years: *M (SD)*	40.37 (9.87)	45.27 (14.64)	36.63 (10.14)	$F(2,87) = 4.07$	.020	
Range	(25–60)	(26–81)	(24–65)			
Diagnosis% (*n*) of consumers and those the carers care for						
Depression	16.67 (5)	16.67 (5)				
Depression & anxiety	13.33 (4)	13.33 (4)				
Bipolar affective disorder	16.67 (5)	16.67 (5)				
Schizoaffective disorder	10.00 (3)	3.33 (1)				
Schizophrenia	10.00 (3)	26.67 (8)				
Psychotic illness	10.00 (3)	–				
Borderline personality disorder	13.33 (4)	3.33 (1)				
Generalised anxiety disorder	3.33 (1)	–				
Autism spectrum disorder	–	10.00 (3)				
- & Depression	–	3.33 (1)				
Dementia	–	3.33 (1)				
Depression & eating disorder	3.33 (1)	–				
Depression, anxiety & PTSD	3.33 (1)	–				
Mental illness due to physical conditions	–	3.33 (1)	–	–	–	

Table 3
Differences between groups on the items of the F-SIM.

Section & Question	Consumer	Family Member or Carers	General Community	Test statistic	df	*p*-value
Housing, Neighbourhood & Services						
Who do you currently live with? (n = 90)	33.3 (10)	10.0 (3)	6.7 (2)	χ^2 = 9.12	2	.010
-Living Alone: % (n)						
How much per week do you personally spend on your rent or mortgage? (n = 87)	197.25 (192.48)	309.33 (289.56)	431.90 (300.00)	F = 5.61	2	.005
-M (SD)	(0–800)	(0–1000)	(0–1100)			
-Range						
Would you prefer to be living in a different area or location? (n = 90)	40.0 (12)	13.3 (4)	3.3 (1)	χ^2 = 14.07	2	.001
-Yes: % (n)						
Have you experienced neighbourhood crime and/or violence whilst you've been living in the area? (n = 90)	53.3 (16)	33.3 (10)	16.7 (5)	χ^2 = 8.96	2	.011
-Yes: % (n)						
In the past 12 months I have: Dropped in to a neighbour's house or stopped and chatted to them at least weekly (n = 90)	46.7 (14)	30.0 (9)	63.3 (19)	χ^2 = 6.70	2	.035
-Yes: % (n)						
Does the internet fill a need for you socially that you aren't getting elsewhere? (n = 90)	60.0 (18)	33.3 (10)	23.3 (7)	χ^2 = 9.07	2	.011
-Yes: % (n)						
Relationships, Activities & Setbacks						
How often do you: Talk to a family member or friend on the telephone (n = 90)						
- At least daily: % (n)	50.0 (15)	23.3 (7)	30.0 (9)	χ^2 = 10.02	4	.040
- At least once or twice a week: % (n)	26.7 (8)	40.0 (12)	56.7 (17)			
- Monthly or less: % (n)	23.3 (7)	36.7 (11)	13.3 (4)			
I don't have very good self-confidence or self-esteem (n = 90)	53.3 (16)	26.7 (8)	13.3 (4)	χ^2 = 11.61	2	.003
-Yes: % (n)						
I often feel unwelcome, like I don't belong (n = 90)	53.3 (16)	23.3 (7)	6.7 (2)	χ^2 = 16.72	2	<.001
-Yes: % (n)						
I feel excluded or not part of the group when taking part in new activities or joining new groups (n = 90)	46.7 (14)	33.3 (10)	10.0 (3)	χ^2 = 9.84	2	.007
-Yes: % (n)						
Relationships, Activities & Setbacks						
I'm unhappy with some parts of my life but I just don't seem to have the motivation to improve things (n = 90)	76.7 (23)	46.7 (14)	43.3 (13)	χ^2 = 8.19	2	017
- Yes: % (n)						
I don't know what I need to do to improve my circumstances (n = 90)	43.3 (13)	26.7 (8)	6.7 (2)	χ^2 = 10.63	2	.005
- Yes: % (n)						
Employment & Education						
Poor employment opportunities (n = 90)	56.7 (17)	33.3 (10)	23.3 (7)	χ^2 = 7.47	2	.024
- Yes: % (n)						
Having an illness that is likely to impair your ability to either perform your occupational role or disrupt employment (n = 90)	62.1 (18)	13.3 (4)	3.3 (1)	χ^2 = 30.24	2	<.001
- Yes: % (n)						
Having an illness that has previously impaired your ability to obtain skills or qualifications necessary for employment (n = 90)	50.0 (15)	3.3 (1)	3.3 (1)	χ^2 = 28.43	2	<.001
- Yes: % (n)						
Not having skills or qualifications that are required for employment (n = 90)	33.3 (10)	13.3 (4)	3.3 (1)	χ^2 = 10.08	4	.006
- Yes: % (n)						
Finances						
How much nett income do you receive each week, prior to any deductions? (n = 79)	606.43 (364.44)	940.84 (472.95)	1160.96 (665.91)	F = 7.96	2	.001
- M (SD)	(0–1625)	(0–2000)	(0–3200)			
- Range						
Do you receive enough income to cover your basic everyday costs (n = 90)	60.0 (18)	10.0 (3)	96.7 (29)	χ^2 = 15.66	2	<.001
- Yes: % (n)						
Is your income is so low that you suffer from financial strain (n = 90)	46.7 (14)	10.0 (3)	0.0 (0)	χ^2 = 23.64	2	<.001
- Yes: % (n)						
Do you feel that you earn considerably less or suffer more financial strain than others in your community (n = 89)	40.0 (12)	10.3 (3)	3.3 (1)	χ^2 = 15.38	2	<.001
- Yes: % (n)						
Have you experienced long-term poverty (n = 90)	40.0 (12)	6.7 (2)	6.7 (2)	χ^2 = 15.20	2	<.001
- Yes: % (n)						
Have you experienced financial hardship for longer than 5 years (n = 90)	36.7 (11)	16.7 (5)	10.0 (3)	χ^2 = 6.94	2	.031
- Yes: % (n)						

(*continued on next page*)

Table 3 (*continued*)

Section & Question	Consumer	Family Member or Carers	General Community	Test statistic	df	*p*-value
Considering the income that you receive, have you experienced the following financial hardships over the past 12 months?						
Unable to keep up with paying the bills (n = 89) - Yes: % (n)	36.7 (11)	16.7 (5)	3.4 (1)	χ^2 = 10.70	2	.005
Unable to afford healthcare (n = 90) - Yes: % (n)	36.7 (11)	13.3 (4)	3.3 (1)	χ^2 = 12.01	2	.002
Unable to afford a variety of healthy food (n = 90) - Yes: % (n)	26.7 (8)	3.3 (1)	0.0 (0)	χ^2 = 14.07	2	.001
Unable to attend important events such as weddings, funerals, birthday celebrations due to a lack of funds (n = 90) - Yes: % (n)	30.0 (9)	10.0 (3)	6.7 (2)	χ^2 = 7.27	2	.026
Unable to take up a hobby or leisure activity of choice (n = 90) - Yes: % (n)	43.3 (13)	20.0 (6)	16.7 (5)	χ^2 = 6.48	2	.039
No holiday in past 5 years (n = 90) - Yes:% (n)	36.7 (11)	10.0 (3)	3.3 (1)	χ^2 = 13.44	2	.001
Lack of savings for use in an emergency (n = 90) - Yes: % (n)	53.3 (16)	30.0 (9)	23.3 (7)	χ^2 = 6.50	2	.039
Health & Wellbeing						
Do you have any ongoing physical ailments that prevent you from:						
Achieving all you would like in your life? - Yes:% (n)	40.0 (12)	33.3 (10)	6.7 (2)	χ^2 = 9.55	2	.008
Do you feel that your emotional health interferes in your ability to						
Achieve all you would like in your life? (n = 90) - Yes: % (n)	63.3 (19)	33.3 (10)	6.7 (2)	χ^2 = 21.36	2	<.001
Access services that would help to improve your life or circumstances? (eg. health services, public transport, internet) (n = 90) - Yes: % (n)	26.7 (8)	10.0 (3)	0.0 (0)	χ^2 = 10.15	2	.006

regarding: having an illness likely to impair or disrupt their occupational functioning, having an illness that previously impaired their ability to obtain qualifications necessary for employment, and not having the skills or qualifications required for employment. Differences were also seen regarding the experience of poor employment opportunities (p = .024).

Post-hoc comparisons indicated that Consumers noted significantly more limitations to their employment than Community members (p < .05) as a result of poor employment opportunities, and not having the skills or qualifications required for employment. Consumers noted in greater proportions than both Family/Carer and Community members that their employment opportunities were limited by: having an illness likely to impair or disrupt their occupational functioning, and having an illness that previously impaired their ability to obtain qualifications necessary for employment (both significant at p < .05).

3.2.4. Finances

Groups differed with respect to the amount of net income received weekly $F(2, N = 79) = 7.96$, p = .001. Consumers received significantly less than those in the Family/Carer (p = .048) and Community groups (p = .001).

Group differences were also seen regarding participants' current financial situation (p = .001): receiving less income than required to cover basic everyday costs, an income so low that they suffer financial strain, earning considerably less income or suffering more financial strain than others in their community, experiencing long-term poverty and at p = .031, experiencing financial hardship for longer than 5 years. More differences were seen regarding financial hardships over the past 12 months including (at p < .01) being unable to: keep up with paying the bills, afford healthcare, afford a variety of healthy food, take a holiday over the past 5 years; and at p < .05; attend important events such as weddings, funerals and birthday celebrations, take up a hobby or leisure activity of choice, and contribute to any savings for use in an emergency.

Post-hoc comparisons consistently indicated poorer results for Consumers. Consumers reported significantly greater financial stress than Family/Carer and Community members on the following items (at p < .05): receiving an income so low that they suffer financial strain, earning considerably less income or suffering more financial strain than others in their community, experiencing long-term poverty; and an inability to afford a variety of healthy food, attend important events such as weddings, funerals and birthday celebrations and take a holiday in the past 5 years due to financial restrictions. Post-hoc comparisons also revealed that Consumers differed from Community members regarding the experience of financial hardship for longer than 5 years, and the inability to keep up with paying bills, and afford healthcare.

Post-hoc comparisons were not able to differentiate between groups (due to Bonferroni corrections) regarding the items: receiving less income than required to cover basic everyday costs, unable to take up a hobby or leisure activity, or contribute to any savings for use in an emergency.

3.2.5. Health and wellbeing

In the domain of Health and Wellbeing, group differences (p < .01) were observed regarding: having ongoing physical ailments that prevent you from achieving all you would like in life, emotional health interfering in the ability to achieve all you would like in life, and emotional health interfering in the ability to access services that would help to improve life or circumstances.

More Consumers and Family/Carer members than Community members reported feeling prevented from achieving all they would like in their lives due to ongoing physical ailments and their emotional health (both significant at p < .05). Consumers also differed significantly from Community members regarding their emotional health and ability to access services to assist in improving their lives or circumstances (p < .05).

Of the 41 participants who reported receiving a diagnosis of mental illness, over half (51.2%, n = 21) had previously been admitted to a mental health facility (Range = 1–50 admissions, M = 7.90, SD = 13.04). The 21 participants reported lengthy admissions, with the average admission lasting for days for only 19.1%, weeks for 42.9% and months for 38.1% of participants.

3.3. The F-SIM Experience

Participants reported the F-SIM as taking an average of 15.85 min to complete (SD = 6.40). Most didn't think it took too long to complete (84.4%, n = 76); only 12.2% (n = 11) indicated that it may have taken a little too long to complete.

56.7% (n = 51) of the sample reportedly considered the F-SIM to measure social inclusion *very well* and 41.1% (n = 37) *somewhat well*. One person thought it did not measure it very well; another noted it did not seem to be measuring social inclusion at all.

A large majority of participants didn't find the questionnaire difficult to complete (92.2%, n = 83). Of the seven participants that did find it difficult to complete, six were Consumers and one from the Family/Carer group. Reasons for finding it difficult included: wording of items, including the use of double negatives in some situations; switching from positive to negative scoring; questions that were too personal, specific or intrusive; and situations where there was not an answer true for the person's situation.

4. Discussion

This measure of social inclusion was developed for use with people with lived experience of mental illness. Successful pilot testing of the measure was completed, and analyses conducted, to assess usability and preliminary psychometric properties. Clear differences between groups were observed, As the scale has yet to undergo complete psychometric assessment, we present these findings tentatively. We have outlined where findings are in line with previous research, but place a greater emphasis on the ability to demonstrate group differences using the scale, rather than making independent inferences from the data.

4.1. Findings from the F-SIM

Group differences were observed across the five domains of the F-SIM. Differences were consistent, with Consumers faring significantly worse in most cases than the Community group. This is not an unexpected finding; people with mental illness commonly experience significant levels of marginalisation and disadvantage (Stewart et al., 2010).

Group differences were also observed regarding the Family/Carer group. This group was consistently seen falling somewhere between the Consumer and Community groups, with findings demonstrating poorer social inclusion than the Community members. The burden of caring for a person with mental illness has itself been noted as a potential contributor to social exclusion (Dorling and Rees, 2003; Merton and Bateman, 2007; Psychiatric Disability Services of Victoria (VICSERV), 2008; Social Inclusion Division, 2009; Spoehr et al., 2007; Taket et al., 2009). It may be concluded that the burden and impact of caring for, or simply of having a close family member with mental illness, was evident in the findings.

Consumers' living circumstances differed to those in the Community group. About a third of Consumers lived alone and paid less for accommodation, which could indicate the standard of accommodation they live in. They were also more likely to be living in a location other than their preference, and over half of Consumers had experienced neighbourhood crime compared to only 16.7% of Community. This is in line with previous research highlighting an increased vulnerability to victimisation of people with mental illness (Fitzgerald et al., 2005; Morgan et al., 2011).

Where setbacks, limitations or circumstances of stigma and discrimination were outlined, Consumers were more likely to encounter them as compared to Community members. Family/Carer members did not differ significantly from either group, indicating that they were not immune from the experience of setbacks or discrimination - an important reminder to consider as a potential contributor to caregiver social isolation.

While it appears in this sample that Consumers were likely to have encountered greater difficulties in achieving social inclusion due to negative experiences, Consumers reported in more instances than the Community group that the internet filled a social need for them, not met elsewhere. In an increasingly digital age, this mode of interaction was at least seen here as providing social connectedness for those with difficulties in other areas.

Higher than expected numbers of participants, particularly in the Consumer group, were currently employed, as rates of unemployment in populations of serious mental illness reported at or above 85% (Evans and Repper, 2000; Shepherd and Parsonage, 2011). However, this may have been influenced by recruitment bias. Many participants in the Consumer group had participated in previous research where they were specifically recruited in their role as paid consumer advocates. Participants in the Consumer group did report more difficulties with employment though than both Community and Family/Carer members, noting factors related to their illness as limiting them.

Financially, Consumers reported considerably less income on average and noted greater financial strain than the other groups. Consumers not only reported difficulties in keeping up with bills and covering everyday costs but also difficulties with covering the costs associated with taking part in social activities, preventing them from taking part at all in certain situations.

These findings highlight the disadvantages and difficult circumstances people with mental illness too commonly experience. Despite the negative nature of findings, it is reassuring that the F-SIM easily demonstrated significant and expected group differences.

4.2. The F-SIM Experience

The F-SIM appeared to have good acceptability and face validity, based on the F-SIM Experience findings. Participants largely did not consider the measure to take too long to complete, and did not find it terribly difficult to complete. Some difficulties were encountered with item wording. The entire measure has now been reviewed prior to the next stage of its development. Revisions have been made to the wording of items, to increase readability, make responses more intuitive and ensure that it is clear that participants can choose a not applicable option where appropriate, Good face validity was demonstrated, with most participants noting that they thought it was measuring social inclusion.

4.3. Strengths and limitations

As noted, a potential limitation includes the possibility that findings were influenced by sampling techniques, with a large proportion of consumers employed (predominantly in consumer advocacy roles). Outcomes likely affected include employment, finances, and the subsequent impact on housing and opportunities for social interactions. However, differences were still seen between groups with respect to these outcomes.

Strengths of the measure highlighted throughout this research include its versatility and the considerable input provided by consumers and caregivers during development.

The versatility of administration of the F-SIM is a significant strength, in particular the option for it to be completed as a self-report measure online. This is not only cost-effective, it also allows for greater dispersion, larger sample sizes and greater participant convenience. Individuals who may face obstacles to participation such as distance or geographical isolation, a lack of transport, restrictions on their time, or mental health issues that may limit their ability to attend a different setting or welcome an unfamiliar person into their homes have a greater opportunity to participate. This is particularly relevant with respect to social inclusion, allowing for the collection of information from people at greatest risk of social exclusion. As noted by Dorer et al. (2009), collecting information directly from the individual is a much more

socially inclusive and valid method than relying upon interviewer judgement or information sourced from caregivers or source notes.

The most significant strength of the measure however is the considerable input of people with lived experience of mental illness in the development of items, and in initial testing. A large emphasis was placed on obtaining the opinions of people from the population for whom the scale is intended. Also considered an essential element was receiving additional feedback from participants at each step of development. It is expected that the positive responses seen on the F-SIM Experience were a result of this input.

4.4. Implications and future directions

Following a complete psychometric evaluation, there will be many benefits to having a standardised, reliable and valid measure of social inclusion such as the F-SIM. The F-SIM will enable the collection of sound, empirical data, including normative data, data on at-risk and patient groups, and effectiveness data from trials of interventions. Practical implications include those relevant for both clinical and academic settings.

Implications from this study include obtaining the understanding that the measure as it exists currently is able to differentiate between groups, and is acceptable and user-friendly for participants. Feedback from participants allowing for revision of the measure prior to the next stage of its development will assist in improving it.

There are some logical next steps in the F-SIM's development, including shortening and psychometrically evaluating the shortened version. Despite participants reporting the F-SIM as not being terribly burdensome to complete, measures are rarely completed in isolation and not as part of a greater assessment package. It is also important that only the most relevant items are included in the final F-SIM. Once the underlying structure of the measure has been identified, and redundant items removed, the shortened measure will be psychometrically assessed collecting data from participants with and without a mental illness, across a range of ages, to allow for comparisons between groups.

Some progress is being made with respect to this. We have commenced a larger study of the F-SIM, and have reported on some preliminary findings (Gardner et al., 2019). The underlying structure of the measure has been observed in a group of young people without lived experience of mental illness, with dimensions related to interpersonal connection and community integration processes identified (Gardner et al., 2019) and will be confirmed in a larger sample, with data collection underway. (populations include similarly aged young people with non-psychotic illness, older people aged 25+ with severe mental illness and older, similarly aged people from the general community).

4.5. Conclusions

Social inclusion is a concept that shows great promise in assisting people with mental illness to improve their circumstances and reduce the impact of illness on their lives. To facilitate progress, it is essential that a psychometrically sound measure of social inclusion is available for use. As noted by Coombs et al. (2013) “Social inclusion is too important not to measure properly” (p. 918).

Findings presented here indicate that the F-SIM is a measure of social inclusion that is easy to complete, well-accepted by the population for which it is intended and appears to have good face validity. Findings also demonstrate the ability to differentiate between groups expected to differ with respect to social inclusion. It is anticipated that future development and testing of the measure will further demonstrate sound psychometric properties. Findings also reinforced the viewpoint that people with mental illness are likely to fare worse than their counterparts in aspects related to good social inclusion.

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Declaration of interest

None.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.psychres.2019.06.038.

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