What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies

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Background. Individuals often avoid or delay seeking professional help for mental health problems. Stigma may be a key deterrent to help-seeking but this has not been reviewed systematically. Our systematic review addressed the overarching question: What is the impact of mental health-related stigma on help-seeking for mental health problems? Subquestions were: (*a*) What is the size and direction of any association between stigma and help-seeking? (*b*) To what extent is stigma identified as a barrier to help-seeking? (*c*) What processes underlie the relationship between stigma and help-seeking? (*d*) Are there population groups for which stigma disproportionately deters help-seeking?

Method. Five electronic databases were searched from 1980 to 2011 and references of reviews checked. A meta-synthesis of quantitative and qualitative studies, comprising three parallel narrative syntheses and subgroup analyses, was conducted.

Results. The review identified 144 studies with 90 189 participants meeting inclusion criteria. The median association between stigma and help-seeking was $d = -0.27$, with internalized and treatment stigma being most often associated with reduced help-seeking. Stigma was the fourth highest ranked barrier to help-seeking, with disclosure concerns the most commonly reported stigma barrier. A detailed conceptual model was derived that describes the processes contributing to, and counteracting, the deterrent effect of stigma on help-seeking. Ethnic minorities, youth, men and those in military and health professions were disproportionately deterred by stigma.

Conclusions. Stigma has a small- to moderate-sized negative effect on help-seeking. Review findings can be used to help inform the design of interventions to increase help-seeking.

Introduction

In Europe and the USA, 52–74% of people with mental disorders do not receive treatment (Alonso *et al.* 2004; Kessler *et al.* 2005; Wittchen & Jacobi, 2005; Thornicroft, 2007). In low- and middle-income settings, where provision is lower, even more go untreated (Wang *et al.* 2007). Although mental health problems may be self-limiting or respond to self- or lay-help (Oliver *et al.* 2005*a*), when individuals delay or avoid formal care this can have problematic consequences. For psychosis, delays may contribute to

adverse pathways to care (Morgan *et al.* 2004), and the duration of untreated illness is associated with worse outcomes in psychosis, bipolar disorder, and major depressive and anxiety disorders (Boonstra *et al.* 2012; Dell'Osso *et al.* 2013). After initiation of mental health care, non-adherence to treatment programmes and early withdrawal from services are common and may result in adverse outcomes (Nose *et al.* 2003; Barrett *et al.* 2008).

The stigma associated with mental illness may be an important factor reducing help-seeking. Stigma may be defined as a process involving labelling, separation, stereotype awareness, stereotype endorsement, prejudice and discrimination in a context in which social, economic or political power is exercised to the detriment of members of a social group (Link & Phelan, 2001). Several different types of stigma have been identified and are used in this review. These are: anticipated stigma (anticipation of personally being

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perceived or treated unfairly); experienced stigma (the personal experience of being perceived or treated unfairly); internalized stigma (holding stigmatizing views about oneself); perceived stigma (participants views about the extent to which people in general have stigmatizing attitudes/behaviour towards people with mental illness); stigma endorsement (participants' own stigmatizing attitudes/behaviour towards other people with mental illness); and treatment stigma (the stigma associated with seeking or receiving treatment for mental ill health).

To date, six non-systematic reviews on mental health-related stigma and help-seeking have been published (Kushner & Sher, 1991; Corrigan & Rüsch, 2002; Corrigan, 2004; Gary, 2005; Schomerus & Angermeyer, 2008; Thornicroft, 2008). Each reported that there was some evidence that stigma impedes help-seeking, potential mechanisms were proposed, and these reviews concluded that the field is currently poorly understood. To our knowledge, no systematic review has been conducted.

The present review is concerned with help-seeking from formal services, specifically health care (primary care or secondary/tertiary mental health services) or talking therapy services. The term 'help-seeking' is used to denote all stages of the process, encompassing initiation of, and engagement with, care (Kovandžić *et al.* 2011). Through identifying and synthesizing relevant quantitative and qualitative studies, this systematic review sought to address the overall research question: What is the impact of mental health-related stigma on help-seeking for mental health problems? We aimed to investigate the following subquestions: (*a*) What is the size and direction of any association between stigma and help-seeking? (*b*) To what extent is stigma identified as a barrier to help-seeking? (*c*) What processes underlie the relationship between stigma and help-seeking? (*d*) Are there population groups for which stigma disproportionately deters help-seeking?

Method

The review methodology is a modification of the method introduced by the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre; Oliver *et al.* 2005*b*), which was designed for broad research questions for which there is both quantitative and qualitative evidence. It involves an initial scoping and mapping to prioritize and specify subquestions and relevant study types. This revealed three main sets of literature: (1) quantitative 'association studies', which present statistical data on the possible relationship between scores on a scale measuring stigma and a measure relating to any aspect

of help-seeking; (2) quantitative 'barriers studies', which present data on the proportion of participants who report experiencing one or more stigma-related barriers to help-seeking; and (3) 'qualitative process studies', which present analyses of text-based data from interviews, focus groups or ethnographic observational studies about stigma and help-seeking and say something about the processes that may underlie the relationship between stigma and help-seeking. Following the next stage of the EPPI-Centre method, parallel systematic reviews were conducted, one for each subquestion (*a*) to (*c*), with subquestion (*d*) addressed by subgroup analyses. In the final stage of the EPPI-Centre method, findings from the parallel syntheses are juxtaposed in a meta-synthesis to produce an overall picture of the evidence (Pope & Mays, 2007). A protocol for this review was registered with the PROSPERO systematic review protocol registry (www.crd.york.ac.uk/prospero/; ID: CRD42011001647). Additional methodological details are given in Supplement 1.

Search strategy and selection of studies

Five electronic databases (Medline, EMBASE, Sociological Abstracts, PsycInfo and CINAHL) were searched from January 1980 to December 2011, with no language restrictions. The following subject heading and keywords were used: (stigma-related terms AND help-seeking-related terms AND mental health-related terms) OR (stigma-related terms AND mental health service-related terms) (full database search strategies in Supplement 2). In addition, reference lists of included studies and reviews were checked for further possible studies.

Inclusion criteria were data-based studies on the relationship between mental health-related stigma and help-seeking for mental ill health that addressed one or more of subquestions (*a*)–(*c*) (i.e. quantitative association or barriers studies or qualitative process studies) (see Table 1). Titles and abstracts were screened and full reports of potentially relevant studies were obtained. Two authors independently assessed the reports for eligibility, with discrepancies resolved by discussion.

Data extraction, analysis and synthesis

Data on study design, sample characteristics, findings and methodological quality were extracted independently by two authors. Narrative synthesis was undertaken because of substantial methodological and clinical heterogeneity between studies (Popay *et al.* 2006). For association studies, the statistic for the association between stigma and help-seeking was extracted and converted to a standardized effect size

Table 1. *Inclusion and exclusion criteria*

Participants
Include
    Any population group of any age
Exclude
    Persons help-seeking on behalf of another individual (e.g. family members, informal carers)
    Professional caregivers, unless providing data about seeking help for their own mental health problems
    If a study includes data from both people with mental health problems and informal or professional caregivers, only the
      data from the former group will be extracted. Where the two cannot be distinguished, the study will be excluded

Outcomes
Stigma
Include
    Any type of stigma including public stigma, perceived stigma, internalized stigma, anticipated stigma/discrimination,
      experienced stigma/discrimination, stigma by association/family stigma and treatment stigma
    Mental health-related stigma
    Stigma as measured on a scale or a subscale that has been referenced or examined for reliability and/or validity
    Minor adaptations of the scales are acceptable as long as the objective was to measure the same construct as the original scale
Exclude
    Stigma relating to other social attributes, e.g. racism, homophobia
    Scale developed by the authors not assessed for any psychometric properties
    Stigma measured using a single item
    Stigma-related barriers that do not report dichotomous data (barrier reported or not) or cannot be definitely transformed
      into this format

Help-seeking
Include
    Help-seeking for a mental health problem, defined as any mental disorder listed in DSM-IV-TR or any self-defined
      psychological, emotional or behavioural problem
    Measures of help-seeking-related attitudes, intentions and behaviours
    Help-seeking from a health practitioner or service (including primary, secondary or tertiary care) or talking therapy
      (psychotherapy/psychology/counselling services or practitioner)
    Measures relating to any stage of help-seeking from seeking initial formal help to service use
Exclude
    Help-seeking for intellectual disabilities, substance abuse or dementia

Study type
Include
    Studies that address at least one of the three specified subquestions using the methodology indicated: (1) What is the size
      and direction of association between stigma and help-seeking? (quantitative studies); (2) To what extend is stigma identified
      as a barrier to help-seeking? (quantitative studies); or (3) What processes underlie the relationship between stigma and
      help-seeking? (qualitative studies)
    Any data-based journal article
    Articles published in any language
    Articles published between 1980 and January 2012
Exclude
    Association studies for which findings cannot be classified into a standardized effect size, despite using conversion approaches
      and attempting to contact authors
    Studies that only report an association or prevalence of barriers in a sociodemographic subgroup of the study sample, unless
      these data can be provided by the authors or can be calculated

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(Cohen's *d*), where possible. The median effect size across studies was calculated and presented alongside the number of associations in each direction together with statistically significant effects obtained (Grimshaw *et al.* 2003).

Stigma-related barriers were grouped into shame/embarrassment, negative social judgement, disclosure concerns/confidentiality, employment-related discrimination and general stigma/other stigma barriers. For studies with five or more barriers of any type, the rank of the most highly reported stigma barrier and the total number of barriers examined were used to calculate a 'standardized rank' by dividing the rank of the stigma barrier by the total number of barriers in that

study and multiplying that number by 10. This indicates the importance of stigma in relation to other possible barriers, with all studies thereby standardized to having a notional 10 barriers of any type. To synthesize the barriers studies, the median and range of the percentage of participants reporting the different types of stigma barriers were presented, along with the median and range of the standardized rank. The median is used as this gives a better indication of the average, given that effect sizes and rankings are unlikely to be normally distributed.

A thematic analysis was undertaken to synthesize the qualitative process studies (Thomas & Harden, 2008). An initial coding frame was developed following preliminary inductive open coding of a subset of the qualitative studies ($n=39$) using QDA-MAX software by T.G. and by discussion and data examination (S.C., T.G. and C.M.). The relevant data were all of the participant quotations and study author interpretations/summarizing statements relating to the processes by which stigma may relate to help-seeking reported in the results section of the papers. Using data from the full set of qualitative process studies ($n=51$), S.C. copied these data verbatim into a spreadsheet containing the preliminary coding frame, grouping and regrouping the data into a revised set of inter-related themes and subthemes to form a final coding framework and draft synthesizing conceptual model. The relationships between the themes were based on finding at least one quotation or author interpretation in the data supporting the relationship and its direction. A second author (O.S. or N.B.) then independently repeated the data extraction process using the final coding frame. T.G. and C.M. examined the draft model, exemplar quotations and theme/subtheme names to corroborate and finalize the model.

For the association and barriers studies, methodological quality was rated using a cross-sectional survey checklist (Crombie, 1996) with minor adaptations for the different contexts (eight criteria for association studies and six for barriers studies). The methodological quality of the process studies was assessed using the seven-item Critical Appraisal Skills Programme (CASP) tool for qualitative research (Public Health Resource Unit, 2006). Two authors independently assessed the studies against these criteria and resolved discrepancies through discussion.
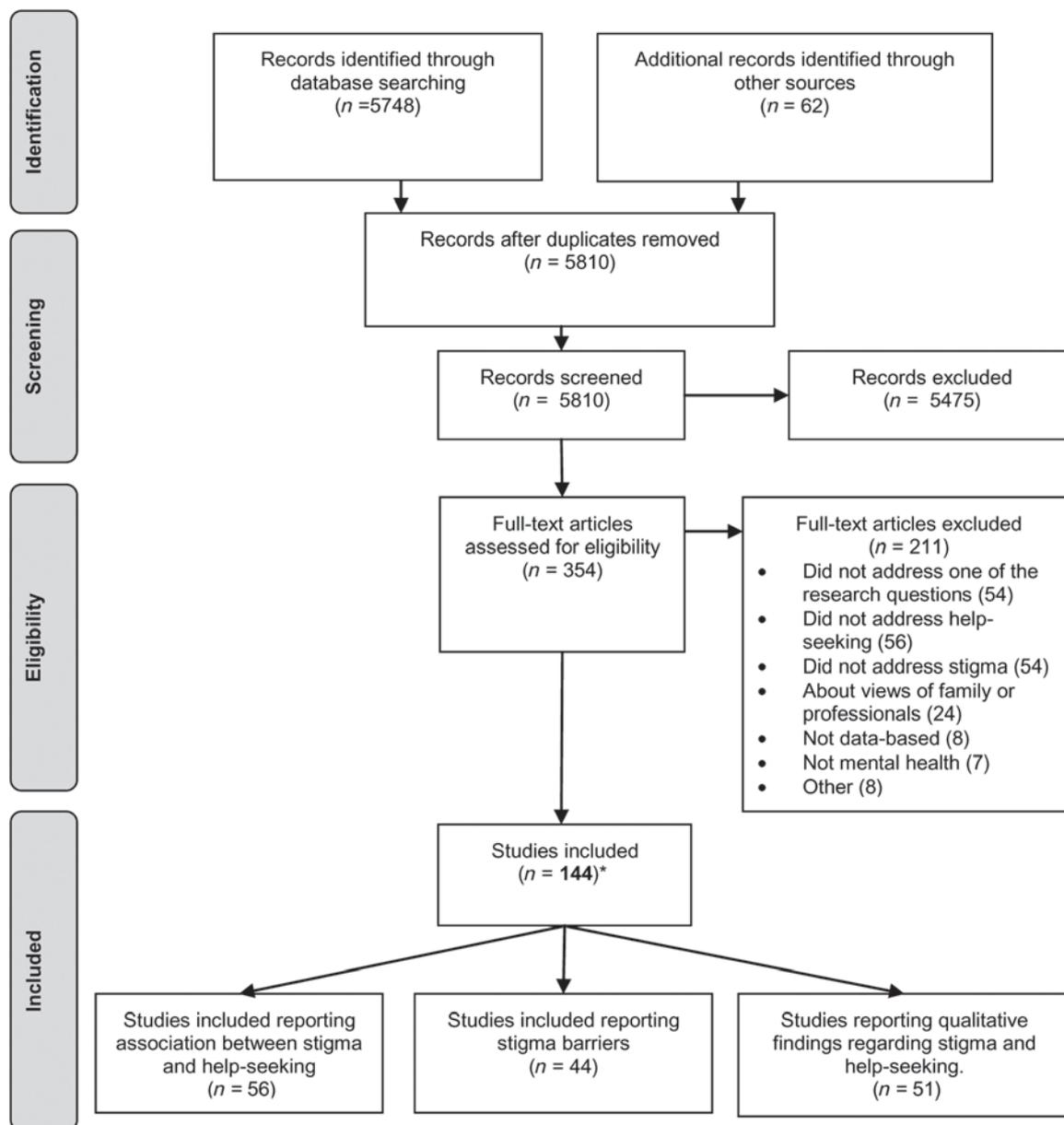
The size of the association, the reported barriers and qualitative processes were examined in subgroups relating to: age, ethnicity, gender, rural setting, occupational group, mental health of participants and whether participants were currently receiving care. For association studies, we also undertook subgroup analyses on type of stigma and methodology. In a sensitivity analysis to investigate the effect of

methodological quality on the results, one-third of the studies within each of the three parallel syntheses that had the lowest quality rating were excluded from the analyses.

Lastly, we conducted a two-stage meta-synthesis. In the first stage we extended the conceptual model derived from the qualitative process studies to produce an overarching conceptual framework. We did this by (i) checking back in the barriers papers to see which subthemes identified in the qualitative process studies were also reported as barriers to help-seeking in this set of papers; (ii) ascertaining whether any barriers in the quantitative studies were not identified in the subthemes from the qualitative process data; and (iii) three authors meeting to consider if any concepts were missing from the model and adding these to the model (clearly marked as not derived from the data). In the second stage we presented the findings from the three parallel syntheses in juxtaposition to produce a tabular view of the evidence on the impact of mental health-related stigma on help-seeking.

Results

Database searching yielded 5810 non-duplicate items; 354 papers were identified as potentially relevant and full papers were assessed against eligibility criteria, resulting in the exclusion of 211 papers. A quarter of these ($n=54$) were data-based studies on help-seeking and stigma in mental health but did not address at least one of the specific research questions (e.g. intervention studies with both stigma and help-seeking as outcomes, qualitative studies reporting that stigma deterred help-seeking but not elucidating any processes). These studies are listed in Supplement 3. Overall, 144 studies, including data from 90 189 participants, were included in the review, including 56 studies on the association between stigma and help-seeking, 44 on stigma-related barriers and 51 qualitative studies on processes underlying the stigma–help-seeking relationship; see the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram, Fig. 1. The majority of the studies (69%, 99/143) were conducted in the USA or Canada; 20 were undertaken in Europe; 10 in Australia and New Zealand; eight in Asia; and one in South America. In addition, five of the studies were conducted across more than one continent. Thirty studies (21%) were on students in higher education, and 14 (10%) on school students. In 56 studies (39%), all participants had experience of mental health problems/being in treatment. Of the 62 studies that focused on a specific condition, 28 investigated depression; eight severe mental illness/psychosis; seven perinatal depression; seven self-harm; four

Fig. 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram.

anxiety disorders; four eating disorders; and four other conditions. Full details of study and sample characteristics are in given Supplement 4.

Association studies

Fifty-six studies reported an association between stigma and help-seeking and included data from 27 572 participants, with 26 313 contributing effect size data. Five studies reported longitudinal data and

26 (46%) of the studies were conducted on university students.

The median effect size in the association studies was −0.27, and ranged from −2.73 to 0.36 for individual studies, the negative association indicating that stigma reduces help-seeking. The median size of this association could be interpreted as small (Cohen, 1992). The majority of the association studies reported a negative association, with the majority being statistically significant (Table 2).

Table 2. *Synthesis of studies examining the association between stigma and help-seeking and associated main subgroup analyses*

	No. of participants (studies)	Direction of the association (no. of studies with $p<0.05$ association)			Cohen's d	
		Negative	Positive	Median	Range	Interpretation[a]
Overall sample	27 572 (56)[b]	42 (30)	14 (3)	−0.27	−2.73 to 0.36	Small negative association
Subgroup analysis 1: Stigma type[c]						
Anticipated stigma	2438 (2)	2 (0)	0	−0.15	−0.26 to 0.04	No association
Experienced stigma	483 (2)	1 (0)	1 (0)	<−0.01	<−0.01 to<0.01	No association
Internalized stigma	1710 (7)	5 (4)	2 (0)	−0.23	−1.78 to 0.01	Small negative association
Perceived stigma	10 579 (19)	12 (3)	7 (0)	−0.02	−1.61 to 0.22	No association
Stigma endorsement	9741 (12)	8 (4)	4 (0)	−0.05	−0.87 to 0.28	No association
Treatment stigma	14 966 (33)	25 (21)	8 (3)	−0.41	−2.73 to 0.36	Small negative association
Other stigma	424 (3)	1 (1)	2 (0)	0.06	−0.02 to 0.14	No association
Subgroup analysis 2: Methodology						
Attitudes and intentions	11 297 (33)	29 (25)	4 (1)	−0.52	−2.73 to 0.34	Medium negative association
Behavioural indicators	15 368 (18)	9 (3)	9 (2)	<−0.01	−0.26 to 0.36	No association
Prospective behaviour	907 (5)	4 (2)	1 (0)	−0.07	−0.46 to 0.02	No association
Subgroup analysis 3: Ethnicity						
African American (USA)	570 (4)	3 (2)	1 (0)	−0.25	−0.50 to <0.01	Small negative association
Arabic students (Israel/USA)	297 (2)	2 (2)	0 (0)	−1.21	−1.76 to −0.66	Large negative association
Asian American (USA)	898 (6)	4 (4)	2 (1)	−1.20	−2.73 to 0.34	Large negative association
Latino, Cuban and Puerto Rican (USA)	328 (2)	2 (0)	0 (0)	−0.09	−0.16 to −0.02	No association
Other/Mixed	25 479 (42)	31 (22)	11 (2)	−0.23	−2.45 to 0.36	Small negative association

[a] Based on published guidance by Cohen (1992): small >0.2, medium >0.5, large >0.8.

[b] A total of 26 313 participants contributed to the effect size (Cohen's d) analysis.

[c] More than one outcome was extracted for each study for this analysis if the study reported results on different types of stigma measures: anticipated stigma (anticipation of personally being perceived or treated unfairly); experienced stigma (the person experience of being perceived or treated unfairly); internalized stigma (holding stigmatizing views about oneself); perceived stigma (participants views about the extent to which people in general have stigmatizing attitudes/behaviour towards people with mental illness); stigma endorsement (participants' own stigmatizing attitudes/behaviour towards other people with mental illness); and treatment stigma (stigma associated with seeking or receiving treatment for mental ill health).

Subgroup analyses for association studies

When we investigated associations by type of stigma, the two types of stigma that exhibited a small and consistent negative association with help-seeking were internalized stigma and treatment stigma (Table 2). Although a few studies showed significant negative associations with stigma endorsement and with perceived stigma, the median effect sizes were negligible, at −0.05 and −0.02 respectively.

When study methodology was taken into account, cross-sectional studies with attitudinal/intentional help-seeking measures reported a moderate median effect size of −0.52 (range −0.273 to 0.34), with the majority (25/33) reporting a statistically significant negative association between stigma and help-seeking. Cross-sectional studies using behavioural indicators of help-seeking exhibited more mixed results, with nine studies reporting a negative association (three statistically significant) and nine a positive association (two statistically significant). Four out of the five prospective studies reported a negative association (two were statistically significant). Both behavioural indicators and prospective studies groups reported a median association that was very close to zero (<−0.01 and −0.07 respectively, see Table 2).

Finally, the population subgroup analyses indicated that there was a median large negative association in samples of Asian Americans (−1.20) and in Arabic students (−0.21). There was a small negative median association in the samples of African Americans (−0.25) and mixed samples (−0.23) (see Table 2). For all other subgroup comparisons (age group, gender, psychosis/non-psychosis, currently receiving mental health care or not, occupational group, rural/non-rural), the number of studies within each subgroup was small (<5), rendering findings inconclusive, or no differences were found.

Quality assessment and sensitivity analyses for association studies

The quality criteria ratings indicate that the quality of the association studies was moderate, as six of the eight criteria were met by the majority (55–100%) of studies. The main problems identified by the quality rating tools were: no sample size justification; lack of evidence for the reliability and validity of help-seeking measures; and selection bias. The sensitivity analyses indicated that, when the studies in the bottom third for quality (⩾3 criteria unmet) were excluded from the analyses, the median effect size for the overall association between stigma and help-seeking was reduced from −0.27 to −0.18.

Barriers studies

Forty-four studies reported data on stigma barriers and included 60 036 participants. In contrast to the association studies, only two of the barriers studies were conducted in a university student population, undertaken with the majority of the studies undertaken in general population (36%, 16/44) or clinical (32%, 14/44) samples.

Overall, the analyses indicated that stigma ranks as the fourth highest barrier to help-seeking when the total number of barriers investigated is standardized to 10. Given that there is no rule of thumb for interpreting this ranking, we suggest that this may be interpreted as indicating that stigma has a moderate negative effect on help-seeking compared to other types of barrier. The barriers data also show that stigma is typically reported as a barrier to care-seeking by 21–23% of participants across the studies for shame/embarrassment, negative social judgement and employment-related discrimination. Disclosure concerns/confidentiality had the highest median endorsement, with 32% reporting this as a barrier. However, there was wide variation (4–73%) in reported stigma-related barriers to help-seeking across studies (see Table 3).

Subgroup analyses for barriers studies

Subgroup analyses for the barriers studies indicated that stigma is generally ranked much higher among individuals in the military than in other population groups, especially when considering employment-related discrimination. For health professionals, disclosure/confidentiality concerns and negative social judgement were more frequently reported than in the other groups although the standardized rank was not different (see Table 3).

When comparing gender groups, stigma was ranked lower among studies that only included women. The types of stigma-related barriers reported most frequently in mixed gender samples were shame/embarrassment and negative social judgement.

The third subgroup analysis categorized study samples as psychosis/serious mental illness (SMI), non-psychosis, and samples of the general population (which will include people with and without mental illness of either type). The findings indicated that the two former categories reported more shame and embarrassment barriers than studies with general population samples. However, the relative rank of stigma as a barrier was greatest in the general population samples group (see Table 3). The results for subgroups with three or fewer studies in all subgroups (age group, ethnicity, rural/non-rural, currently receiving mental health care or not) were inconclusive.

Table 3. *Synthesis of studies reporting stigma-related barriers and associated main subgroup analyses*

Sample/subgroup	No. of participants (studies)	Shame/ embarrassment, median (range) %	Negative social judgement, median (range) %	Disclosure concerns/ confidentiality, median (range) %	Employment-related discrimination, median (range) %	Stigma generally/other, median (range) %	Standardized rank, median (range)[a]
Overall sample	60 036 (44)	21 (8–59)	22 (4–73)	32 (4–68)	23 (9–71)	9 (5–43)	4.3 (0.6–9.5)
Professional groups							
Military	17 961 (10)	21 (13–54)	23 (15–73)	23 (14–31)	28 (19–71)	8 (5–11)	0.9 (0.6–2.0)
Health professionals	2834 (3)	–	46	50 (21–50)	14 (9–35)	21	5.3 (1.7–4)
Other	39 241 (31)	26.5 (8–59)	16 (4–46)	32 (4–52)	–	8 (7–24)	5.0 (0.6–8.2)
Gender							
Men	35 (1)	–	9	11	–	–	9.5
Women	18 072 (11)	18 (14–19)	17 (4–55)	36 (35–36)	–	25 (7–43)	6.9 (2.2–8.3)
Mixed	41 929 (32)	24 (8–59)	23 (4–73)	31 (4–68)	23 (9–71)	9 (5–24)	4.2 (0.6–8.2)
Mental health of participants							
Psychosis/SMI	120 (2)	38	15	–	–	–	8
Non-psychosis	13 298 (12)	35 (13–58)	18 (4–46)	31 (4–68)	–	21 (7–43)	5.0 (0.6–8.2)
Population samples	46 618 (30)	20 (8–59)	23 (7–73)	32 (4–54)	23	8 (5–24)	4.0 (0.6–9.5)

SMI, Serious mental illness.

[a] Where a study measured ⩾5 barriers of any type, the barriers were ranked by endorsement and the standardized stigma rank is the rank of the barrier (or the highest ranked if ⩾2 stigma barriers) standardized for number of barriers (1=highest endorsed barriers, 10=least endorsed barrier).

Quality assessment and sensitivity analyses for barriers studies

Overall, the quality of the barriers studies was considered moderate because, for four of the six quality criteria, the majority of studies (73–100%) met the criteria. The main problems identified were no sample size justification and lack of evidence for the reliability and validity of barriers measures. A sensitivity analysis revealed that the results were not affected by the exclusion of studies in the bottom third for quality (⩾3 criteria unmet) as the median standardized rank remained at 4.3.

Qualitative process studies

Fifty-one qualitative studies with a total of 5540 participants were included. Participants were mainly from clinical (51%, 26/51) and population (37%, 19/51) samples. Five themes and 43 subthemes were identified describing processes that underlie the relationship between stigma and help-seeking. The five themes were: dissonance between preferred self/social identity and mental illness stereotypes/beliefs; anticipation/experience of stigma/discrimination; need/preference for non-disclosure; stigma-related strategies used by individual; and stigma-related aspects of care. The themes, subthemes, their frequencies and relationship to help-seeking are represented by the solid-lined boxes and linking arrows in a conceptual model, shown in Fig. 2. Dissonance between a person's preferred self-identity or social identity and common stereotypes about mental illness (e.g. that it denotes weakness or being crazy) resulted in individuals anticipating or experiencing negative consequences (e.g. labelling and unwanted disclosure; public stigma such as social judgement and rejection, employment discrimination, shame/embarrassment and family stigma). To avoid these consequences, individuals did not tell others about their mental health problems and masked the symptoms, and this, together with the anticipated or experienced negative consequences, deterred them from help-seeking. We also identified stigma-related enabling factors that facilitated help-seeking. These were strategies used by individuals (such as selective disclosure and non-disclosure and normalizing mental health problems), along with service factors such as less stigmatizing forms of care and confidential services. What constituted non-stigmatizing forms of care included non-clinical approaches, talk-based care, help in community centres and generic medical settings, care that is welcoming and preserves dignity and practitioners who use terms that reflect clients' understandings of their problems. Exemplar quotations from participants in the primary studies are presented in Supplement 5 to illustrate the subthemes.

Subgroup analyses for qualitative process studies

The subgroup data can be seen in Supplement 6. Studies with African American samples were more likely to include the subthemes 'weak', 'keeping it within the family' and 'non-disclosure', and those with samples from any ethnic minority were more likely to include the subthemes 'stigma for family'. Studies with samples of young people (aged <18 years) were more likely to include the subtheme 'not normal'. The subtheme 'difficulty talking to professionals' was more common in the studies with male samples and the subthemes 'selective/controlled disclosure' and 'non-disclosure' were more common in mixed gender groups. Studies with community samples were more likely to include the subthemes 'weak', 'social rejection', 'difficulty talking to professionals' and 'confidential/anonymous services'. Studies with samples who were currently receiving mental health care were more likely to include the subthemes 'crazy' and 'non-disclosure' but less likely to include the subtheme 'difficulty talking to professionals'.

Quality assessment and sensitivity analysis for qualitative process studies

The overall quality of the qualitative process studies was considered good as the majority (75–96%) of the studies met six of the seven quality criteria. The main methodological limitation was failure to provide a reflexive account of the researchers' influence. The sensitivity analysis revealed that, when the bottom third of studies were removed, all subthemes were retained.

Meta-synthesis

We found that 16 of the 43 subthemes identified in the qualitative process studies data were also apparent in the quantitative barriers studies. One stigma-related barrier in the quantitative studies was found that had not appeared in the qualitative data, namely fear of psychiatric patients. The authors considered that five types of structural stigma also interfered with help-seeking, two by increasing or maintaining stereotypes and three by a direct effect on help-seeking (see Fig. 2). A meta-synthesis table juxtaposing the findings for the research questions about association, barriers and processes, and placing these in a matrix with the subgroup and methodological quality findings, can be found in Table 4.
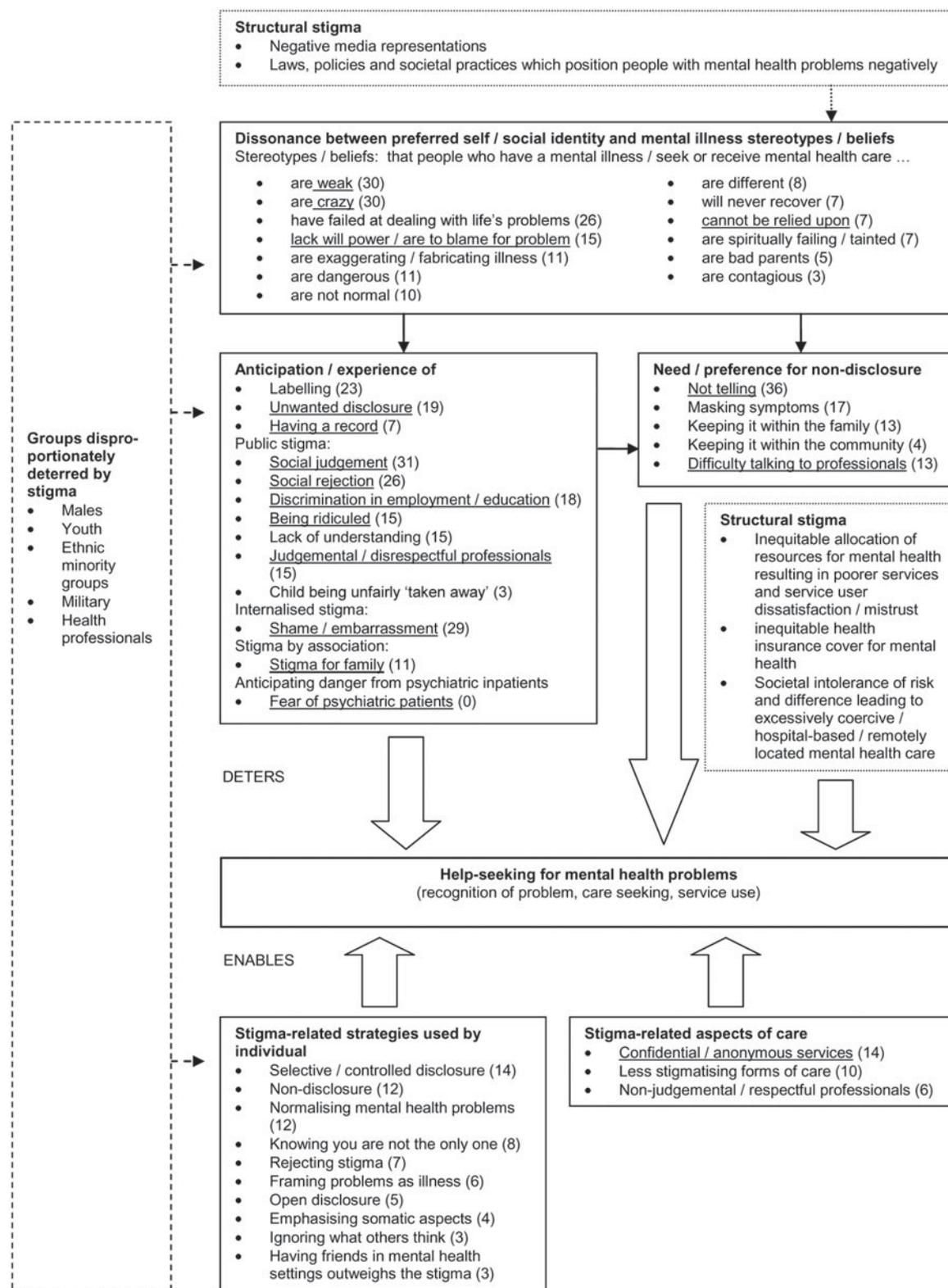
Fig. 2. Synthesizing conceptual model representing the processes underlying the relationship between stigma and help-seeking for mental health problems. Boxes with solid lines represent themes identified in the synthesis of the qualitative process data. Figures in parentheses denote the number of qualitative process studies (of *n*=51 studies) containing each subtheme. Underlined subthemes are those that also appeared in the quantitative barriers studies. Boxes with dashed lines denote groups found to be disproportionately deterred by stigma. Boxes with dotted lines represent the processes by which structural stigma (not assessed in this review) may theoretically affect help-seeking.

Discussion

This is the first systematic review to examine the relationship between stigma and mental health help-seeking. It provides a comprehensive overview of the large body of existing literature, combining evidence from both quantitative and qualitative studies to clearly map out what is known about this complex relationship. Our syntheses of quantitative studies provide evidence that mental health-related stigma has a small to moderate detrimental impact on help-seeking for mental ill health. The conceptual model, initially derived from our synthesis of qualitative process studies, details the multiple factors that contribute to this detrimental effect, along with some that help to ameliorate it. This model was partially validated by our finding that over a third (37%, 16/43) of the subthemes had also been endorsed as barriers in the quantitative studies, and the latter studies only yielded one barrier not identified in the qualitative data ('fear of psychiatric patients'). The subthemes not replicated in the quantitative data may be an indicator of the value of qualitative data for providing a nuanced, detailed picture of multifaceted processes. The conceptual model was further extended by the addition of our findings on population group moderators and our propositions about the potential impact of structural stigma on help-seeking. This model will be an important foundation for future research and the development of interventions to increase help-seeking.

Quantitative studies

The findings from the association studies indicate that the majority of studies report a negative association, and that the size of the association can be interpreted as small. However, a large proportion of these studies identified in this review were cross-sectional. Most help-seeking outcomes were attitudinal or intentional, although there is evidence that help-seeking attitudes are associated with actual service use (ten Have *et al.* 2010). Cross-sectional association studies that use behavioural measures of help-seeking behaviour exhibit much more mixed results, which could be partly accounted for by 'reverse causation' (the probability of the presumed outcome being causally related to the presumed exposure), that is seeking of help/receipt of mental health care increasing stigma.

When comparing effect sizes for different types of stigma, the key types are treatment stigma (the stigma associated with seeking or receiving treatment for mental ill health) and internalized stigma, as only they show a small consistent negative association with help-seeking. Internalized stigma (shame/embarrassment) also features in the findings from the barriers and qualitative process studies as a help-seeking deterrent. Vogel *et al.* (2007) have found that internalized stigma is a mediator in a pathway from public stigma to health care avoidance. It is possible that treatment stigma may also be on this pathway, and this may explain the strength of their association with reduced help-seeking. Endorsed stigma and perceived stigma are only weakly negatively associated with help-seeking. Although there is some support for the importance of anticipated stigma, only two of the 56 association studies examined the effects of this type of stigma, indicating that this is understudied.

The studies that investigated stigma barriers indicate that stigma is a moderately important barrier, ranking fourth out of 10 barriers, and was generally reported as a barrier by approximately a quarter to one-third of the participants. Disclosure and confidentiality concerns seem to be the most prominent type of stigma barrier. This finding was echoed in the qualitative process studies synthesis, where there was one theme and four subthemes relating to disclosure concerns. A major national population study concluded that by far the largest treatment barriers was wanting to handle the problem on one's own, followed by low perceived need for care (Mojtabai *et al.* 2011). Although not considered to be stigma-related barriers, these factors may be influenced by stigma (Clement *et al.* 2012*a*). A systematic review of barriers and facilitators to mental health help-seeking in young people showed the key barriers to be stigma, confidentiality issues, lack of accessibility, self-reliance, low knowledge about mental health services and fear/stress about the act of help-seeking or the source of help itself (Gulliver *et al.* 2010). Consequently, it is important to see stigma as part of a larger network of beliefs and other constraints deterring help-seeking (Schomerus & Angermeyer, 2008).

Qualitative studies

The synthesis of the qualitative studies produced a detailed conceptual model of the processes underlying the relationship between stigma and help-seeking, with five major themes: (1) dissonance between a person's preferred self-identity or social identity and common stereotypes about mental health; (2) anticipation/ experience of negative consequences; (3) need/preference for non-disclosure; (4) stigma-related strategies used by individuals to enable help-seeking; and (5) stigma-related aspects of care that facilitate help-seeking.

These themes, and the subthemes within them, extend existing models about how stigma reduces help-seeking. For example, Corrigan (2004) hypothesized that stigma may deter help-seeking through two routes: (1) by people wanting to avoid the label that

Table 4. *What is the impact of mental health-related stigma on help-seeking? Meta-synthesis of main findings from the association, barriers and process studies: total 144 studies[a] (90 189 participants)*

	Association studies (56 studies, $n=27\,572$)	Barriers studies (44 studies, $n=60\,036$)	Qualitative process studies (51 studies, $n=5540$)
Research question	What is the direction and extent of the association between stigma and help-seeking?	To what extent is stigma reported to be a barrier to help-seeking?	What are the processes underlying the relationship between stigma and help-seeking?
Overall finding	Small negative association	Ranked fourth highest reported barrier when all types of barriers are considered and the number of barriers investigated standardized to 10	Anticipated and experienced stigma based on stereotypes deters help-seeking directly and through non-disclosure. Some stigma-related personal and service factors facilitate help-seeking
Impact of different aspects of stigma			
Stereotypes			Theme, 13 subthemes (3–30 studies)
Labelling			Subtheme (23 studies)
Anticipated/experienced prejudice/negative social judgment)	No association (anticipated/experienced stigma)	Barrier reported by 22% (median)	Two subthemes (15, 31 studies)
Anticipated/experienced employment-related discrimination		Barrier reported by 23% (median)	Subtheme (18 studies)
Anticipated/experienced other types of discrimination			Three subthemes (3, 15 and 26 studies)
Disclosure concerns		Barrier reported by 32% (median)	Theme, nine subthemes (4–36 studies)
Anticipated/experienced internalized stigma/shame/embarrassment	Small negative association	Barrier reported by 21% (median)	Subtheme identified in 29 studies. Partial theme: dissonance between self-identity and stereotypes
Treatment stigma	Small negative association		
Population groups disproportionately affected			
Ethnic minorities	Asian Americans: large negative association. Arabic minorities: large negative association		African Americans: more studies with subthemes of weak, stigma for family, keeping it in the family, and non-disclosure. Other ethnic minorities: more studies with subtheme of stigma for family

Age			Youth (<18 years): more studies with subtheme of not normal
Gender		Females: less reporting of stigma-related barriers	Males: more studies with subtheme of difficulty talking to professionals
Profession		Military: more reporting of stigma-related barriers (especially employment-related discrimination) Health professionals: more reporting of shame/embarrassment and negative social judgement barriers	
Experience of mental health problems		Experience of mental ill health: more shame/embarrassment	Experience of mental health problems: fewer studies with themes of weak, social rejection, difficulty talking to professionals, and confidential/anonymous services
Rural setting	Insufficient data	Insufficient data	Insufficient data
Methodological quality			
Overall quality	Low No association with behavioural indicators, prospective studies, or when low quality studies were removed	Moderate	Good
Main methodological limitations	Sample size not justified Lack of evidence for reliability and validity of help-seeking measures Selection bias in samples (student samples, low response rates) Predominance of attitudinal/intentional data Lack of prospective studies	Sample size not justified Lack of evidence for reliability and validity of measures	Lack of reflexive account of researchers' influence

[a] References for the 144 included studies are given in Supplement 7.

receiving formal care often brings, so as to escape public stigma, and (2) by the desire to avoid experiencing internalized stigma such as shame and embarrassment. Others (Schomerus & Angermeyer, 2008) have proposed that help-seeking may be impeded by the stigma attached to help-seeking (treatment stigma), anticipated discrimination and internalized stigma. The model produced in the present review includes these elements, but also includes disclosure issues that were found to play a key role, along with stigma-related facilitators, such as ignoring what other's think or forms of care being named in less stigmatizing ways. It therefore provides a considerably more comprehensive and detailed account of processes, in addition to being systematically grounded in the extant literature.

Population group moderators

The subgroup analyses identified certain population groups for whom stigma had a disproportionate effect on help-seeking: those from Asian, Arabic, African American and other minority ethnic groups; young people; males; and those in military and health occupations (barriers studies). Studies of individuals with experience of mental ill health were more likely to report shame or embarrassment and less likely to include the themes 'weak', 'social rejection', 'difficulty talking to professionals' and 'confidential/anonymous services'. The former may reflect the fact that shame is inherent in many disorders (Rüsch et al. 2007), and the latter may indicate that need is overcoming concerns; care changing perceptions; or those who feel less stigma are more able to access services. These findings are in line with individual studies that have investigated whether sociodemographic characteristics interact with stigma to reduce help-seeking. However, such studies are small in number and have used disparate methods. Consequently, our review has made a significant addition to the literature of population group moderators in the relationship between stigma and help-seeking.

Gary (2005) proposed that people from ethnic minority groups experience double stigma whereby racism outside and within mental health services is added to the public and internalized stigma of mental illness to deter help-seeking. For males, gender stereotypes (e.g. being strong and stoical) may be interacting with mental illness stereotypes (mental illness indicates weakness) to exacerbate the effect of stigma on help-seeking (Judd et al. 2008). As identity and peer group issues are both highly salient in adolescence (Kroger, 2004), young people may feel the dissonance between their preferred self- and social identity and mental illness stereotypes more acutely than others

and this may increase the effects of stigma of help-seeking for this group. The ethos of invincibility in medicine (Henderson et al. 2012) and of machismo in the military (Held & Owens, 2013) may contribute to explaining why these groups are particularly likely to be deterred from help-seeking by stigma.

Limitations

The individual studies were limited by several methodological issues, with the association and barriers studies judged as having moderate methodological quality. For the association synthesis, excluding lower quality studies lessened the effect size of the overall findings. The vast majority of the studies were undertaken in high-income countries and so the findings are limited in their generalizability to other settings.

The review has several strengths such as its breadth of research questions and inclusion of both quantitative and qualitative studies, its comprehensive multi-database search strategy and dual-author data extraction. However, some relevant studies may have been missed because of publication bias or the exclusion of grey literature. As we adopted the EPPI-Centre's method of pre-specifying the main study types, some pertinent areas were not included. We did not include quantitative studies on processes, for example through path analysis (Vogel et al. 2007), or anti-stigma intervention studies with help-seeking outcomes (except where such studies provided data of relevance to the association research question). A systematic review of randomized controlled trials (RCTs) of interventions aiming to increase help-seeking reported that of two out of three anti-stigma interventions improved help-seeking attitudes (Gulliver et al. 2012). However, two anti-stigma intervention RCTs not included in that review reported no change in help-seeking intentions (Han et al. 2006; Clement et al. 2012b). Furthermore, we did not include mental health literacy interventions (Kitchener & Jorm, 2006), which may directly, or indirectly through stigma reduction, increase help-seeking attitudes (Jorm et al. 2000; Gulliver et al. 2012). In addition, we did not gather data on studies on the impact of structural stigma (e.g. underfunding of mental health services, insufficient health insurance coverage for mental ill health, media stereotypes) on access to mental health care (Schomerus & Angermeyer, 2008; Vogel et al. 2008), although we have delineated the potential role of structural stigma in our conceptual model. Although the use of subgroup analysis was informative, and for qualitative studies innovative, this was limited by the small number of studies in some subgroups in each study type (e.g. populations in rural settings or in later life).

Future research

Our review highlights several key evidence gaps. There are particular needs for further research (i) set in low- and middle-income countries; (ii) on help-seeking for under-represented conditions such as bipolar, personality and anxiety disorders (substance misuse disorders were excluded from this review but may also be under-represented in the literature); (iii) on stigma and help-seeking by school age youth; (iv) studies with prospective study designs; and (v) studies on stigma-related factors that facilitate help-seeking. Furthermore, as most research has focused on initial access to care, we need to know more about how stigma contributes to disengagement and discontinuation by those already in contact with services. The impact of anti-stigma interventions on help-seeking warrants further research. Disclosure issues were found to be a particular concern, and although other reviews have mapped out the benefits and harms of disclosure in employment contexts (Brohan *et al.* 2012), we need to understand more about disclosure in relation to help-seeking. It would also be useful to investigate how different types of stigma may relate to other help-seeking barriers, such as wanting to deal with problems oneself, and low perceived need. Further research is also needed to establish what constitutes a minimally stigmatizing service and on the effectiveness of the strategies individuals use to overcome treatment stigma and access services. Future studies are needed to add to the literature about groups particularly likely to be deterred from help-seeking by stigma, especially for under-researched groups such as older people and those in rural settings.

Implications for practice

Stigma has a clear, but small to moderate, deterrent effect on help-seeking for mental health problems, and this review can help towards the development of interventions to increase access to care. The data we reviewed demonstrate that multiple different types and aspects of stigma contribute to this effect, consequently multi-faceted approaches are likely to be most productive.

Examination of the major associations, barriers and themes indicates that anti-stigma programmes, services and practitioners should focus on countering stereotypes (particularly weakness and 'craziness'); social judgement and rejection of people with mental health problems; employment discrimination; and shame/embarrassment. Disclosure issues were found to be a particular concern, and interventions to aid decision making around disclosure may be warranted (Henderson *et al.* 2013). Our syntheses also have implications for interventions directed at individuals already in receipt of care. Services and practitioners could, for example, support service users to develop additional strategies to cope with, and counter, treatment stigma and to address internalized stigma. One approach to countering treatment stigma would be to discuss with service users the facilitative strategies individuals were found to have used in the studies in this review, such as non-disclosure, selective and open disclosure, rejecting stigma, ignoring what others think, and normalizing mental health problems. Mittal *et al.* (2012) have identified several interventions with preliminary evidence of effectiveness in reducing internalized stigma, including psycho-education (with or without cognitive behavioural therapy), acceptance and behaviour therapy, and multimodal interventions. There is a need to configure services to minimize their stigmatizing effect. Our syntheses indicate that this is likely to be one that avoids unnecessary labelling (Marshall *et al.* 2004; Brown *et al.* 2006), respects confidentiality and is community based (Brown *et al.* 2004; Johnson *et al.* 2004; Mishra *et al.* 2009). In light of our finding that certain groups are particularly vulnerable to stigma compromising help-seeking, interventions that provide destigmatizing care for such groups are warranted, such as universal post-deployment programmes incorporating psycho-education for military personnel (Adler *et al.* 2009) and mental health programmes based in 'Black churches' (Blank *et al.* 2002). Lastly, given that stigma is not the only or main factor compromising help-seeking, future interventions should embed stigma-reducing strategies within broader approaches so that both stigma-related and other key treatment barriers are addressed, for example combining anti-stigma programmes with those addressing mental health literacy (Wright *et al.* 2006).

Supplementary material

For supplementary material accompanying this paper visit http://dx.doi.org/10.1017/S0033291714000129.

Declaration of Interest

None.

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