

## Special Article

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# Stigma against mental health disorders in Nepal conceptualised with a ‘what matters most’ framework: a scoping review

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## Abstract

**Aims.** Stigma related to mental disorders is a barrier to quality mental healthcare. This scoping review aimed to synthesise literature on stigma related to mental disorders in Nepal to understand stigma processes. The anthropological concept of ‘what matters most’ to understand culture and stigma was used to frame the literature on explanatory models, manifestations, consequences, structural facilitators and mitigators, and interventions.

**Methods.** We conducted a scoping review with screening guided by the Preferred Reporting Items for Systematic Review and Meta-analysis Extension for Scoping Reviews (PRISMA-ScR). A structured search was done using three international databases (PsycINFO, Medline and Web of Science), one Nepali database (NepJol) and cross-referencing for publications from 1 January 2000 through 24 June 2020. The search was repeated to include structural stigma-related terms. Quality of quantitative studies was assessed using the Systematic Assessment of Quality in Observational Research (SAQOR) tool. The review was registered through the Open Science Framework (OSF) ([osf.io/u8jhn](https://osf.io/u8jhn)).

**Results.** The searches yielded 57 studies over a 20-year period: 19 quantitative, 19 qualitative, nine mixed methods, five review articles, two ethnographies and three other types of studies. The review identified nine stigma measures used in Nepal, one stigma intervention, and no studies focused on adolescent and child mental health stigma. The findings suggest that ‘what matters most’ in Nepali culture for service users, caregivers, community members and health workers include prestige, productivity, privacy, acceptance, marriage and resources. Cultural values related to ‘what matters most’ are reflected in structural barriers and facilitators including lack of policies, programme planning and resources. Most studies using quantitative tools to assess stigma did not describe cultural adaptation or validation processes, and 15 out of the 18 quantitative studies were ‘low-quality’ on the SAQOR quality rating. The review revealed clear gaps in implementation and evaluation of stigma interventions in Nepal with only one intervention reported, and most stigma measures not culturally adapted for use.

**Conclusion.** As stigma processes are complex and interlinked in their influence on ‘what matters most’ and structural barriers and facilitators, more studies are required to understand this complexity and establish effective interventions targeting multiple domains. We suggest that stigma researchers should clarify conceptual models to inform study design and interpretations. There is a need to develop procedures for the systematic cultural adaptation of stigma assessment tools. Research should be conducted to understand the forms and drivers of structural stigma and to expand intervention research to evaluate strategies for stigma reduction.

## Introduction

Stigma is a complex and multifaceted phenomenon that can have multiple, detrimental effects on individuals, family members and society (Wahl and Harman, 1989; Corrigan *et al.*, 2014). In the case of mental health, stigma has been identified as sometimes being more distressing and debilitating than the illness itself (Thornicroft, 2003). Various studies have reported on the nature of stigma, its types and effective interventions. However, most of the evidence on the topic comes from high-income countries (HICs). Reviews conducted of effective interventions to reduce mental health stigma showed very few studies conducted in low- and middle-income countries (LMICs) (Semrau *et al.*, 2015). Although stigma and discrimination are considered

universal phenomena, their manifestations may vary according to culture and contexts. Cultural context is known to influence many aspects of mental disorders (Alarcón *et al.*, 2009). Developing a stigma intervention and measuring its effectiveness in a particular setting is a challenge if the context-specific understanding of stigma, its causes and manifestations are missed.

One way to understand this cultural context is evaluating ‘what matters most’, an approach that conceptualises structural stigma as a moral experience and explains how threats to personal and group identity, or what is most at stake, may lead to stigmatizing behaviours (Yang *et al.*, 2014a). In healthcare settings, a provider’s role as a healer in society may be jeopardised when encountering a patient with mental disorders whom they are not equipped to care for – this should be considered along with threats to other societal norms and values that are shaped by the provider’s life experience, gender, caste, ethnicity and religion (Kleinman, 1999; Yang *et al.*, 2007). By identifying stigma as a moral experience and addressing what matters most, anti-stigma interventions can be better tailored to local contexts.

There is a growing burden of mental disorders in Nepal, an LMIC in South Asia. However, fewer than 10% of people with mental disorders receive any form of treatment (Luitel *et al.*, 2017). There are various supply-side challenges to this treatment gap, such as lack of mental health services in primary healthcare, and lack of regular supply of medicines (Luitel *et al.*, 2017). However, on the demand side, stigma related to mental disorders has been identified as a dominant barrier to mental healthcare (Clement *et al.*, 2015). Despite this, limited studies have been conducted to understand the local context and concepts of stigma in Nepal. Therefore, we conducted this scoping review to understand the stigma in the context of Nepal. The aim of this study was to synthesise the literature on mental health stigma in Nepal and understand stigma processes. Stigma processes include drivers, manifestations and consequences of stigma and the influence of ‘what matters most’ on these processes in the context of Nepal.

## Methods

We employed a scoping review method (Arksey and O’Malley, 2005) with a focus on exploring the literature on mental health stigma in Nepal. Our guiding questions for the review were:

- (1) What are the causes or drivers of stigma related to mental disorders in Nepal?
- (2) How is stigma related to mental disorders manifested at different levels, what behaviours, where, by whom and why?
- (3) What approaches have been used to reduce stigma for mental health conditions, and what evidence supports these approaches?

### Search and screening strategy

The databases searched included PsycINFO, Medline, Web of Science and NepJol (a Nepali database) and for a 20-year period from 1 January 2000 to 24 June 2020. Box 1 includes search terms used in all databases. As this is a sub-review of a broader scoping review of stigma for all health conditions in Nepal, the initial strategy used for the review included all health conditions and was not just restricted to mental health. Due to the limited search strategy that could be used in NepJol, only ‘Stigma’ was used as a search term. As a modification from the protocol, the search was repeated in PsycINFO, Medline and Web of Science with added terms for structural stigma. This was because during the data extraction

#### Box 1. Search terms used

##### Search terms used for stigma and health in international databases:

Medline ( $n = 288$ ), Web of Science ( $n = 407$ ), PsycINFO ( $n = 96$ )  
 stigma\* OR ‘stigma’ OR stereotyp\* OR ‘stereotype’ OR prejudic\* OR  
 ‘prejudice’ OR discriminat\* OR ‘discrimination’ OR ‘social perception’ OR  
 ‘social distance’ OR ‘social stigma’) AND (Nepal\* OR ‘Nepal’) AND (health  
 condition terms)

##### Search terms used in Nepali data base: NepJol ( $n = 145$ )

‘Stigma’

##### Search terms used for structural stigma for all databases: Medline ( $n = 23$ ), Web of Science ( $n = 59$ ), PsycINFO ( $n = 14$ )

structur\* OR ‘Institution’ OR system\* OR ‘policy’ OR service\*) AND (‘social  
 discrimination’ OR ‘stigma’ OR barrier\* OR ‘exclusion’ OR ‘inequity’ OR  
 ‘disparit’) AND (‘mental health’ OR ‘mental disorder’ OR ‘depression’ OR  
 ‘mood disorder’ OR ‘anxiety’ OR ‘Schizophrenia’ OR ‘psychotic disorder’ OR  
 ‘bipolar disorder’ OR ‘substance related disorder’) AND ‘Nepal’.

phase, we noticed that we may have missed some literature given the vagueness in how ‘structural stigma’ is defined in existing literature. The same inclusion criteria applied, with the specification for mental health-related structural stigma and discrimination. See Box 2 for the inclusion criteria used. The review was registered through the Open Science Framework (OSF) ([osf.io/u8jhn](https://osf.io/u8jhn)).

The title and abstract screening were completed by three reviewers (LW, DG and AP). The full-text screening was completed by one reviewer (LW) with 20% of the articles re-assessed for eligibility by two other reviewers (AP and DG). Any disagreements between reviewers were resolved through discussion and additional review by the supervisor (BK). The screening was guided by the Preferred Reporting Items for Systematic Review and Meta-analysis Extension for Scoping Reviews (PRISMA-ScR) (Tricco *et al.*, 2018).

### Data extraction and synthesis

Following the full-text screening, four authors (LW, DG, AP and MN) extracted information from the included articles using a framework developed by the authors (BK and SW). The framework covered key themes on stigma: (a) key stigma-related findings, (b) explanatory models, (c) characteristics of stigmatised groups, (d) myths, (e) ‘what matters most’, (f) locations and types of stigmatisation, (g) cultural norms and social interactions, (h) structural stigma, (i) impact of stigma and (j) recommended interventions. In addition, a separate sheet was created to extract information on any stigma-related interventions that were conducted or evaluated. The themes related to interventions included (a) intervention name, (b) type of intervention, (c) duration and (d) materials used.

After data extraction, DG collated the findings using narrative synthesis and shared them with the review team for inputs. Additionally, we conducted a quality review of 18 quantitative studies with stigma as primary outcome. We used the Systematic Assessment of Quality in Observational Research (SAQOR) tool with a modification for Cultural Psychiatric Epidemiology, SAQOR-CPE (Ross *et al.*, 2011; Kohrt *et al.*, 2014) to understand the scope and generalisability of the findings.

## Results

### Study selection

Figure 1 includes an overview of the search process. The search strategy for the international database resulted in 887 references, out of which 278 were duplicates. After removing duplicates,

**Box 2.** Inclusion criteria

Inclusion criteria for eligibility of searched texts:

- (1) Articles published in English or Nepali only
- (2) Articles published between 01/01/2000–06/24/2020
- (3) Articles focused on Nepal as a geographical location (excludes studies carried out among Nepali population outside geographical area of Nepal such as Bhutanese refugees)
- (4) Articles published in both Nepali and international peer-reviewed journals
- (5) Relates to articles focused on stigma and its definitions such as discrimination, prejudice or stereotype
- (6) Articles focused on stigma related to health conditions (excludes studies in other forms of stigma and discrimination such as gender and ethnicity and its effects on health outcomes)
- (7) Includes data regardless of its 'quality' and study design
- (8) Articles that include or mention at least one stigma-related outcome or domain

and adding 145 articles identified from the Nepali database, a total of 754 articles were included for the title and abstract screening. We removed 574 after the title and abstract screening because they did not meet our inclusion criteria. For full-text review, we added 13 articles identified through cross-referencing. We completed a full-text review for 193 articles and excluded 136 that did not meet the inclusion criteria or were of conditions other than mental disorders. A total of 57 articles were included in the study for data extraction and synthesis.

Table 1 gives an overview of the publications that were included in this review. Out of 57 studies included, 19 were quantitative, 19 were qualitative, nine were mixed methods, five were review articles (including literature reviews and scoping reviews), two were ethnographies, and three were other types of publications (including reports, opinion articles and protocols). The quality assessment of 18 relevant quantitative observational studies showed that only three were of 'moderate quality', while the remaining 15 were of 'low-quality'. The main reasons for 'low-quality' were inadequacy in measurement quality (no mention of tool adaptation and validation in the local context), and sampling method (biased group not generalisable beyond research study and recruitment methods not well described). No articles were excluded after quality review. Hence, although we summarise the findings from these quantitative studies below, results need to be interpreted with caution because of the quality limitations.

Most of the qualitative studies with stigma as the major theme or domain focused on public stigma of either general community members or healthcare workers. Quantitative or mixed methods studies predominantly focused on self or internalised stigma of people with lived experiences of mental disorders (PWLE) (Adhikari, 2015; Neupane *et al.*, 2016; Amatya *et al.*, 2018; Rathod *et al.*, 2018; Maharjan and Panthee, 2019; Shrestha, 2019), public stigma (family and community members) (Neupane *et al.*, 2016; Amatya *et al.*, 2018; Koirala *et al.*, 2019; Luitel *et al.*, 2019; Pandey, 2019), health workers' stigma (Gartoulla *et al.*, 2015; Pathak and Montgomery, 2015; Kohrt *et al.*, 2018b, 2020), medical and pharmacy students' stigma (Panthee *et al.*, 2010; Adhikari, 2018; Jalan, 2018; Shakya, 2018), and perceived stigma among PWLE and family members (Adhikari *et al.*, 2008; Lamichhane, 2019). Four studies exclusively focused on courtesy stigma (Angermeyer *et al.*, 2003). Twenty publications focused on PWLE's experiences and their

perceptions, of which two reported to have involved PWLE in the research and publication process (Drew *et al.*, 2011; Gurung *et al.*, 2017) and two reported to have involved PWLE in the stigma reduction interventions (Upadhaya *et al.*, 2018; Kohrt *et al.*, 2020) while the remaining had included PWLE as research participants.

The findings from the scoping review are collated into six broad themes related to stigma:

- (1) 'What matters most': cultural factors that influence mental health stigma.

Although most studies did not explicitly explore the concept of 'what matters most', the theme was identified from the description of cultural contexts that shape stigma related to mental disorders in Nepal. Various studies discussed what mattered most to PWLE, their family members, the general community and health workers. Identified topics included social acceptance, productivity and income generation, social prestige and honour (*ijjat*), privacy or anonymity, marriage and equality.

For PWLE in Nepal, social acceptance and anonymity were described to matter the most (Kaiser *et al.*, 2020). This was reflected in their interest in engaging in productive activities, so they are looked upon as contributing members of society. Anonymity and privacy were primary concerns for PWLE and their families. Their concerns included privacy while visiting health facilities particularly because some PWLE were hiding their disorders from family and community members. Family members who could afford to take PWLE to India or big cities for treatment would do so due to fear of the community finding out about their disorders. This also resulted in PWLE not being willing to seek treatment or take medications because of potential discovery by family and community members. The greatest hesitation was related to seeking care in one's community and local health facilities.

Similar to PWLE, what mattered most for family and community members were productivity and economic contribution (Angdembe *et al.*, 2017; Pandey, 2019). The community members felt that the biggest support for PWLE was their involvement in income-generating activities (Angdembe *et al.*, 2017). In one of the studies (Pandey, 2019), the family members described financial burdens for taking care of PWLE and negative financial impacts on their professional lives. Family members mentioned losing prestige (Nepali: *ijjat*) in the society as an important cultural reason for not disclosing the diagnosis or seeking care (Kohrt and Harper, 2008; Brenman *et al.*, 2014). Another reason, especially for parents of PWLE, was not being able to marry off their children as a result of mental illness, particularly for daughters. Not being able to marry off one's daughter was considered one of the biggest cultural burdens for parents in Nepal, which is further amplified by the myth that marriage would heal mental disorders (Brenman *et al.*, 2014).

For the health workers, what mattered most were the structures required for delivering quality mental health care. Health workers reported physical threat (possibility of personal harm and experiencing violence while treating PWLE), loss of social prestige in the community for treating PWLE, and lack of professional knowledge and competence (how to treat illness) as the most important to them (Kohrt *et al.*, 2020). Several publications reported public and health workers' perceptions of PWLE as violent and aggressive people who can damage property and harm themselves or others. Thus, fear of harm or danger was a prominent driver of

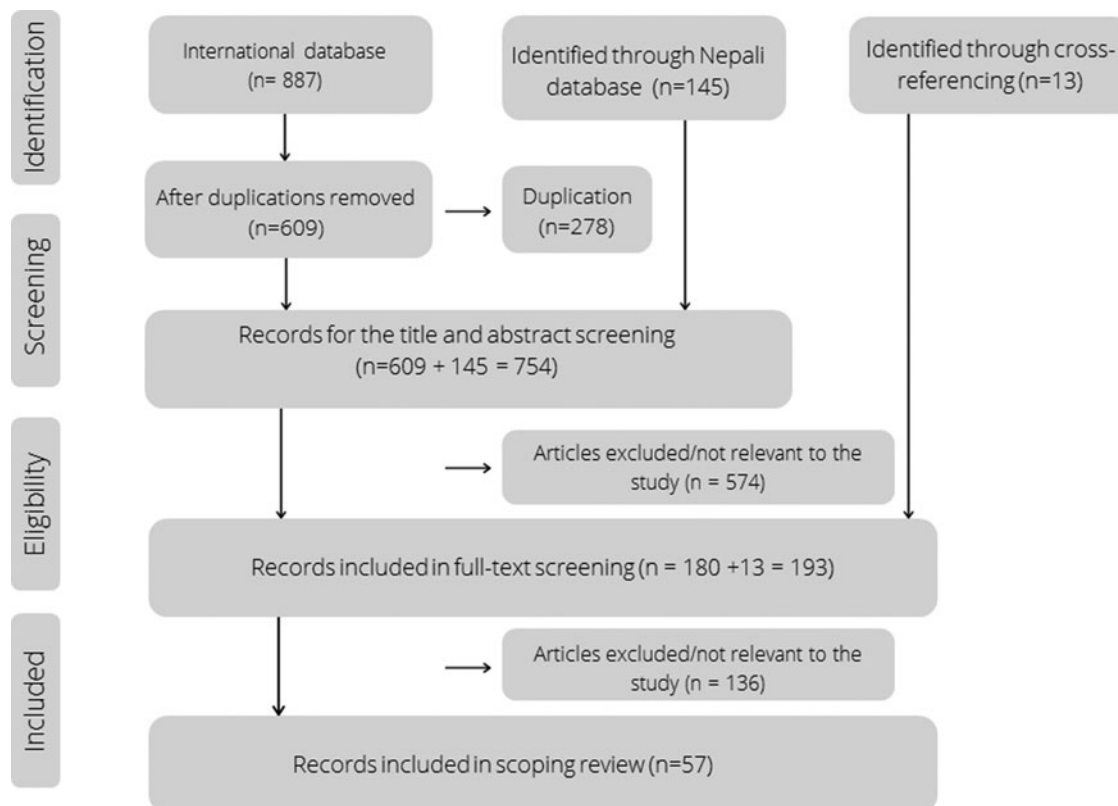


Fig. 1. PRISMA-ScR search strategy.

mental disorders stigma among health workers in Nepal (Kohrt and Harper, 2008; Neupane *et al.*, 2016; Mahato *et al.*, 2018; Upadhaya *et al.*, 2020).

For the handful of PWLE working as advocates in Nepal, what mattered most focused on equality in decision making regarding policies (Gurung *et al.*, 2017; Koirala *et al.*, 2019). They expressed a sense of frustration for not having equal rights or not being taken seriously in decision-making processes.

## (2) Structural facilitators and barriers (structural stigma)

Although structural forms of stigma were not directly reported in any of the publications, many studies (13 of 57) reported structural barriers and facilitators that perpetuated mental disorders stigma or contributed to the treatment gap. Lack of mental health-related policies and strategies, adequate allocation of budget, and issues in supply of medicines were some of the frequently reported barriers.

Studies cited low political will to prioritise mental health services that resulted in the lack of supportive mental health policies and strategies (Luitel *et al.*, 2017; Petersen *et al.*, 2017). The situation was further aggravated by discriminatory policies such as those encouraging imprisonment and forcibly initiating treatment that violated the rights of PWLE (Drew *et al.*, 2011). Another policy-level barrier was the vagueness of suicide policies that led to public misunderstanding of suicide as illegal in Nepal (Hagaman *et al.*, 2016; Ramaiya *et al.*, 2017). This led to under-reporting of suicides, which hampers accurate data collection and programme planning (Hagaman *et al.*, 2016). Another policy-level challenge to reporting is the lack of mental disorder-related indicators in government-level health reporting. Under-

reporting of mental disorders negatively influenced the government resource management during the 2015 earthquake in Nepal (KC *et al.*, 2019). The disaster risk reduction and management plans did not include mental health care packages resulting in the massive rise of cases post-earthquake that were almost exclusively addressed through international/national non-government organisations' effort (KC *et al.*, 2019). A key barrier to developing and implementing inclusive mental health policies was poor involvement of PWLE in the policy-making process. The long-standing structural hierarchy and power dynamics between service providers and PWLE as noted by many advocates made it difficult for PWLE to actively participate in planning and decision-making process (Lempp *et al.*, 2018). This was also cited as the main reason behind systematic marginalisation of PWLE within the policy-making and other health systems processes (Gurung *et al.*, 2017).

In terms of programme planning, mental health was not as prioritised as other sectors (e.g. maternal health) where the most budget was allocated (Upadhaya, 2014). This led to inadequate mental health-related training and lack of supervision for primary healthcare providers. Another important structural challenge was an inadequate supply of psychiatric medications. Health workers also pointed out how there was a lack of referral mechanisms and private rooms for counselling that reduced health workers' motivation to treat patients with mental disorders (Luitel *et al.*, 2017; Upadhaya *et al.*, 2018, 2020; Lamichhane, 2019). Health professionals were also concerned about being stigmatised for choosing 'psychiatry' or 'mental health' as a speciality which led to a lack of mental health specialists in Nepal (Hagaman *et al.*, 2018). Even for those interested in specializing in mental health, the coursework had a strong focus on



**Table 1.** Overview of publications included in the scoping review

SN	Study article no., title, (citation)	Study population	Sample size	Study design	Type of stigma mentioned	Stigma-related measures used/tools validation	Quality assessment (for quantitative study only)
1.	Situational analysis to inform development of primary care and community-based mental health services for severe mental disorders in Nepal (Angdembe <i>et al.</i> , 2017)	Policy makers, primary healthcare workers, service users and community members	FGD ( $n = 69$ ); KII ( $n = 25$ )	Cross-sectional qualitative study	Public stigma	NA	NA
2.	Maternal mental health in primary care in five low- and middle-income countries: a situational analysis (Baron <i>et al.</i> , 2016)	Mothers with mental health problems	NA	Cross-sectional situation analysis using mixed methods	Public stigma and health worker stigma	NA	NA
3	Pathways and access to mental health care services by persons living with severe mental disorders and epilepsy in Uganda, Liberia and Nepal: a qualitative study (Kisa <i>et al.</i> , 2016)	Key informants (policy makers, health care workers, community leaders, teachers, service users)	26 KIIs and 9 FGDs (of 6 participants each)	Cross-sectional qualitative study	Public stigma, health worker stigma	NA	NA
4	Prevalence of self-stigma and its association with self-esteem among psychiatric patients in a Nepalese teaching hospital: a cross-sectional study (Maharjan and Panthee, 2019)	Patients with mental illness attending psych outpatient department	180	Cross-sectional quantitative study	Self-stigma	Internalised Stigma of Mental Illness (ISMI); Rosenberg Self Esteem Scale (RSES) – translation and adaptation in Nepali	Moderate quality
5	Knowledge status on mental health among health professionals of Chitwan District, Nepal (Gartoulla <i>et al.</i> , 2015)	Health professionals	100	Descriptive cross-sectional study	Health worker stigma	Semi-structured tool developed and used to measure knowledge, attitude and practice	Low quality
6	Mental health care in Nepal: current situation and challenges for development of a district mental health care plan (Luitel <i>et al.</i> , 2015)	Publicly available information; government officers, psychiatrists, service providers	NA	Cross-sectional qualitative	Public stigma and structural barriers	NA	NA
7	Nepal's silent epidemic of suicide (Cousins, 2016)	NA	NA	Report	Public stigma and structural barriers	NA	NA
8	Suicide surveillance and health systems in Nepal: a qualitative and social network analysis (Hagaman <i>et al.</i> , 2016)	Health system workers, foreign aid agency workers, government workers, hospital workers, legal/law enforcement, NGO workers	36 in-person interviews, 23 of 36 participated in social network analysis	Cross-sectional qualitative	Public stigma, health worker stigma	NA	NA

(Continued)

Table 1. (Continued.)

SN	Study article no., title, (citation)	Study population	Sample size	Study design	Type of stigma mentioned	Stigma-related measures used/tools validation	Quality assessment (for quantitative study only)
9	Caregivers' attitude towards people with mental illness and perceived stigma: a cross-sectional study in a tertiary hospital in Nepal (Neupane <i>et al.</i> , 2016)	Caregivers of patients	170	Cross-sectional quantitative study	Public stigma, internalised stigma	Internalised Stigma of Mental Illness (ISMI) Community Attitude towards Mental Illness (CAMI) tool	Low quality
10	Mental health needs and resources in Nepal (Hall <i>et al.</i> , 2016)	Mental health professionals	35	Cross-sectional qualitative study	Public stigma and self-stigma	NA	NA
11	Needs assessment of mental health training for auxiliary nurse midwives: a cross-sectional survey (Simkhada <i>et al.</i> , 2016)	Auxiliary nurse midwives	76	Cross-sectional quantitative study	Public stigma, health worker stigma	NA (no stigma outcome measure used)	NA
12	Service user and care giver involvement in mental health system strengthening in Nepal: a qualitative study on barriers and facilitating factors (Gurung <i>et al.</i> , 2017)	Mental health service users and caregivers	24	Cross-sectional qualitative study	Public stigma, structural barriers, health provider stigma	NA	NA
13	Persistent complex bereavement disorder and culture: early and prolonged grief in Nepali widows (Kim <i>et al.</i> , 2017)	Widows, key informants (individuals who've worked professionally with widows)	37 interviews and 3 focus groups consisting of 20 widows	Cross-sectional qualitative study	Public stigma	NA	NA
14	Treatment gap and barriers for mental health care: a cross-sectional community survey in Nepal (Luitel <i>et al.</i> , 2017)	Adults	1983	Cross-sectional survey	Self-stigma, public stigma	NA (no stigma outcome measure used)	Moderate quality
15	Strengthening mental health system governance in six low- and middle-income countries in Africa and South Asia: challenges, needs and potential strategies (Petersen <i>et al.</i> , 2017)	Policy makers, health care planners	141 (28 in Nepal)	Cross-sectional qualitative study	Public stigma, structural barriers, health provider stigma	NA	NA
16	Current situations and future directions for mental health system governance in Nepal: findings from a qualitative study (Upadhaya <i>et al.</i> , 2017)	National-level policy makers, district-level planners	17 policy makers, 11 planners	Cross-sectional qualitative study	Public stigma, structural barriers, health provider stigma	NA	NA

17	Health risks and challenges in earthquake responders in Nepal: a qualitative research (KC <i>et al.</i> , 2019)	Experts in the field of disaster management	11 experts in the field of disaster management	Cross-sectional qualitative study	Public stigma	NA	NA
18	Change in treatment coverage and barriers to mental health care among adults with depression and alcohol use disorder: a repeat cross-sectional community survey in Nepal (Luitel <i>et al.</i> , 2019)	General public	The baseline ( $N = 1983$ ) and the follow-up ( $N = 1499$ )	Repeat cross-sectional survey	Public stigma	Barriers to Access to Care Evaluation (BACE) – translation and adaptation reported	Moderate quality
19	Internalised stigma, coping and social support with mental illness in Manipal Teaching Hospital, Pokhara, Nepal (Shrestha, 2019)	Psychiatric patients	136 patients with mentally ill people	Cross-sectional quantitative study	Self-stigma	Internalised Stigma of Mental Illness (ISMI) Scale – reliability and validity tested and reported	Low quality
20	A study to assess the knowledge regarding human right of mentally ill patient among community people in Kaski, Pokhara, Nepal (Koirala <i>et al.</i> , 2019)	Community members	40 community people residing in Ward no 27 of Pokhara Municipality of Kaski District, Nepal.	Cross-sectional quantitative study	Knowledge on human rights of PWLE	Self-developed semi-structured questionnaire	Low quality
21	Stigma perceived by family members of psychiatric patients attending outpatient department of a teaching hospital (Lamichhane, 2019)	Family members of psychiatric patients	180 family members accompanying the patients in outpatient department	Cross-sectional quantitative study	Perceived-stigma	Standardised tool for Self-stigma of Mental Illness Scale (SSMIS) – not validated in Nepal	Low quality
22	Perception of stigma among caregivers of mentally ill people (Pandey, 2019)	Family members of patients with mental illness	50 family members of patients with mental illness	Cross-sectional quantitative study	Public stigma (caregiver stigma)	Self-stigma of Mental Illness Scale (SSMIS) – not validated or adapted	Low quality
23	Eliciting recovery narratives in global mental health: benefits and potential harms in service user participation (Kaiser <i>et al.</i> , 2020)	Service users		Qualitative	Public stigma	NA	NA
24	Reducing mental illness stigma in healthcare settings: proof of concept for a social contact intervention to address what matters most for primary care providers (Kohrt <i>et al.</i> , 2020)	Primary health care providers	Forty-one primary care workers (19 non-prescribers and 22 prescribers; 4 FGDs and 25 KIIs)	Mixed-methods proof-of-concept intervention study	Public stigma, health worker stigma	Social Distance Scale (SDS) and mhGAP attitudes assessment – previously used in Nepal	NA
25	Mental health and psychosocial support services in primary health care in Nepal: perceived facilitating factors, barriers and strategies for improvement (Upadhaya <i>et al.</i> , 2020)	Primary health care workers and female community health volunteers	55 primary care health workers and female community health volunteers	Cross-sectional qualitative	Public stigma, perceived stigma	NA	NA

(Continued)

Table 1. (Continued.)

SN	Study article no., title, (citation)	Study population	Sample size	Study design	Type of stigma mentioned	Stigma-related measures used/tools validation	Quality assessment (for quantitative study only)
26	Reducing stigma among healthcare providers to improve mental health services (RESHAPE): protocol for a pilot cluster randomised controlled trial of a stigma reduction intervention for training primary healthcare workers (Kohrt <i>et al.</i> , 2018a)	Health workers	NA	Intervention protocol	Provider stigma	NA	NA
27	Medical students' attitude towards psychiatry and mental disorders (Adhikari, 2018)	Medical students at their first, third and fourth year of medicine	270	Cross-sectional quantitative study	Provider stigma	Stigma tools not mentioned or described	Low quality
28	How competent are non-specialists trained to integrate mental health services in primary care? Global health perspectives from Uganda, Liberia and Nepal (Kohrt <i>et al.</i> , 2018b)	Primary healthcare workers	44	Interventional longitudinal study	Provider stigma	mhGAP attitude, MICA, Social Distance Scale – translated but not validated in Nepal	NA
29	Service user and caregiver involvement in mental health system strengthening in low- and middle-income countries: a cross-country qualitative study (Lempp <i>et al.</i> , 2018)	Service user advocates/ representatives from user led organisations, family members/caregivers, service users from community	24	Cross-country qualitative study	Self-stigma, public stigma, structural barriers	NA	NA
30	Qualitative evaluation of mental health training of auxiliary nurse midwives in rural Nepal (Mahato <i>et al.</i> , 2018)	Auxiliary nurse midwives (ANMs)	15 ANMs	Qualitative study	Public stigma	NA	NA
31	A service user co-facilitated intervention to reduce mental illness stigma among primary healthcare workers: utilizing perspectives of family members and caregivers (Rai <i>et al.</i> , 2018)	Caregivers and service users	17 service users and caregivers	Qualitative study	Public stigma, self-stigma	NA	NA
32	Prevalence and correlates of alcohol use in a central Nepal district: secondary analysis of a population-based cross-sectional study (Rathod <i>et al.</i> , 2018)	Community people	1983 (first round); 1499 (second round)	Community-based survey	Internalised stigma	ISMI – tool not validated for Nepal	Low quality



33	Psychotropic drugs in Nepal: perceptions on use and supply chain management (Upadhaya <i>et al.</i> , 2018)	Drugs producers/promoters/distributers; policy makers/government actors; service providers; service users	65	Qualitative study	Public stigma	NA	NA
34	Culture and mental health in Nepal: an interdisciplinary scoping review (Chase <i>et al.</i> , 2018)	NA	38 publications	Scoping review	Public stigma	NA	NA
35	Stigma causing delay in help-seeking behaviour in patients with mental illness (Amatya <i>et al.</i> , 2018)	Patients from outpatient clinic in Manipal teaching hospital, Pokhara – Dept of Psychiatry	90	Cross-sectional quantitative study	Self-stigma, public stigma	Self-reported public stigma scale Internalised Stigma of Mental Illness-10 (ISMI10) No mention of the tool being translated or adapted for Nepal	Low quality
36	Attitudes of undergraduate medical students towards the persons with mental illness in a medical college of western region of Nepal (Jalan, 2018)	MBBS students	68	Longitudinal prospective survey	Medical student's stigma	Attitude Scale for Mental Illness (ASMI)-not translated, adapted for Nepali population	Low quality
37	How intern doctors view 'psychiatry and mental health'? (Shakya, 2018)	Intern doctors in psychiatry department	50	Cross-sectional semi-qualitative survey	Medical student's stigma	Self-prepared semi-qualitative questionnaire	Low quality
38	Nepal mental health country profile (Regmi <i>et al.</i> , 2004)	NA	NA	Literature review	Public stigma	NA	NA
39	Cultural challenges to psychosocial counselling in Nepal (Tol <i>et al.</i> , 2005)	NA	NA	Literature review		NA	NA
40	Experiencing stigma: Nepalese perspectives (Adhikari <i>et al.</i> , 2008)	Inpatients in psych ward	65 recruited	Retrospective cross-sectional quantitative study	Perceived stigma	Questionnaire with items derived from numerous stigma measures	Low quality
41	Navigating diagnoses: understanding mind-body relations, mental health and stigma in Nepal (Kohrt and Harper, 2008)	Published literature, traditional healers, general population	NG	Mixed methods – review and ethnographic study	Public stigma	NA	NA
42	Nepali concepts of psychological trauma: the role of idioms of distress, ethnopsychology and ethnophysiology in alleviating suffering and preventing stigma (Kohrt and Hruschka, 2010)	Persons with psychological trauma, counsellors, health professionals	35	Ethnography	Public stigma	NA	NA

(Continued)

Table 1. (Continued.)

SN	Study article no., title, (citation)	Study population	Sample size	Study design	Type of stigma mentioned	Stigma-related measures used/tools validation	Quality assessment (for quantitative study only)
43	Nepalese pharmacy students' perceptions regarding mental disorders and pharmacy education (Panthee <i>et al.</i> , 2010)	Undergrad pharmacy students in year 1 and 3 from different universities: KU, TU, PU	200	Cross-sectional survey	Public stigma	Self-developed with items derived from Mental Illness Performance Scale	Low quality
44	Human rights violations of people with mental and psychosocial disabilities: an unresolved global crisis (Drew <i>et al.</i> , 2011)	People with mental and psychosocial disabilities	9	Mixed methods – review, expert consultation/ interview	Public stigma	NA	NA
45	Mental health first aid programme in Nepal (Jha <i>et al.</i> , 2012)	NA	NA	Literature review	Public stigma	NA	NA
46	Illness causation and interpretation in a Newar Town (Subedi, 2011)	Local elderly people	NA	Ethnography	Public stigma	NA	NA
47	Mental health, mass media and stigma reduction (Upadhyaya, 2014)	NA	NA	Opinion article	Self, public stigma and structural barriers	NA	NA
48	Stigma in mental illness: relative's perspective (Adhikari, 2015)	Relatives or care givers of patients	67	Cross-sectional retrospective study	Self, public stigma	Self-stigma of Mental Illness Scale (SSMIS) – adapted for Nepal	Low quality
49	Setting priorities for mental health care in Nepal: a formative study (Jordans <i>et al.</i> , 2013)	Psychiatrists, psychologists and psychiatric nurse, primary health care staff, policy makers or health managers, representatives of mental health organisations, and 1 representative of a mental health user group, community members	26 (priority setting exercise) 27 (TOC workshop); 33 (KII interviews); 9 FGDs ( $n = 84$ )	Mixed methods (ToC, KIIs, FGDs, priority setting)	Public stigma, health worker stigma	NA	NA
50	Conflict and mental health: a cross-sectional epidemiological study in Nepal (Luitel <i>et al.</i> , 2013)	Adult population	720	Cross-sectional mixed-methods study	Public stigma	NA	NA

51	Demand and access to mental health services: a qualitative formative study in Nepal (Brenman <i>et al.</i> , 2014)	Those working at health organisation level, working at the health facility level, and member of the community	KII 33, FGD 83	Qualitative study	Health worker/ provider stigma Public stigma Family/relative stigma Self-stigma	NA	NA
52	Breaking through barriers and building disaster mental resilience: a case study in the aftermath of the 2015 Nepal earthquakes (KC <i>et al.</i> , 2019)	Individuals representing institutions working in post-earthquake setting	Interview with 12 institutions	Qualitative case study	Public stigma, structural barriers	NA	NA
53	Stigma in mental illness: perspective from eight Asian nations (Kudva <i>et al.</i> , 2020)	NA	NA	Narrative review	Public stigma, health worker stigma	NA	NA
54	Development and pilot testing of a mental healthcare plan in Nepal (Jordans <i>et al.</i> , 2016)	Routine monitoring and evaluation data	135 patients	Mixed-methods formative study	Structural barriers	NA	NA
55	Suicide in Nepal: qualitative findings from a modified case series psychological autopsy investigation of suicide deaths (Hagaman <i>et al.</i> , 2018)	Family members of the person who had committed suicide	39 cases	Mixed-methods psychological autopsy case-series method	Structural barriers, public stigma	NA	NA
56	A cultural adaptation of dialectical behaviour therapy in Nepal (Ramaiya <i>et al.</i> , 2017)	Professional/ para-professional mental healthcare providers, psychosocial providers, and women scoring 1 or above in item 9 of BDI	12 professional/ para-professionals, 15 psychosocial providers, 10	Mixed-methods study (KIIs, process evaluation)	Public stigma, structural barriers	NA	NA
57	General practitioners' knowledge, practices and obstacles in the diagnosis and management of dementia (Pathak and Montgomery, 2015)	General practitioners from hospitals in Nepal	380 GPs from 12 public hospitals	Cross-sectional survey	Health worker knowledge and attitude, structural barriers	Self-reported KAP questionnaire- tool adapted to Nepali language from US instruments on knowledge tests related to Alzheimer disease	Low quality

biomedical treatment and use of drugs, with a lack of alternative treatment such as psychotherapies and counselling (Subedi, 2011).

### (3) Explanatory models of mental disorders

The terminology used for mental disorders and the explanatory models invoked by community members and health workers perpetuated stigma against PWLE. Regarding explanatory models, the most perceived causes included supernatural forces, curses, sinful behaviour, improper rituals or cultural practices and witchcraft. Bad *karma* (negative effects of past misdeeds including prior lives) or *bhagya* (fate) that prompted stigma towards PWLE (Kohrt and Harper, 2008; Subedi, 2011; Kisa *et al.*, 2016; Angdembe *et al.*, 2017). This led to the labelling of PWLE as *abhagi* (unlucky or ill-fated) or *paapi* (sinful persons). The general public also perceived mental disorders to be hereditary, which extended the use of these terms when describing the entire family such that anyone in the family of PWLE would be labelled with derogatory terminology (Subedi, 2011). Similarly, common symptoms of mental disorders as reported in several studies were exhibiting violent behaviour, being dishevelled, roaming around the road aimlessly, not taking care of personal hygiene, laughing spontaneously and not being able to do given tasks; these beliefs amplified the negative perceptions towards PWLE and increased stigma (Kohrt and Harper, 2008; Kohrt *et al.*, 2020; Upadhaya *et al.*, 2020).

Another belief was that mental disorders were incurable. Health workers reported that mental disorders were life-long conditions that had no effective treatment. The general public stated that mental disorders could not be cured by Western biomedicine but only through traditional healing (Kisa *et al.*, 2016; Simkhada *et al.*, 2016; Koirala *et al.*, 2019; Lamichhane, 2019; Kaiser *et al.*, 2020). This was also reflected in conceptions about the use of psychotropic medications for mental health conditions; most people described that once a person starts taking medications, she/he must take it for life (Upadhaya *et al.*, 2018). Some studies reported public views that mental disorders are contagious and can be spread through touch. Similarly, an ethnographic study (Kohrt and Harper, 2008) described how Nepali community differentiated mental disorders as dysfunctions of 'brain-mind' (*dimaag*) while psychosocial distress as that of 'heart-mind' (*man*) and how the mental disorders and dysfunction of 'brain-mind' were more stigmatised as it was associated with lack of behavioural control, inability to abide by social norms and more likely to be permanent compared to transient distress associated with problems in the 'heart-mind'.

Community members, sometimes even health workers, labelled PWLEs with stigmatizing terms such as *paagal/baulaa-haa* (mad/crazy), *taar khuskeko* (loose wire), *dimaag nabhayeko* (no brain-mind), *bokshi laageko* (afflicted by witchcraft), *paapi/paap ko bhogi* (sinful), *khusket* (someone whose mind has become lose), *dimaag crack bhayeko* (one whose brain-mind has cracked) (Kohrt and Harper, 2008; Kisa *et al.*, 2016; Angdembe *et al.*, 2017; Lempp *et al.*, 2018; Upadhaya *et al.*, 2020). Such stigmatizing terms were mostly used towards people with low socio-economic conditions such as Dalits (low caste groups, historically referred to as untouchables), women, widows and other minorities (Mahato *et al.*, 2018); this highlights the intersectionality of the perception of mental disorders with female gender, marginalised ethnicities and persons of low socio-economic status. The public perceived that PWLE, especially women, showed

symptoms such as talking incessantly, and should be isolated from society (Mahato *et al.*, 2018). A study carried out among caregivers and relatives of PWLE reported higher correlates of negative attitudes toward mental disorders if PWLE had low education status and were females (Neupane *et al.*, 2016).

### (4) Manifestations of stigma and locations of discrimination

The review identified a number of manifestations of mental disorders. Studies reported the prevalence of self-stigma ranging from 34 to 54% of patients in psychiatric Outpatient Department (OPD) of national hospitals, and 80% of persons screening positive for alcohol use disorder in the community reported internalised stigma (Amatya *et al.*, 2018; Maharjan and Panthee, 2019; Shrestha, 2019). The patients scored high on components such as stereotype endorsement, discrimination experience and social withdrawal. Similarly, family members reported high perceived stigma (52.2%) including the perception that PWLE were violent and burdensome financially (Pandey, 2019), and needed the same kind of discipline and control as a young child (Neupane *et al.*, 2016). PWLE reported feeling rejected by family members (Jordans *et al.*, 2013). More than 50% slightly or strongly agreed to being avoided by others, asked to resign from work and neglected by health professionals (Adhikari *et al.*, 2008). Several studies also reported how PWLE are isolated in the communities, often avoided and considered ineligible to take part in social activities and festivities (Kisa *et al.*, 2016; Lamichhane, 2019). PWLE are also considered ineligible for work or marriage and even if they do get married, mental disorders are considered acceptable grounds for divorce (Drew *et al.*, 2011; Hagaman *et al.*, 2018). High levels of perceived stigma were reported among patients in the context of marriage, such as having their opinions taken less seriously, feeling of being looked down upon and feeling of being treated as less intelligent or as a failure.

Advocates for PWLE reported explicit discrimination from stakeholders in policy-making or decision-making processes via exclusion or tokenistic involvement (Gurung *et al.*, 2017; Lempp *et al.*, 2018). Human rights abuses were mentioned in some publications where the PWLEs were subjected to violence by the community members and chained/locked up by the family members. Hence, the locations of stigma mostly reported by the studies were home, community or social setting, and healthcare settings (Angdembe *et al.*, 2017).

### (5) Consequences and impacts of stigma

The studies reported consequences and impacts of mental disorders stigma, which included low help-seeking behaviour, treatment non-adherence, concealment of disorders, poor resource allocation and poor engagement of PWLE (Regmi *et al.*, 2004; Jordans *et al.*, 2013; Upadhaya, 2014; Adhikari, 2015).

Studies overall reported poor help-seeking behaviour among PWLE and their families. Even among those seeking treatment, studies reported low medication adherence among PWLE (Adhikari, 2015; Upadhaya *et al.*, 2018, 2020). The belief that mental disorders are incurable was linked to non-adherence (Jordans *et al.*, 2013) and the use of alternative treatments such as traditional healing (Luitel *et al.*, 2015; Kisa *et al.*, 2016; Angdembe *et al.*, 2017; Upadhaya *et al.*, 2017; Lamichhane, 2019). Studies reported that idioms of distress in Nepal focused mainly on physical symptoms such as *gyastrik* (a Nepali idiom

encompassing both gastritis and psychological distress) which made it difficult to identify mental disorders (Kohrt and Hruschka, 2010). Similarly, families often registered PWLE under false names in health facilities, which later created problems in continuity of care and follow-up (Kaiser *et al.*, 2020). Low help-seeking behaviour also contributed to reduced demand for mental health services in health facilities which then impacted resource allocation and supply in procurement and policies (Upadhaya *et al.*, 2018). A major consequence of concealment of illness by PWLE and families was disruption in the involvement of PWLE and family members in stigma reduction activities, advocacy and health systems strengthening processes because such engagement typically relies on disclosure of mental disorders to the community (Tol *et al.*, 2005; Gurung *et al.*, 2017; Rai *et al.*, 2018).

#### (6) Measures and interventions

Our review identified only nine standard stigma measures used in quantitative and mixed-methods studies. The tools assessed self and internalised stigma with the Internalised Stigma of Mental Illness (ISMI) and Self-stigma of Mental Illness (SSMIS); public stigma with the Community Attitude towards Mental Illness (CAMI), public stigma scale (PSS), and Social Distance Scale (SDS); clinician's attitudes with the Mental Illness Clinician's Attitudes (MICA), mhGAP attitude scale and Attitude Scale for Mental Illness (ASMI); and stigma-related barriers to care with the Barriers to Access to Care (BACE). Five of the studies reported development of their own tool, either by generating new items, or consolidating items from multiple tools (Adhikari *et al.*, 2008; Gartoulla *et al.*, 2015; Pathak and Montgomery, 2015; Shakya, 2018; Koirala *et al.*, 2019). Although ISMI was the most popular tool ( $n = 4$  studies) to measure internalised stigma in Nepal, only one study reported a translation and adaptation process and reported tool reliability (Cronbach's  $\alpha = 0.87$ ) (Shrestha, 2019). Studies using the SSMIS reported varying item numbers. The translation and adaptation process were reported for other measures except ASMI, CAMI and PSS. However, the studies did not report reliability or validity scores.

Only four of the reviewed publications mentioned implementation and evaluation of interventions to reduce mental disorder-related stigma in Nepal (Kohrt *et al.*, 2018a, 2020; Rai *et al.*, 2018; Kaiser *et al.*, 2020). All four publications addressed the same intervention: REducing Stigma among HealthcAre ProvidERs (RESHAPE), which was explicitly designed using a 'what matters most' framework (Kohrt *et al.*, 2020). The intervention embedded anti-stigma components such as myth-busting, PWLE recovery narrative through a PhotoVoice technique, and aspirational figures within the mhGAP training of primary healthcare workers in Chitwan District to reduce their stigma attitudes and improve competencies.

## Discussion

Our scoping review identified a modest number of publications on stigma and discrimination related to mental disorders in Nepal ( $n = 57$ ) from 2000 through 2020. The studies focused on a range of stigma types (internalised, perceived, public, courtesy, practitioner and medical students' stigma) and used diverse methods (quantitative, qualitative, mixed methods, ethnography) to understand stigma. However, few studies had mental health stigma as their primary outcome or domain. Additionally, most quantitative studies were conducted in specific populations and

were of poor methodological quality and used measures that were not culturally adapted to the population under study. The stigma-related information and findings from these studies were extracted and collated under the themes of: (1) what matters most; (2) structural facilitators and barriers; (3) drivers and markers of stigma; (4) manifestations and locations; (5) consequences and impacts; and (6) measures and interventions. These themes are summarised and mapped into a conceptual framework (Fig. 2). This framework helps to understand the stigma processes in Nepal and also to identify the gaps in literature and the areas/domains where further interventions can be planned to help reduce mental health-related stigma in Nepal. The key findings, recommendations and contribution to the field are summarised in Table 2.

Structural barriers identified in our review included lack of mental health policies, low budgeting for mental healthcare, lack of trained human resources in primary healthcare settings and lack of medications. As shown in the conceptual framework, these structural barriers, and 'what matters most' for people in Nepali culture, interact with each other to influence the stigma processes such as stigma drivers, its manifestations and impacts. This influence of what matters most to cultures and structural barriers on stigma has also been highlighted by Yang *et al.* (2014a, 2014b). An example of this interaction is how what matters most to health workers can be influenced by availability of resources. For instance, if there is a scarcity of medications for the treatment of mental disorders, then health workers would prioritise conditions where resources are easily available. Similarly, if what matters most to the public is productivity then these attitudes will be reflected in policies, where less productive people experience structural discrimination.

The explanatory models of mental disorders including causal beliefs and symptoms and markers of stigma in Nepal are similarly influenced by these domains of what matters most and structural barriers and facilitators. Conflicts between the explanatory models of mental disorders such as perceived causes and symptoms, and what matters most to Nepali culture, exacerbated by the structural barriers may lead to marking of PWLE as being violent, sinful or not being able to make an independent living. This in turn manifests into various human rights abuses such as being chained or locked-up, discrimination in health facilities, refusals in marriage proposals and exclusion of PWLE in community or religious activities. These stigma manifestations related to mental disorders appear to be heightened when it intersects with other forms of drivers and markers such as gender, ethnicity and socio-economic conditions in Nepal. Women, widows, Dalits and people living in poverty were identified to face more stigma in Nepal.

Another example of the interactions between the domains can be seen in how suicide is perceived by the culture (sin) and is reflected in policies (an illegal act), which has then shaped how people who attempt suicide are perceived as sinful or criminal (drivers and markers) (Hagaman *et al.*, 2016, 2018). This is reported to manifest as internalised stigma and public stigma where such people perceive themselves as weak-minded with reduced potential for marriage. This leads to them not seeking or adhering to treatments (Jordans *et al.*, 2013).

The conceptual framework describes how the domains interact with each other to shape and reshape stigma processes. It also helps suggest pathways to design interventions that may reduce mental health-related stigma by breaking these processes. As causal beliefs of mental disorders, lack of awareness, fear of harm or burden are some of the key drivers, interventions could target



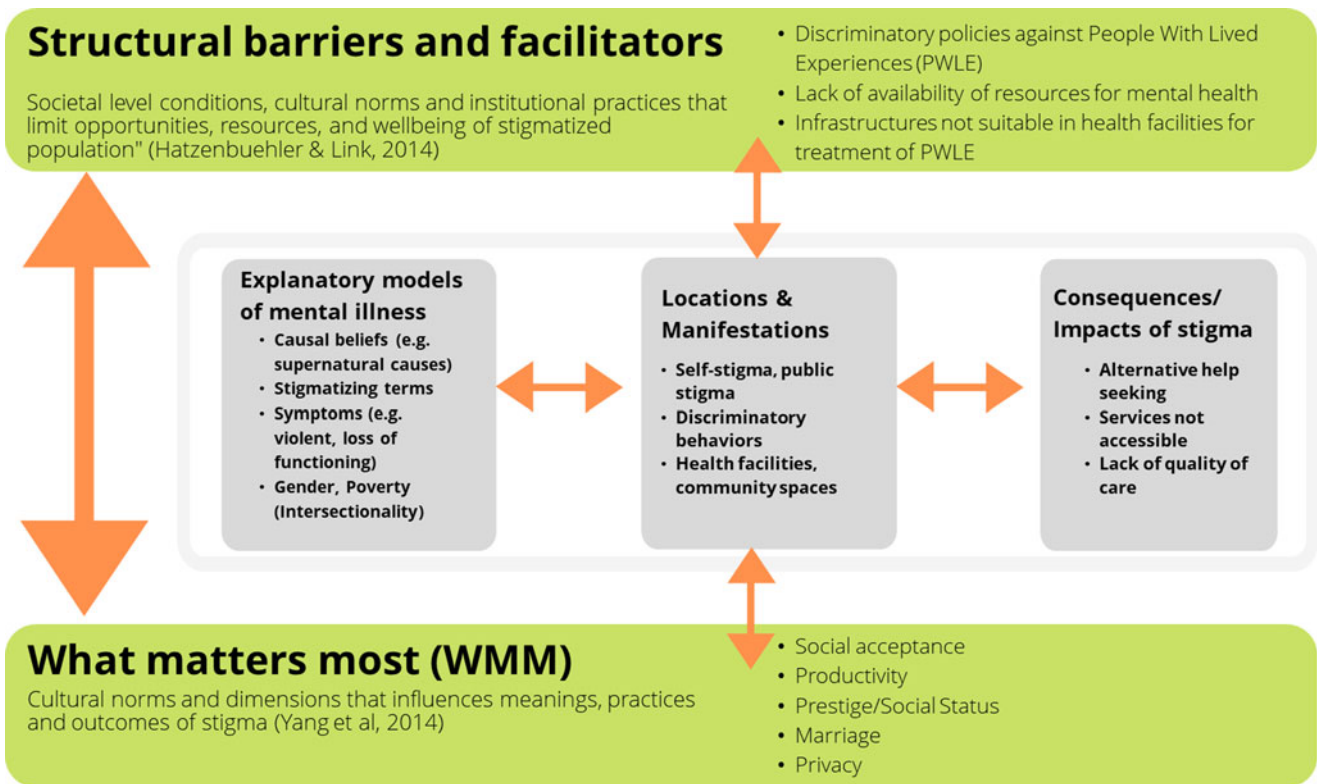


Fig. 2. Conceptual framework for mental disorder-related stigma in Nepal.

these drivers through myth-busting exercises, awareness campaigns and education-based interventions. Interventions such as RESHAPE (Kohrt *et al.*, 2018a, 2020) address what matters most to PWLE and the drivers of stigma among health workers through contact, myth-busting and recovery narratives (Rai *et al.*, 2018). Other interventions may focus on the intersectionality that exacerbates stigma or tackle what matters most to the public by focusing on productivity or livelihoods. Studies have shown benefits of stigma interventions targeting multiple stakeholders and multiple domains (Richman and Hatzenbuehler, 2014; Rao *et al.*, 2019). Currently, only one stigma intervention (RESHAPE) was identified through the review which points to a glaring gap in the mental health-related stigma field in Nepal. Since the time of the review, there have been more recent studies of stigma interventions in Nepal. A recent publication on the RESHAPE intervention demonstrated that stigma reduction not only contributed to improved attitudes over 16-month period, it was also associated with improved accuracy of clinical diagnoses (Kohrt *et al.*, 2021). Another recent study, which used video-based recovery testimonials from PWLE, showed that stigma attitudes reduced with testimonials about depression but stigma increased with video testimonials about psychosis (Tergesen *et al.*, 2021).

Another gap in the literature identified in the review is a sparse understanding of the mechanisms of how mental illness stigma intersects with other socio-demographic and economic factors. Also, there is limited knowledge on the impact of stigma related to mental disorders on PWLE, family members and the larger public outside the health system. The structural barriers and stigma have an overarching influence on other domains of stigma processes. Therefore, structural barriers, indicators to measure the structural barrier and discrimination and interventions to reduce structural barriers need to be explored further.

Similarly, the review revealed a focus mainly on internalised and public stigma. More studies need to be conducted to explore the anticipated and experienced stigma by PWLE and caregivers, especially in contexts such as the workspace, educational institutions, health facilities and other religious or community organisations. For example, a recent multi-country study conducted after the review period found that in many LMICs, PWLE had low expectations of how they would be treated by health workers and therefore they did not consider the experiences discriminatory, e.g. 'this is how we expect to be treated' (Koschorke *et al.*, 2021). No publications were identified that focused on the mental health stigma and discrimination among children and adolescents, although a number of studies have explored the role of other forms of stigma (e.g. gender and caste discrimination, discrimination against former child soldiers) on poor mental health outcomes (Kohrt and Maharjan, 2009; Kohrt *et al.*, 2010; Morley and Kohrt, 2013; Kohrt and Bourey, 2016) and social attitudes influencing what is labelled as mental illness among children (Burkey *et al.*, 2016; Langer *et al.*, 2019).

Another area where the review revealed paucity in information was measures of mental disorder-related stigma. Only nine stigma tools were reported across studies and most did not provide details on adaptation and measures of reliability/validity. Studies need to identify indicators that are most relevant to Nepali context and what matters most in Nepal to capture the stigma processes and evaluate the effectiveness of stigma interventions. Along with the measures, evaluation methods need to be diversified with intervention and longitudinal studies.

Finally, as the studies report on stigma and discrimination of PWLE, the researchers must be mindful of PWLE's dynamics and influences in the discourse. PWLE led movements have highlighted the need for their involvement in all aspects of intellectual



**Table 2.** Key learnings, contribution to the field and recommendations for stigma research in Nepal

Key learnings from the Nepal review
<ul style="list-style-type: none"> <li>• Few studies include stigma as a primary outcome</li> <li>• Only one anti-stigma intervention has been evaluated</li> <li>• Large systemic and structural barriers are shaped by what matters most for the general public, people with lived experiences and health workers, and their explanatory models of mental disorders</li> <li>• The labelling of people living with mental illness as violent, sinful and not able to make an independent living stems from interactions among explanatory models of mental disorders, what matters most to Nepali culture, and structural barriers</li> <li>• Intersection of mental illness stigma with other socio-demographic and economic factors has received limited research attention</li> <li>• Studies predominantly focus on internalised and public stigma, and few studies focus on experienced stigma</li> <li>• Studies with mental illness stigma have not been conducted among children and adolescents</li> <li>• Few tools have been locally adapted for stigma research</li> </ul>
Key contribution in the field
<ul style="list-style-type: none"> <li>• The conceptual framework for mental disorder-related stigma in Nepal provides visual representation on the complexity of stigma processes with domains that interlink with and influence each other. Although there are conceptual models for stigma processes, most do not describe the structural and cultural factors, using a what matters most perspective, that has impact on the drivers, manifestations and consequences of stigma</li> </ul>
Key recommendations
<ul style="list-style-type: none"> <li>• Future studies and interventions should target the complex process and multiple domains while addressing mental health-related stigma</li> <li>• Mental health-related stigma studies should focus on intersectionality of stigma with other socio-demographic and economic factors as well as drivers and consequences of stigma on children and adolescents</li> <li>• Procedures are needed for systematic cultural adaptation of stigma assessment tools</li> <li>• Research should be conducted to understand the forms and drivers of structural stigma and expand intervention research to evaluate strategies for structural stigma reduction</li> </ul>

and decision-making processes including research with slogans such as ‘Nothing about us without us’ (Charlton, 1998). Only a few of the articles in the review reported involving PWLE and caregivers in the research and publication process, while most of the studies limited the roles of PWLE to research participants. This in itself reflects the systemic marginalisation and discrimination of PWLE within the research and academic field. Hence, future mental health research, especially in the area of stigma and discrimination, should focus on the roles and process of effective involvement of PWLE to help enhance the findings and make it more relevant. Another issue to consider is who is leading mental health research in Nepal. A recent review of mental health research publications found that only 23% were led by Nepali women, and only 15% were led by researchers from Nepali ethnic minorities or low caste groups (Gurung *et al.*, 2021). This is a notable under-representation of persons from stigmatised groups in Nepal leading research on stigma. A change in who conducts research about stigma is likely to impact what is learned about stigma and how to effectively reduce its detrimental impacts.

## Limitations

We acknowledge a number of limitations of this scoping review. The qualitative coding process is inherently subjective. We have however tried to reduce some of the subjectivity through the involvement of multiple reviewers and discussion with senior researchers, including discussion of results with a co-author who is PWLE. We were also limited to conducting quality assessments of only quantitative studies and no studies were excluded due to low methodological quality. This decision was made as the major objective of this review was to explore existing stigma-related knowledge and information, rather than quality assessment. However, some quantitative studies had serious methodological flaws that we wanted to point out for the generalisability of the findings and for future studies. Similarly, despite our comprehensive search strategy, we acknowledge that the search terms may not have been exhaustive. Another limitation was that the study did not include approximately the past 12 months of publications. As with any review, there might have been new publications that may have come out after the review process and have not been included in this review. We have tried to address this in the discussion by including notable recent publications related to stigma. A final limitation is that our presentation of results and discussion did not account for change over time. From a popular media perspective, health professional education curricula, mental health training initiatives in primary care and community settings and major events impacting mental health, such as the 2015 earthquakes and recent COVID-19 pandemic, there are several factors that have likely influenced changes in attitudes over time. Because our review predominantly summarised content qualitatively, we are unable to conclude whether there have been significant changes over the past 20 years.

## Conclusion

In this study, we highlight what matters most to key stakeholders regarding stigma related to mental disorders. Additionally, we summarised how mental disorders were explained, discussed and recognised in the community as documented in peer-reviewed journal publications in the past 20 years. We also highlighted several structural barriers that further aggravated mental health stigma in Nepal. As stigma processes are complex and interlinked, more studies are required to understand this complexity and establish effective interventions targeting multiple domains. Future stigma research should clarify what conceptual models can inform study design and interpretation. There is a need to develop procedures for systematic cultural adaptation of stigma assessment tools. Research should be conducted to understand the forms and drivers of structural stigma and expand intervention research to evaluate strategies for stigma reduction. Finally, greater opportunities for researchers with lived experience of mental illness and researchers from stigmatised groups are needed to guide the science of tackling stigma in Nepal.

## Data

Additional data and materials related to the scoping review are available from the corresponding author [dristy.1.gurung@kcl.ac.uk](mailto:dristy.1.gurung@kcl.ac.uk).

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**Conflict of interest.** None.

**Ethical standards.** Not applicable.

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