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Unmet depression information needs in the community

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Abstract

Background: Despite the well acknowledged importance of consumer health information, little is known about the public's depression information needs. This study aimed to investigate the level of unmet need for depression information in the community, develop a formal measure of this need and identify its predictors.

Methods: Data were collected as part of a survey of 12319 Australian adults aged 18 to 83 years. This survey incorporated 21 questions targeting depression information need, together with measures of demographic status, self-reported current depression and personal stigma. The information needs data were subjected to Principal Components Analysis followed by linear regression analyses to determine the demographic and other predictors of each of the resulting components.

Results: Between 50 and 75% of participants endorsed the need for more information on each of the 21 information need topics. The PCA yielded a 20-item Depression Information Needs Scale (DINS) of high reliability and factor validity comprising four subscales: *General* (facts about depression), *Specific Treatments*, *Structural* (policies and research) and *Lived experience*. Controlling for other factors, those with self-reported current depression and those with less education had greater information needs across all four factors.

Limitations: The survey response rate was low and further research is required to establish the adequacy of the psychometric properties of the DINS.

Conclusions: Given the high unmet need for depression information there is a need to develop and implement evidence-based strategies for ensuring the accessibility and uptake of depression information relevant to the needs of members of the community.

Keywords: Depression, information needs, measure, scale

1. Introduction

High quality consumer health information is believed to improve self-management (Coulter et al., 1999), facilitate shared decision making and consumer empowerment (Coulter et al., 1999; Garfield et al., 2004), improve adherence to treatment (Bowskill et al., 2007) and improve mental health (Donker et al., 2009). It is not surprising then that clinical practice guidelines typically emphasise the importance of providing information to mental health consumers (National Institute for Clinical Excellence, 2009, 2011).

However, a number of researchers have reported significant levels of unmet information needs among those with a mental illness. In a Dutch study focusing on people with depression and anxiety disorders in primary care, one-third of the participants reported an unmet or only partially met need for information about their condition (Prins et al., 2008). Other studies have reported consumer dissatisfaction with the information that health professionals provide about antidepressants and other psychotropic medications (Bell et al., 2006; Bowskill et al., 2007; Garfield et al., 2004; Happell et al., 2004; Pollock et al., 2004). Further, Powell and Clarke (Powell and Clarke, 2006) in a qualitative study found that service users with mild to moderate mental health problems reported a lack of information about diagnosis and treatment options including side effects of medications.

With the advent of the Internet and a proliferation of information about the common mental disorders in books, brochures, and newspapers, consumers are not solely reliant on health professionals to satisfy their mental health information needs. However, mental health educational resources are rarely informed by a consideration of consumer-reported

needs (Chien et al., 2001; Powell and Clarke, 2006). Appropriately targeted information is important not only for consumers with mental illness but also for members of the community since mental health literacy is likely to assist individuals to recognize and act on the early signs of mental illness in themselves should it occur in the future, facilitate help seeking, and provide support to others. However, to our knowledge there have been no investigations of the level and type of mental health information needs of the general community.

Given that depression is the primary cause of disability internationally, there is a particular need to ensure that adequate depression information is available for all members of the community. The current study seeks to (i) determine what these information needs are; and (ii) identify the predictors of different types of information need in the community. Since there are currently no formal measures of depression information needs the study also sought to (iii) develop a formal measure of information need for depression (the Depression Information Needs Scale).

2. Method

Depression information needs were investigated using a hard copy survey mailed to members of the general community in rural and metropolitan Australia. The survey was designed for the joint purposes of investigating mental health needs, attitudes and knowledge among Australians and to identify a subset of participants who might be suitable for recruitment to an online intervention study for depression (Griffiths et al., 2010). The latter is not the subject of the current paper. Approval for the study was

obtained from The Australian National University Human Research Ethics Committee (Protocol 2007/2259).

2.1 Participants

Participants were 12,319 respondents to a “WellBeing Screening Survey” which was sent to a total of 70,000 Australians aged between 18 and 65 years who were randomly selected from each of eight Australian Electoral Rolls in the regions of New South Wales, Victoria and the Australian Capital Territory (response rate 18.1%). Electoral enrolment is compulsory in Australia. Each survey was accompanied by a pre-paid addressed envelope for its return. The rural regions were oversampled by 50% relative to the urban sample for the purposes of the intervention recruitment phase.

2.2 Measures

The survey comprised a number of self report measures and items including those designed to measure demographic status, psychological distress, depressive and anxiety symptoms, self-perceived mental health status, self and personal stigma and information needs. The measures relevant to the current study are described below.

2.2.1 Depression Information Needs Survey (DINS)

A series of 21 items were devised to assess information need in the areas of depression symptoms, epidemiology, treatment, lived experience of government and workplace policy, and research funding and findings. Each item was rated on a 5-point scale from strongly disagree (0) to strongly agree (7). A final open-ended item requested respondents to list any other depression topics about which they needed information.

2.2.2 Sociodemographic characteristics

Sociodemographic status was obtained for age (mean centered at 46 years), gender (male = 0, female = 1), marital status (not married = 0, married/de-facto = 1), years of education (0 = less than 15 years secondary, 1 = 15+ years secondary), employment status (0 = not employed full-time, 1 = employed full-time), Internet access available at home or work (0 = no, 1 = yes), and rurality status (city = 0; rural/remote = 1). Rurality status was based on the participant's current home of residence and was derived using population statistics obtained from the ABS 2006 census data and based on the Rural, Remote and Metropolitan Area (RRMA) classification system. Respondents were classified based on their responses to the questions: "Do you usually live in a town/city?", "If yes, what town/suburb do you live in" and their residential postcode. The locations in which participants resided were classified as Metropolitan (population > 100,000), Large rural (25,000 – 100,000), Small rural (10,000 – 24,999), Remote (5,000 – 10,000), Other remote (population < 5,000). Participants were further categorized as residing in a city (0) or a rural or remote (1) area

Self-reported current depression: This was assessed using a single item taken from a series of questions purpose constructed for the current study and designed to assess self-perceived emotional status. The items were introduced by the statement: "Do you think you currently suffer from any of the following conditions or problems" and the relevant item was "Do you suffer from depression" (Yes/No).

2.2.3 Personal stigma (DSS-Personal) (Griffiths et al., 2004)

This 9-item self-report measure of stigma assesses the participant's personal attitudes to depression (e.g., "People with depression should snap out of it"). Each item was rated on

a 5-point likert scale (0 to 4) with total scores ranging from 0 to 36. The measure has demonstrated reliability and validity (e.g., (Griffiths et al., 2008; Griffiths et al., 2004).

2.3 Statistical analysis

The level of unmet need for depression information was investigated in the first instance by dichotomizing responses for each of the 21 information needs items into a rating of 1 if the information need was endorsed (agree/strongly disagree) or 0 if it was not (neither agree nor disagree/disagree/strongly disagree). In addition, the (undichotomised) depression information need data were subjected to a principal components analysis (PCA) after testing if the data satisfied the requirements for a PCA by scrutinising Kaiser-Meyer-Olkin measures of sampling adequacy, Barlett's tests of sphericity and Anti-Image correlations. The PCA was repeated after excluding cross-loading items. Once an adequate solution was obtained, mean scores across component scales were compared using a repeated measures ANOVA followed by Bonferonni-corrected post hoc tests and a series of linear regression analyses were undertaken to determine the predictors of each depression information need component score.

3. Results

3.1 Sample characteristics:

The characteristics of the sample are summarized in Table 1. Participants represented a broad age range (18-83 years), and were predominantly female, married and employed. Over half were from rural or remote regions, fewer than half university educated and most participants had access to the Internet from home or work. Twenty-percent of the participants self-reported current depression.

3.2 Information needs for depression

3.2.1 Level of unmet need (individual items):

Table 2 summarises the percentage of participants self-reporting a need for information about depression for each of the 21 items of the DINS. Overall, there was a high level of unmet need with approximately half to three-quarters of all participants citing a need for information on the specified topics. The items which were endorsed by the greatest percentage of respondents were: how to help someone with depression, treatments for depression, self-help, alternative and lifestyle treatments (73-78.1%); symptoms, causes and the course of depression and professional groups who can help (69.9-71.5%); and research findings about depression (69.5%). The least, albeit still commonly endorsed items were how it feels to be depressed, the prevalence of depression and which prescription medications are effective for depression (48.7-51.3%).

3.2.2 Psychometric characteristic of the Depression Information Needs Scale

The data satisfied the requirements for conducting a PCA (Kaiser-Meyer-Olkin=0.965; Bartlett's Test of Sphericity, $p < .001$; Anti-image correlations all $> .9$).

A consideration of Eigen factors greater than one yielded a three factor solution but with cross loadings on items with varimax and oblique rotations. Inspection of the scree plot raised the possibility that a four factor solution may be appropriate. A PCA using a four component extraction with varimax rotation accounted for 79.8% of the variance but yielded cross-loadings on six items. By contrast, a four component solution with oblique (Oblimin with Kaiser Normalisation) rotation produced cross loadings on one variable only (Item 12) and four interpretable components: *General*, *Lived Experience*, *Structural*, and *Specific Treatment*. The *General* factor comprised items concerned with the overall

facts about depression including the symptoms, causes course, treatments, prevalence, source of help and how to assist someone with depression. The *Lived experience* factor was concerned with the personal stories of individuals with depression about coping strategies during the acute and recovery period of depression, the subjective experience of depression, its treatments and the attitudes of others. The *Structural* component focused on aspects of depression and in particular on workplace and government policies and research funding and research results. The final factor *Specific Treatment* was concerned with information about the specific treatments of depression including medications and their side effects, psychological treatments. A further PCA with Oblimin rotation was undertaken after removing the cross-loading item (see Table 3). The data from the remaining 20 items yielded the same four component solution as above. The Cronbach alpha values for each of the components were high: *General*: 0.95 , *Lived Experience*: 0.96 , *Structural*: 0.91 and *Specific Treatment*: 0.92.

3.2.3 Component means

The mean level of unmet need scores for the four components (out of 5) were *General*: 2.73 (SD=.87); *Lived Experience* 2.49 (SD=0.98); *Structural* (2.65 (SD=.88); and *Specific Treatment* 2.68 (SD=.94) (n=12,075). A repeated measures ANOVA demonstrated a significant main effect for Component ($F(3, 36222)=434.58, p<.001$). Post-hoc tests with Bonferonni adjustment indicated that each of the differences between component scores was significant with the level of unmet need highest among members of the community for *General* information, followed by *Specific Treatment*, *Structural*, and information regarding *Lived experience*. However, the magnitudes of the effect sizes were small for those involving *Lived Experience* (ranging from 0.16 for the contrast with

Structural need to 0.24 for the contrast with *General* need) and very small for the remaining contrasts (0.02 to 0.08). The above pattern of lower *Lived experience* information need was also seen amongst those with a self-reported past history of depression ($p < .001$) with effect sizes ranging from 0.17 *General* to 0.20 *Specific* ($n=6030$).

3.2.4 Predictors of unmet need

The mean DINS subscale scores are summarized in Table 4 as a function of demographic characteristics, self reported clinical status and personal stigma. T-tests yielded significant effects for most factors, but these were either very small or small (range 0.06 to 0.43). Considering only effect sizes of 0.20 or greater, information needs were greater for those with self-reported current depression and those with less education.

The results of linear regression analyses of gender, age, employment, marital status rurality, self reported current depression, Internet access and personal information need for each of the four factors are shown in Table 5. Controlling for other factors, those with self-reported current depression and less education reported greater information needs across all four information need factors; general, lived experience, structural and specific treatment. Other effects although statistically significant due to the large sample sizes involved, were small. In particular, being unemployed and living in a metropolitan area were associated with a greater need for general information about depression. Being a woman, lack of internet access and lower personal stigma predicted a need for information about the lived experience of depression. The latter factors also predicted need for structural information as did being older. Finally, being a woman, unemployed,

unpartnered, older, lacking Internet access and having low personal stigma predicted a need for specific treatment information about depression.

4. Discussion

There were four main findings from this study. First there was a high level of unmet need in the community for information about a broad range of depression topics with *between* 50 and 75% of participants in the current study endorsing the need for more information on each of the 21 information need topics. Secondly, it was found that these information needs could be grouped, based on principal components analysis into four components: *General*, *Lived experience*, *Structural* and *Specific Treatments*. This yielded a 20-item Depression Information Needs Scale (DINS) of high reliability and factor validity comprising four subscales: 1. The *General* subscale (7 items) concerned with facts about depression (symptoms, causes, course, treatments, prevalence, source of help, how to assist); 2. The *Lived experience* subscale (5 items) with personal stories, coping strategies and the subjective experience of depression, its treatment and stigma; 3. A *Structural* component (4 items) with policies and research funding and findings; and 4. A *Specific* subscale (4 items) with specific treatments for depression. Third, unmet need for *Lived experience* information was lower than for other component types both for the overall group of participants and for the subset of participants with a past history of depression. Finally, overall, and controlling for other factors, persons with self-reported current depression and those with less education had greater information needs across all four factors: *General*, *Lived Experience*, *Structural* and *Specific Treatment*.

The high level of unmet information need both in the general community and among those with depression is a significant cause for concern given the potential for depression knowledge to enable members of the community to facilitate help seeking in others and the potential for this knowledge to promote early help seeking, and effective self-management, shared decision making and adherence among those with depression. This substantial level of unmet need might at first seem surprising given the prominence of the national depression initiative *beyondblue* in Australia and previous evidence that improvement in depression literacy was higher among members of the community living in regions most exposed to the campaign (Jorm et al., 2005). Significantly, a 2010 Ipsos MORI World Questions Global survey revealed that over one-third of Australians rated mental health as one of the two or three greatest challenges faced in their own country, a level of concern well in excess of that reported for other countries. It is possible that the high profile of Australia's national depression initiative and a recent focus on mental health in the media in Australia has served to sensitise Australians to the importance of mental health and mental health literacy. There may however be a *knowledge access* 'gap' even where educational information is available to meet an information need (e.g., on a website). The findings suggest that further research is needed to investigate optimal strategies for delivering the level and type of information sought by members of the community and those with depression. Such an investigation would need to identify the system and personal barriers and facilitators of such delivery and how they might inform the information dissemination. For example, personal factors such as lack of time or motivation to find and process information could leave an individual with an unmet information need even when that information is publically accessible. Finding and

evaluating for effectiveness, innovative methods of delivering such information, for example, through workplace induction or school-based mental health education programs involving consumer delivery of information, may circumvent some of these barriers. The information needs detailed in the current paper could inform the content of such programs.

The finding that those with a lower level of education expressed a greater level of perceived information needs is not consistent with other studies which have reported that higher education is positively associated with perceived information need (Chien et al., 2001). Nevertheless the finding does raise two possibilities. First, lower education if it is associated with a low level of reading literacy and a lack of information literacy (e.g., knowing how to search for and locate relevant information) may be an important barrier to accessing existing depression resources even controlling as we did in this study for other factors such as internet access. These literacy problems might be addressed by developing information interventions that require a low level of literacy and by employing communication systems that minimise the difficulty of locating them. Secondly, care should be taken to ensure that mental health education programs reach those with lower levels of education. For example, tailored work-based educational programs should be delivered to those in the manual workforce as well as those in office jobs. Universal school-based programs should be made available to school students prior to the age at which they can legally leave school.

Finally, the current study reports a promising four-factor measure of information needs. The Depression Information Needs Scale requires further research to establish its construct validity and test-retest reliability. However, it demonstrates good factor

validity and internal reliability and may prove a useful instrument for investigating unmet needs for depression information in different subpopulations, the effect of different interventions on information need, and in further exploring the predictors of depression information need.

4.1 Limitations

This study has a number of limitations. The survey response rate was low, the sample is not representative of the general population, and accordingly the findings must be treated with caution. Secondly, as noted above, further research is required to establish the adequacy of the psychometric properties of the Depression Information Needs Scale. This includes replication using confirmatory factor analysis. Thirdly, the sample sizes were very high so that even small effect sizes resulted in statistically significant results. For this reason, very small but statistically significant effects sizes have not been discussed in this paper.

Despite its limitations, this study suggests that there is a high level of unmet need for a diverse range of depression topics. These topics range from specific and general facts about depression to information about depression policies, depression research and the lived experience of depression. It may be beneficial if those charged with raising awareness about depression systematically work with consumers and members of the community to develop and implement evidence-based strategies for ensuring the accessibility and uptake of depression information by consumers and the public.

Competing interests

None.

Authors' contributions

KG conceived, designed and supervised the study, undertook the statistical analyses and wrote the paper. DC served as trial and data manager for the study, undertook some data extraction for the paper and edited the paper.

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Table 1

Demographic, clinical characteristics and personal stigma levels of the sample

Characteristics	N*	% (n)*
Gender (female)	12277	61.6 (n=7563)
Employed	12250	77.4 (n=9479)
Married de-facto	12298	71.3 (n=8774)
University degree	12208	35.1 (n=4281)
Rural/remote	11673	56.7 (n=6622)
Internet access	12237	89.7 (n=10971)
Self reported current depression	12193	20.2 (n=2468)
		Mean (Range, SD)
Age	11930	45.8 (18-83, 12.84)
Personal stigma (DSS)	12267	11.1 (0-36, 5.6)

*n values vary due to missing data

Table 2

Percentage of participants endorsing an information need (agree or strongly agree) for each of 21 topics

No.	Item	N*	% (n)*
1	How common depression is	12187	50.4 (6137)
2	Symptoms of depression	12183	69.1 (8416)
3	Causes of depression	12184	70.1 (8539)
4	Course of depression	12177	71.5 (8712)
5	Treatments for depression	12177	76.0 (9260)
6	Professional groups that can help	12152	70.2 (8536)
7	How I can help someone with depression	12144	78.1 (9484)
8	Which prescription medications work	12146	51.3 (6226)
9	Side effects of antidepressants	12151	64.8 (7873)
10	Which psychological treatments work	12148	65.9 (8001)
11	Which alternative/lifestyle treatments work	12148	73.0 (8869)
12	How I can help myself	12089	73.8 (8923)
13	How it feels to be depressed	12149	48.7 (5922)
14	Coping during initial stages of an episode	12145	55.9 (6785)
15	Coping during recovery stage	12140	57.5 (6986)
16	Attitudes of others to their depression	12135	54.9 (6667)
17	Experiences of which treatments work	12106	63.9 (7736)
18	Government policies	12136	55.9 (6790)
19	Workplace depression policies	12121	62.5 (7576)
20	Research findings about depression	12130	69.4 (8420)
21	Funding of research on depression	12128	56.5 (6848)

*n values vary due to missing data

Table 3

Component loadings for the 20-item Depression Information Needs Scale (DINS)

Item	Component			
	General	Lived experience	Structural	Specific treatment
The symptoms of depression and how to tell if someone is depressed.	.973	.019	-.019	.102
The causes of depression and who is most at risk of depression.	.933	.005	.019	.034
The course of depression (how long it lasts and if and how it recurs).	.866	.025	-.009	-.059
The treatments that work for depression.	.736	-.010	-.014	-.249
How common depression is in the community.	.705	.082	.182	.126
Which professionals and groups can help someone who is depressed.	.697	-.008	.040	-.206
How I can help someone who is depressed.	.667	.041	-.040	-.221
People's personal stories about coping with depression during the initial stages of an episode of depression.	.009	.982	-.034	.007
People's personal stories about coping during the recovery phase of depression.	-.012	.962	-.010	-.021
People's personal stories about how it feels to be depressed.	.034	.961	-.019	.072
People's personal stories about the attitudes of others to their depression.	.021	.888	.059	.027
People's experiences of which treatments work for their depression.	-.044	.743	.060	-.214
Workplace depression policies.	.042	-.032	.890	.031
Government policies and strategies for combating depression.	.030	.003	.889	.013
Funding of research on depression.	-.047	.020	.886	-.030
Recent research findings about depression.	.002	.057	.758	-.118
The side effects of antidepressants and how to cope with them.	.007	.048	.062	-.852
Which psychological treatments work for depression.	.097	.059	.044	-.807
Which prescription medications work for depression.	.005	.036	.104	-.776
Which alternative and lifestyle treatments work for depression.	.195	.074	.023	-.685

Table 4

Mean (SD) item information needs scores and effect sizes (ES) for each component as a function of participant characteristics

	General		Lived experience		Structural		Specific Treatment	
	N	Mean (SD)	n	Mean (SD)	N	Mean (SD)	n	Mean (SD)
Overall	12178	2.73 (.87)	12140	2.49 (.98)	12129	2.65 (.88)	12145	2.68 (.94)
Gender								
Male	4655	2.71 (.81)	4638	2.39 (.95)	4631	2.56 (.88)	4640	2.61 (.91)
Female	7481	2.74 (.90)	7460	2.56 (.99)	7457	2.71 (.88)	7464	2.71 (.96)
ES		0.03		0.18**		0.17**		0.11**
Education								
Non-Tertiary	7816	2.80 (.82)	7789	2.56 (.95)**	7779	2.71 (.87)**	7790	2.76 (.90)**
Tertiary	4259	2.60 (.95)	4248	2.36 (1.02)	4250	2.55 (.89)	4254	2.52 (1.00)
ES		-0.24**		-0.21**		-0.19**		-0.27**
Employment								
Unemployed	2719	2.80 (.86)	2714	2.58 (.97)	2711	2.75 (.89)	2706	2.79 (.93)
Employed	9396	2.71 (.87)	9362	2.46 (.98)	9355	2.63 (.88)	9376	2.64 (.94)
ES		-0.11**		-0.12**		-0.14**		-0.16**
Marital status								
Unpartnered	3476	2.75 (.86)	3471	2.52 (.98)	3462	2.71 (.90)	3466	2.71 (.93)
Married/defacto	8682	2.72 (.87)	8649	2.47 (.97)	8647	2.63 (.87)	8659	2.66 (.94)
ES		-0.04		-0.04		-0.09**		-0.06*
Rurality								
Metropolitan	5012	2.72 (.85)	4996	2.46 (.98)	4997	2.64 (.87)	5005	2.64 (.94)
Rural/remote	6528	2.73 (.88)	6506	2.52 (.97)	6494	2.67 (.89)	6503	2.70 (.94)
ES		0.02		0.07**		0.03		0.06**
Current Depression								
No	9615	2.69 (.87)	9587	2.43 (.97)	9580	2.59 (.88)	9591	2.59 (.94)
Yes	2450	2.88 (.86)	2442	2.74 (.98)	2437	2.90 (.87)**	2445	2.99 (.89)**
ES		0.22**		0.30**		0.36**		0.43**
Internet access								
No	227	2.82 (.81)**	1227	2.64 (.96)	1221	2.81 (.91)	1218	2.83 (.89)
Yes	10903	2.72 (.87)	10887	2.47 (.98)	10882	2.64 (.88)	10881	2.66 (.95)
ES		-0.11**		-0.18**		-0.19**		-0.19**
Continuous variables		R		r		r		R
Age		.005		.006		.060**		.050**
Personal stigma		.008		-.065**		-.125**		-.037**

*p<.01, **p<.001

Table 5

Predictors of depression information needs for each component.

	General		Lived experience		Structural		Specific Treatment	
	B*	p	B*	p	B*	p	B*	p
Gender	.151	.22	.691	<.001	.458	<.001	.387	<.001
Age	-.003	.54	.001	.88	.019	<.001	.015	<.001
Tertiary education	-1.383	<.001	-.872	<.001	-.645	<.001	-.851	<.001
Employed	-.343	.019	-.153	.19	-.074	.37	-.176	.049
Married/de-facto	-.016	.91	-.013	.91	-.292	<.001	-.149	.075
Rurality	-.333	.007	-.005	.96	-.124	.076	-.098	.19
Current depression	1.158	<.001	1.437	<.001	1.167	<.001	1.478	<.001
Internet access	-.252	.22	-.524	.002	-.398	.001	-.300	.018
Personal stigma	-.005	.62	-.058	<.001	-.080	<.001	-.031	<.001

*unstandardised coefficient