Research Topics

Cultural considerations in relation to mental health stigma

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Cultural considerations in relation to mental health stigma

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Editorial: Cultural considerations in relation to mental health stigma

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Editorial on the Research Topic
Cultural considerations in relation to mental health stigma

Addressing the phenomenon of mental health stigma and discrimination necessitates a comprehensive understanding of the multifarious factors influencing individuals' perceptions of health and wellbeing. Variability in cultural and societal perspectives on illness molds how individuals comprehend and respond to mental health concerns. This variability, shaped norms, beliefs, and values, critically influences attitudes and behavioral responses toward people experiencing mental health challenges. Stigma can hinder life opportunities, meaningful societal involvement, and the journey to healing, impacting not only those affected but also their families and broader social circles.

The recognition and integration of cultural considerations into the frameworks of strategies for understanding and reducing mental health stigma are imperative. Through this lens we can develop more effective ways to mitigate the negative impacts of stigma and discrimination, supporting social inclusion and building effective healthcare systems that cater to everyone.

To achieve such systems, it is important to actively involve patients/service users and carers (public contributors) in the commissioning and development of services, and in curriculum development of health and social care professionals. The active involvement of patients/service users and carers throughout the research process helps to ensure that outcomes address patient needs, are relevant to diverse communities, impact practice, facilitate sustainability, disseminate findings across patient/carer groups, and reduce stigma.

This editorial introduces an assembly of pivotal studies that illuminate the intricate nature of mental health stigma, underscored by a pronounced focus on the indispensable role of cultural considerations in understanding and addressing this concern. The editors' collective endeavor in curating this compilation mirrors our profound commitment to nurturing a discourse on mental health stigma that is deeply rooted in cultural awareness.

At the forefront of this compilation is a seminal investigation by Daniel et al., which scrutinizes the cultural adaptation of INDIGO mental health stigma reduction interventions in North India. Through the application of the Ecological Validity Model (EVM), this study explored the cultural context needed to customize interventions that resonate with local cultural norms. This method not only amplifies the effectiveness of these interventions but also highlights the critical impact of cultural sensitivity within mental health initiatives. Strategic adaptations—addressing language, personal interactions, metaphors, content, methods, and context—exemplify the profound influence of deeply ingrained cultural elements in augmenting efforts to mitigate stigma.

Augmenting this perspective, Dambrun et al. delve into the social perceptions and stigmatization of mental illnesses in France, offering an insightful exploration into how the notions of vital force and burden contribute to social exclusion. This investigation, by providing the SUBAR model, not only sheds light on the unique facets of mental illness stigmatization within the French context but also highlights the complexity of stigma as a construct intricately woven with cultural narratives and societal frameworks.

Further augmenting this collection is the work of BinDhim et al., who focused on the cultural adaptation and validation of the Mental Illness Associated Stigma Scale (MIAS) for Arabic-speaking populations in Saudi Arabia. This study highlights the necessity of adapting research tools to specific cultural contexts, facilitating accurate stigma measurement.

In Tunisia, Ben Amor et al. validated the Arabic versions of the Mental Health Knowledge Schedule (MAKS) and the Reported and Intended Behavior Scale (RIBS) among Tunisian students. This endeavor not only confirms the psychometric soundness of these instruments in an Arabic-speaking milieu but also identifies sociodemographic and clinical determinants of mental illness stigma. This study explored a variety of factors that contribute to stigma, such as gender, academic background, personal history of health issues and previous encounters with illness. This set the stage for developing strategies to combat stigma effectively.

This compilation is further enriched by a study from van Beukering et al. examining Dutch workers' attitudes toward colleagues with mental health conditions. The findings, which reveal diverse concerns and preferences regarding social distance, positions the workplace as a critical setting for stigma reduction efforts.

Li et al. embarked on an exploration of health stigma in China, concentrating on the unique experiences and challenges encountered by renal dialysis patients. Their study highlights the importance of developing interventions that consider the social backgrounds of the communities involved.

Similarly, Mpango et al. illuminated the physical and sexual victimization of individuals with severe mental illness in Uganda, highlighting the profound impact of stigma on vulnerable groups. This investigation emphasizes the necessity of formulating strategies aimed at preventing victimization and supporting survivors within culturally informed frameworks.

Odukoya et al. presented a comparative analysis on the efficacy of an e-intervention designed to diminish intellectual disability stigma among Nigerian and Kenyan internet users. This novel approach showcases the potential of digital platforms to overcome geographical and cultural barriers, paving new pathways for stigma reduction initiatives.

Finally, Scerri et al. offered a sociocultural examination of mental health stigma within the Maltese context, investigating the influence of cultural beliefs and societal norms on mental health perceptions and approaches. Their study emphasized the importance of family assistance, community unity and societal perceptions in influencing the journeys of individuals dealing with health struggles, emphasizing the necessity of culturally and contextually adapted interventions.

Collectively, the studies in this compilation not only shed light on the diverse manifestations of mental health stigma but also highlight the paramount importance of cultural sensitivity in addressing this pervasive issue. They advocate for an approach to mental health stigma that is deeply attuned to cultural contexts, calling for interventions that are both grounded in empirical evidence and aligned with cultural and contextual nuances.

In conclusion, this editorial and the accompanying suite of studies issue a compelling appeal for a culturally informed strategy for addressing mental health stigma. As the field progresses, it is imperative to leverage the insights from these studies, extending the boundaries of our understanding and interventions to foster an inclusive and empathetic global mental health landscape enabled via the 'voice' of service users/patients and carers. By undertaking this mission, we affirm our shared responsibility to tackle mental health stigma and discrimination, ensuring that cultural considerations remain at the heart of our efforts.

Author contributions

MC: Writing – review & editing, Conceptualization. MV: Writing – review & editing, Conceptualization. PG: Writing – review & editing, Conceptualization. AS: Writing – review & editing, Writing – original draft, Conceptualization.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Dutch workers' attitudes towards having a coworker with mental health issues or illness: a latent class analysis

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Introduction: Workplace mental health stigma is a major problem as it can lead to adverse occupational outcomes and reduced well-being. Although workplace climate is largely determined by managers and co-workers, the role of co-workers in workplace stigma is understudied. Therefore, the aims are: (1) to examine knowledge and attitudes towards having a coworker with Mental Health Issues or Illness (MHI), especially concerning the desire for social distance, (2) to identify distinct subgroups of workers based on their potential concerns towards having a coworker with MHI, and (3) to characterize these subgroups in terms of knowledge, attitudes, and background characteristics.

Materials and methods: A cross-sectional survey was conducted among a nationally representative internet panel of 1,224 Dutch workers who had paid jobs and did not hold management positions. Descriptive statistics and a three-step approach Latent Class Analysis (LCA) were used to address the research aims.

Results: Concerning the desire for social distance, 41.9% of Dutch workers indicated they did not want to have a close colleague with MHI, and 64.1% did not want to work for a higher-ranking manager who had MHI. In contrast however, most workers did not have negative experiences with interacting with coworkers with MHI (92.6%). Next, five distinct subgroups (SG) of workers were identified: two subgroups with few concerns towards having a coworker with MHI (SG1 and SG2; 51.8% of the respondents), one subgroup with average concerns (SG3; 22.7% of the respondents), and two subgroups with more concerns (SG4 and SG5; 25.6% of the respondents). Four out of five subgroups showed a high tendency towards the desire for social distance. Nevertheless, even in the subgroups with more concerns, (almost) half of the respondents were willing to learn more about how to best deal with coworkers with MHI. No significant differences were found between the subgroups on background characteristics.

Discussion: The high tendency to the desire for social distance seems to contrast with the low number of respondents who personally had negative experiences with workers with MHI in the workplace. This suggests that the tendency to socially exclude this group was not based on their own experience. The finding that a large group of respondents indicated to want to learn more about how to deal with a co-worker with MHI is promising. Destigmatizing interventions in the workplace are needed in order to create more inclusive workplaces to improve sustained employment of people with MHI. These interventions should focus on increasing the knowledge of workers about how to best communicate and deal with coworkers with MHI, they do not need to differentiate in background variables of workers.

KEYWORDS

mental health, stigma, discrimination, workplace, coworker

1. Introduction

Mental health stigma and discrimination in the workplace are a major problem for people with Mental Health Issues or Illness (MHI) (1, 2). The concept of stigma consists of three dimensions, problems with: knowledge (misinformation of ignorance), attitudes (prejudice), and behaviour (discrimination) (3). Stigma and discrimination can lead to adverse occupational outcomes and reduced well-being (4). Multiple large studies showed that people with MHI face stigma and discrimination at work. For instance, a study on discrimination among workers with major depressive disorder from 35 countries showed that 62.5% had anticipated and/or experienced discrimination at work (5). Also, a recent study showed that 64% of Dutch line managers were reluctant to hire a job applicant with a mental health issue (6). In addition, 68.4% of Dutch workers expected that disclosure during a temporary contract would decrease the chance that a contract would be renewed, and 56.6% expected that disclosure would lead to a diminished chance to be promoted to a higher position in the future (7). MHI affect a large part of the population, almost half of the adults (48%) in Netherlands (18–75 years old) has ever had one or more mental illnesses (8). As employment is important for health and well-being, workplace stigma and discrimination should be seen as a public health problem.

A recent systematic review showed that most publications on workplace stigma were focused on the roles of employers, while less is known about the roles of workers (9). However, workers have also found to be influential stakeholders with stigmatizing attitudes in the workplace (10). In an American study, workers were found to have concerns about competencies of coworkers with MHI and held unfavourable attitudes to work with a person with MHI (11). Furthermore, mental health stigma by workers can lead to bullying, harassment (11, 12) or social exclusion of people with MHI in the workplace (13). One study showed that examples of social exclusion (or more specific: the desire for social distance) are not wanting to working for or with people with MHI or excluding coworkers from social events at work (11).

Anti-stigma interventions can lead to more inclusive workplaces (14, 15). More specifically, these interventions can help to improve sustained employment of people with MHI by increasing workers' knowledge and helping behaviours (15). Evaluating how processes of stigma are perpetuated in the workplace is essential for guiding the development of anti-stigma interventions (16). One hindering or perpetuating factor can be legislation (17), as are cultural differences (18), which may need to be taken into account when developing destigmatizing interventions. Anti-stigma interventions need to address the diverse needs of the stakeholders in the workplace (19). This way anti-stigma interventions can differentiate in the messages to each target group and therefore be more effective.

In Netherlands, several studies have shown that a variety of workplace stakeholders tend to have negative attitudes towards people with MHI, such as HR managers, line managers and coworkers (1, 6, 7, 19, 20). However, research on this topic is very scarce in Netherlands, especially on attitudes of workers in non-managerial positions, who often make up a large part of the social work environment. If we want to develop effective anti-stigma interventions, we first need to better understand the nature of those negative attitudes, and high quality research on the nature of these stakeholders' concerns is needed. As such, we used a large and representative sample to study the following aims: (1) to examine knowledge and attitudes towards having a coworker with MHI, especially concerning the desire for social distance, (2) to identify distinct subgroups of workers based on their potential concerns towards having a coworker with MHI, and (3) to characterize these subgroups in terms of knowledge, attitudes, and background characteristics.

2. Materials and methods

2.1. Study design and participants

In February 2018, a cross-sectional survey was conducted among a nationally representative internet panel of Dutch workers. Data were collected among an existing panel (Longitudinal Internet Studies for Social Sciences, LISS) administered by CentERdata, which is a Dutch research institute specialized in data collection. The existing panel is a random and representative selection of 5,000 Dutch households (7,357 panel members). The questionnaires include domains like education, work, housing, time use, income, political views, values, and personalities. Three reminders were sent to panel members to increase the response rate, see www.lissdata.nl for more information.

The questionnaire was sent to 1,671 Dutch adults who participated in the panel, had paid jobs, and did not hold management positions. Ethical Approval was obtained by the Ethics Review Board of the School of Social and Behavioral Sciences of Tilburg University (registration number: RP193).

2.2. Research context

In Netherlands, the Gatekeeper Improvement Act and the Extended Payment of Income Act protect Dutch workers with disabilities. The Gatekeeper Improvement Act states that employers, the occupational physician (OP), and the worker, are responsible for the benefits and reintegration when workers are absent due to the occurrence of sickness. Workers have to meet with an OP when sickness absence occurs. The OP is responsible for performing an independent assessment which in cooperation with the worker leads to a reintegration plan. The Extended Payment of Income Act states that employers pay at least 70% of the income for the first 2 years of sickness absence. During these first 2 years employers are not allowed to fire the worker. There is no obligation to disclose MHI in the workplace.

2.3. Measures

At present, validated instruments to measure workplace stigma are scarce (4), and especially questionnaires focusing on workers' attitudes are lacking. Therefore, a questionnaire was developed using a multistep procedure to address the aims of this study. To this end, first, the existing literature on the topic of workplace mental health stigma and discrimination was searched. The main topics of the questionnaire were identified based on the theoretical stigma model proposed by Thornicroft et al. (2007) (3). Specifically, the items on knowledge and attitudes were based on literature of workplace stakeholders' knowledge, experience, and attitudes (21, 22). Second, the main topics found and the subsequent proposed items on the questionnaire were discussed with international experts in the field of mental health and stigma (both senior researchers and experts by experience) to modify and improve the questionnaire. Third, the questionnaire was pilot tested (e.g., concerning clarity) within the researchers' network ($N = 18$) and improved where necessary based on the feedback received. This resulted in the final version of the questionnaire. The items used for this study can be found in Supplementary material Appendix 1. The following topics and items were addressed:

2.3.1. Knowledge of and experience with MHI

Knowledge

- Respondents were asked to indicate the percentage of coworkers they thought will be affected in their organization by MHI during their working life. The ratio response category ranged from 0 to 100%. Due to the distribution of the variable, the variable was converted to 0 (<15%), 1 (15–25%), and 2 (>25%).
- A set of 15 items of different types of MHI, the respondents were asked about which type of MHI they think of when hearing or reading about 'a coworker with MHI'. The response categories were 0 (no) and 1 (yes). The items were converted into three dichotomous variables. Association with stress, mental/emotional exhaustion, and burnout were merged into 'association with work related mental disorders' because these are the most important reasons for work related sickness absence in Netherlands (23). Association with anxiety, depression, addiction, and obsessive–compulsive disorder was converted into 'association with common mental disorders' because these disorders typically refer to common mental disorders. Association with other disorders like manic depressive/bipolar disorder, schizophrenia, post-traumatic stress disorder, borderline disorder, autism, psychosis, and eating disorder was merged into 'association with other mental disorders'.

Personal experience

- As personal experience is a source of knowledge, it was assessed if respondents knew anyone with MHI (i.e., general familiarity with MHI). To assess general familiarity with MHI, the Level of Contact Report was used (24). Therefore, general familiarity with MHI was measured by a set of 9 items, these items represent different kinds of relationships. The nominal response categories were 0 (no) and 1 (yes). To create the general familiarity variable, the individual items were converted into the following categories: 0 (not familiar) if respondents did not know anyone who had or had had MHI; 1 (little familiar) when respondents indicated to know a family member who they had little contact with and/or an acquaintance and/or a coworker with who they did not work much with MHI, and 2 (very familiar) when respondents indicated to know a family member who they had a lot of contact with and/or a friend and/or a coworker with whom worked or had worked intensively with MHI.
- Respondents' actual experience with interacting with coworkers with MHI in the workplace. The response categories of this single item were 1 (very unfavourable), 2 (rather unfavourable), 3 (neutral), 4 (rather favourable), 5 (very favourable), and 6 (not applicable/no experience with this). Personal experience was converted into the categories 0 (negative = very unfavourable/rather unfavourable), 1 (neutral = neutral), 2 (positive = rather favourable/very favourable), and 3 (none = not applicable/no experience with this).

2.3.2. Attitudes towards a coworker with MHI

The desire for social distance

- A set of three items measured the desire for social distance, asking the respondent to what extent they would (1) want to have a coworker who had MHI (but who they would hardly work with), (2) want to have a coworker who had MHI (and who they would work with intensively), and (3) want to work for a higher-ranking manager with MHI. The response categories were 1 (absolutely not), 2 (rather not), 3 (neutral), 4 (would not mind), 5 (would like to very much), and 6 (not applicable). The response categories were merged into the categories 0 (no = absolutely not/rather not), 1 (neutral = neutral/not applicable), and 2 (yes = would not mind/would like to very much).

Willingness to support a coworker with MHI

- A set of six items measured willingness to support a coworker with MHI. Five items asking to what extent respondents agreed with the following statements: (1) I will free up extra time for a coworker with MHI so that we can talk about his/her MHI, (2) I am happy to offer practical support to a coworker with MHI, for example by temporarily taking on some of his/her work, (3) I find it hard to work with a coworker with MHI, (4) I would like to learn more about MHI in general, and (5) I would like to learn more about how I can best deal with coworkers with MHI. The response categories were 1 (strongly disagree), 2 (slightly disagree), 3 (neutral), 4 (slightly agree), and 5 (strongly agree). And additionally, one item (6) asking the respondent to what extent they would (1) want to know if a coworker has MHI. The response categories were 1 (absolutely not), 2 (rather not), 3 (neutral), 4 (would not mind), 5 (would like to very much), and 6 (not applicable). The response categories of the seven items were merged into the categories 0 (no = strongly disagree/slightly disagree/absolutely not/rather not), 1 (neutral = neutral/not applicable), and 2 (yes = slightly agree/strongly agree/would not mind/would like to very much).

Responsibility

- One item measured if workers agreed with the following statement: (1) people are mainly responsible for their MHI. This item was added because attribution of personal responsibility can contribute to stigmatizing attitudes (24). The response categories were 1 (absolutely not), 2 (rather not), 3 (neutral), 4 (would not mind), 5 (would like to very much), and 6 (not applicable). The response categories of the item were merged into the categories 0 (no = strongly disagree/slightly disagree/absolutely not/rather not), 1 (neutral = neutral/not applicable), and 2 (yes = slightly agree/strongly agree/would not mind/would like to very much).

Potential concerns

- A set of 15 items about potential concerns having a coworker with MHI, like: I need to take over his/her duties, I am not sure how to help this coworker, and the coworker will make mistakes. The items were categorized in concerns about incompetency, concerns about helping and dealing with coworker with MHI, and concerns about that the coworker with MHI will damage the workplace. The response categories were 0 (no) and 1 (yes). These specific items were derived from literature on beliefs as barriers to employment (25, 26).

2.3.3. Background characteristics

- Several background characteristics were included in this study because they were expected to be associated with stigma, based on previous research (1, 27, 28). A personal characteristic, personally having (had) MHI, was included. This self-reported variable measured whether workers have (or have had) MHI, it was merged into 0 (no = no/I do not know) and 1 (yes = yes). Sociodemographic characteristics were added, i.e., age, gender, educational level, and marital status. Educational level was converted into the categories 0 (low = primary school/intermediate secondary), 1 (secondary = higher secondary education/preparatory university education) and 2 (high = higher education). Marital status was converted into the categories 0 (unmarried = separated/divorced/widow or widower/never been married) and 1 (married = married). The work-related characteristics included were gross income per month, type of industry, company size and workplace atmosphere. Type of industry was merged into 0 (private = agriculture, forestry, fishery, and hunting/mining/industrial production/utilities production, distribution, and trade/construction/retail trade/catering/transport, storage, and communication/finance/business services) and 1 (public = governments services, public administration, and mandatory social insurances/education/healthcare and welfare). Following the definition of the European Commission (Commission Recommendation 96/280/EC), company size was changed into 0 (small; ≤ 49 workers) and 1 (medium or large; ≥ 50 workers). The item 'In my organization it is customary to look down on workers with MHI' was converted into workplace atmosphere with the categories 0 (negative = slightly agree/strongly agree), 1 (neutral = neutral), and 2 (positive = strongly disagree/slightly disagree).

2.4. Statistical analyses

To address the first research aim (i.e., to examine Dutch workers' knowledge and attitudes towards having a coworker with MHI, especially concerning the desire for social distance), descriptive statistics were used (means, standard deviations, and frequency table).

For the second and third research aim (i.e., to identify distinct subgroups of workers based on their concerns about having a coworker with MHI, and to characterize these subgroups in terms of knowledge, attitudes, and background characteristics), a three-step approach Latent Class Analysis (LCA) was used. In the first step, a latent class model was built using the 15 items that measured potential concerns. In the second step, workers were assigned to the different subgroups. In the last step, the characteristics (i.e., knowledge, experience, attitudes, and background characteristics) that were associated with the different subgroups were evaluated.

In the first step of the LCA, the most suitable number of subgroups (classes) was identified by using several fit indices. The three fit indices that were used were the Bayesian information criterion (BIC), the Akaike information criterion (AIC), and the Akaike information criterion with 3 as penalizing factor (AIC3). These indices weight the fit and parsimoniousness of the model (the best model has the lowest criteria), and the BIC is seen as the best performing goodness-of-fit indice (29). Furthermore, a bootstrap likelihood ratio test (BLRT) (30), was used to compare the different models. Lastly, the theoretical interpretation of the model was taken into account. The size of the smallest subgroup had to be at least 5% of the total sample size (31).

In the second step, the workers were assigned to the latent subgroup based on the posterior subgroup membership probability.

In the third step, to characterize the subgroups the associations with knowledge, attitudes, and background characteristics were examined. Some items contained missing data (i.e., company size and gross income per month), Latent GOLD's imputation procedure helped imputing these missing data (32). Wald tests ($p < 0.05$) were used to examine whether there were differences between the subgroups.

SPSS version 24 was used for the data preparation and descriptive analyses and Latent GOLD 6.0 was used for the three-step approach LCA (33).

TABLE 1 Main features of the sample.

	N	%	M (SD)
Personal characteristic			
Current or past MHI	1,224		
Yes	342	27.9	
Sociodemographic characteristics			
Age (years)	1,224		44.6 (12.1)
Gender	1,224		
Male	525	42.9	
Female	699	57.1	
Educational level*	1,224		
Low	209	17.1	
Secondary	491	40.1	
High	524	42.8	
Marital status	1,224		
Unmarried	609	49.8	
Married	615	50.2	
Work-related characteristics			
Gross income per month (in Euros)	1,117		4,845 (2382)
Type of industry	974		
Private	546	56.1	
Public	428	43.9	
Company size	746		
Small (<=49 workers)	343	46.0	
Medium or large (>=50 workers)	403	54.0	
Workplace atmosphere	1,222		
Negative	135	11.0	
Neutral	381	31.2	
Positive	706	57.8	

*Highest level completed. Low = primary school. Intermediate secondary; secondary = higher secondary education. Preparatory university education; high = higher education.

3. Results

A total of 1,224 respondents with paid jobs (and who were not working in management positions) filled out the questionnaire (response rate = 73.5%), 27.9% of the respondents indicated that they had a current or past MHI. Slightly more respondents were female (57.1%) and they had an average age of 44.6 years (SD = 12.1). More characteristics can be found in Table 1.

3.1. Research aim 1: to examine Dutch workers' knowledge and attitudes towards having a coworker with MHI

Table 2 shows that most of the respondents thought that less than 25% of the coworkers in their organization would be affected by MHI during their working life. Also, most respondents were thinking of work related disorders when they heard or read about 'a coworker with MHI' (71.7%) and fewer respondents thought of common or other (more severe) mental disorders. Three quarters of the respondents were familiar in general with MHI, and a quarter indicated that they did not know anyone who had or had had MHI (27.2%). Most respondents did not have negative personal experiences with interacting with coworkers with MHI (92.6%).

Table 2 also shows the exploration of the attitudes towards having a coworker with MHI. Concerning the desire for social distance, a large proportion of respondents did not want to have a coworker with MHI if they have to work with them intensively (41.9%) or, a smaller proportion of workers, if they would hardly have to work with them (21.9%). The majority would not want to work for a higher-ranking manager who had MHI (64.1%). Though, the majority of the respondents would be willing to free up extra time for a coworker with MHI so that they can talk about his/her problems (60.4%) and is happy to offer practical support (58.7%). Almost half of the respondents would like to learn more about how they can best deal with coworkers with MHI (49.5%) or would like to learn more about MHI in general (34.6%). More than half of the respondents indicated that people are mainly personally responsible for their MHI (53.6%). Most frequently reported were the concerns that a coworker with MHI would not be able to handle the work (45.0%) and that respondents

TABLE 2 Dutch workers' knowledge and attitudes towards having a coworker with MHI (*N*=1,224).

			%
Knowledge and experience	Knowledge	Estimated prevalence of MHI in organization	
		<15%	47.6
		15–25%	20.9
		25%>	31.5
		Association MHI: work related disorders	71.7
		Association MHI: common disorders	47.2
		Association MHI: other disorders	27.0
	Experience	General familiarity with MHI	
		Not familiar	27.2
		Little familiar	18.3
		Very familiar	54.5
		Personal experience with interacting with coworkers with MHI	
		Negative	7.4
		Neutral	29.4
		Positive	32.1
		None	31.1
Attitudes	Desire for social distance	Want to have a coworker with MHI, who you would hardly work with	
		No	21.9
		Neutral	66.2
		Yes	11.8
		Want to have a coworker with MHI, who you would work with intensively	
		No	41.9
		Neutral	46.0
		Yes	12.0
		Want to work for a higher-ranking manager with MHI	
		No	64.1
		Neutral	28.5
		Yes	7.4
	Willingness to support	Free up extra time for a coworker with MHI, so we can talk about his/her problems	
		No	11.7
		Neutral	27.9
		Yes	60.4
		I am happy to offer practical support to a coworker with MHI	
		No	13.3
		Neutral	28.1
		Yes	58.7
		I would like to learn more about MHI in general	
		No	26.1
		Neutral	39.3
		Yes	34.6
		I would like to learn more about how I can best deal with coworkers with MHI	
		No	18.2
		Neutral	32.2
		Yes	49.5

(Continued)

TABLE 2 (Continued)

			%
		Want to know if coworker has MHI	
		No	6.9
		Neutral	29.0
		Yes	64.1
		I do not find it hard to work with a coworker with MHI	
		No	25.5
		Neutral	39.0
		Yes	35.5
	Responsibility	People are mainly personally responsible for their MHI	
		No	22.6
		Neutral	23.8
		Yes	53.6
	Potential concerns	Concerns that coworker with MHI is incompetent	
		A1 The coworker cannot handle the work	45.0
		A2 You cannot count on this coworker	32.7
		A3 It will lead to long-term sickness absence	28.8
		A4 The coworker will make mistakes	24.2
		A5 The coworker has a lower work tempo	11.7
		Personal concerns about helping and dealing with coworker with MHI	
		B1 I am not sure how to help this coworker	38.0
		B2 I need to take over his/her work tasks	33.4
		B3 I am not sure how to deal with this coworker	30.2
		B4 I do not feel like talking about the coworker's personal problems	8.9
		Concerns that the coworker with MHI will damage the workplace	
		C1 It will have a negative impact on the workplace atmosphere	32.9
		C2 It will lead to conflicts	24.4
		C3 The coworker poses a danger to him or herself or to others in the workplace	22.3
		C4 The coworker will cause damage to the relationships that are important to me/the organization	12.8
		C5 Talking about the problems will take up a lot of the other coworkers' time	10.2
		C6 He/she can damage my or the organization's reputation	6.1

do not know how to help a coworker with MHI (38.0%). A small part of the respondents (14.8%) reported not having any concerns.

3.2. Research aim 2: to identify distinct subgroups of workers based on their concerns about having a coworker with MHI

Five distinct subgroups of workers can be distinguished based on the LCA. Table 3 shows the model fit indices for models with 1 to 10 classes. Both the BIC and the bootstrap likelihood ratio test suggest a five-class model, while the AIC suggests a 10-class model and the AIC3 a three-class model. Further inspection of the different models showed that the five-class model was both parsimonious and had a good theoretical interpretation. Therefore, the five-class solution was chosen.

Figure 1 presents the five subgroups of respondents and their concerns about having a coworker with MHI. Significant differences between the subgroups were found on all the concerns. Respondents in the *few concerns* subgroup (SG2) have very few concerns about having a coworker with MHI (24.8% of the sample). Respondents in the *personal concerns* subgroup (SG1), which is the biggest subgroup (27.0% of the sample), have also low probabilities on most concerns, but are concerned about how they can help and deal with a coworker with MHI. Respondents in the *incompetency concerns* subgroup (SG3), have average probabilities on most concerns, but do have concerns that the coworker would be incompetent (22.7% of the sample). Respondents in the *damage and incompetency concerns* subgroup (SG4), have incompetency concerns and they are also concerned about damage to the workplace, but they have few concerns about how to help and deal with coworkers with MHI (17.1% of the sample). Respondents in the *many concerns* subgroup (SG5), the

TABLE 3 Fit indices for LCA.

	LL	BIC	AIC	AIC3	Npar	df	p value BLRT	Entropy R^2
1-Cluster	−9439.000	18984.648	18908.000	18923.000	15	1,209	0.000	–
2-Cluster	−8737.807	17696.021	17537.615	17568.615	31	1,193	0.000	0.740
3-Cluster	−8604.513	17543.190	17303.026	17350.026	47	1,177	0.000	0.702
4-Cluster	−8498.522	17444.967	17123.045	17186.045	63	1,161	0.036	0.680
5-Cluster	−8428.960	17419.602	17015.921	17094.921	79	1,145	0.064	0.674
6-Cluster	−8392.822	17461.083	16975.645	17070.645	95	1,129	0.126	0.689
7-Cluster	−8358.960	17507.117	16939.920	17050.920	111	1,113	0.148	0.683
8-Cluster	−8339.418	17581.791	16932.837	17059.837	127	1,097	0.102	0.672
9-Cluster	−8321.791	17660.294	16929.582	17072.582	143	1,081	0.082	0.682
10-Cluster	−8305.313	17741.096	16928.626	17087.626	159	1,065	0.082	0.691

LL, log likelihood; BIC, Bayesian information criterion; AIC, Aikake information criterion; AIC3, Aikake information criterion 3; Npar, numbers of parameters; BLRT, bootstrap likelihood ratio test.

smallest subgroup (8.5% of the sample), have the highest probabilities on almost all concerns.

3.3. Research aim 3: to characterize these subgroups in terms of knowledge, experience, attitudes, and background characteristics

Respondents in the *few concerns* subgroup (SG2), i.e., with overall few concerns about having a coworker with MHI, scored the lowest on all the social distance items (ranging from 12.2% for not wanting to work with a coworker with MHI who they work intensively with to 28.8% not wanting to work for a higher ranking manager with MHI). SG2 contained the least respondents who were negative about wanting to have a coworker with MHI who they would have to work with intensively (12.0%), and the least respondents who were negative about wanting to work for a higher-ranking manager with MHI (28.8%). In SG2 the workers most often had no personal experience with interacting with coworkers with MHI (42.0%) (See Table 4).

The respondents in the *personal concerns* subgroup (SG1), i.e., with overall few concerns but with concerns about how they can help and deal with a coworker with MHI, scored much higher on the social distance items compared to SG2 (ranging from 38.5% for not wanting to work with a coworker with MHI who they work intensively with to 67.2% not wanting to work for a higher ranking manager with MHI). In SG1 the respondents were slightly more often willing to like to learn more about MHI in general (38.8%) compared to other subgroups, but still, they rather preferred to learn more about how they could best deal with coworkers with MHI (67.4%). SG1 contained relatively more respondents with no personal experience with interacting with coworkers with MHI (41.1%) compared to the other subgroups.

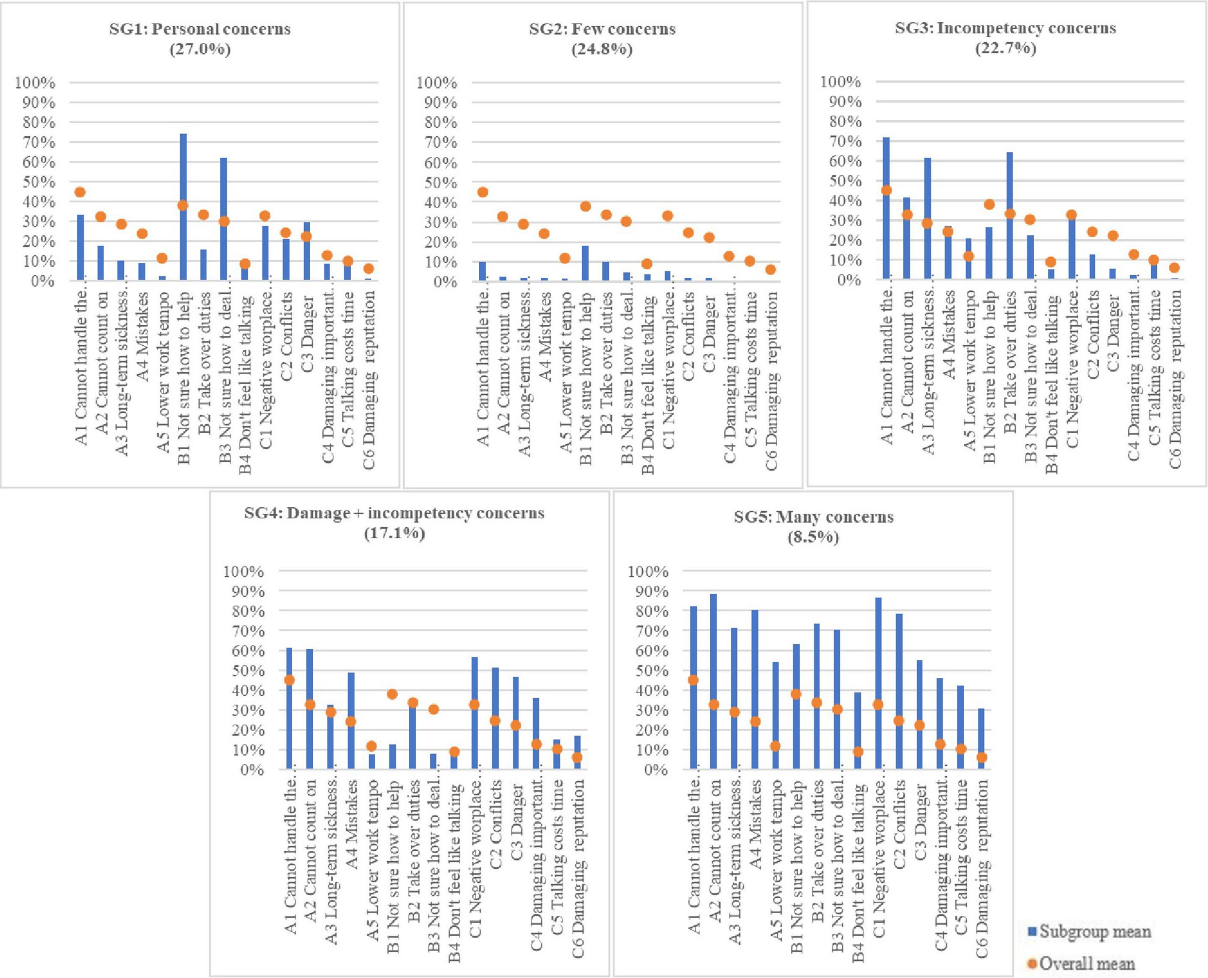
The *incompetency concerns* subgroup (SG3), i.e., with average score on most concerns but with concerns about possible incompetency of the coworker with MHI, Compared to SG1 and SG2, contained more respondents who scored high on the social distance items (ranging from 47.3% for not wanting to work with a coworker with MHI who they work intensively with to 70.2% not wanting to work for a higher ranking manager with MHI). Almost half of SG3 would like to learn more about how they could best deal with coworkers with MHI (45.5%). SG3 differentiated from the other subgroups by containing the most respondents who had positive experiences with interacting with coworkers with MHI (40.9%).

The respondents in the *damage and incompetency concerns* subgroup (SG4), i.e., with slightly more concerns and specifically concerns on incompetency and also damage to themselves and the workplace, compared to the SG1, SG2, and SG3, contained relatively more respondents who scored high on the social distance items (ranging from 57.7% for not wanting to work with a coworker with MHI who they work intensively with to 79.8% not wanting to work for a higher ranking manager with MHI). Just like SG3, almost half of SG3 would like to learn more about how they could best deal with coworkers with MHI (47.1%). Respondents from SG4 were more likely to associate a coworker with MHI with other (more severe) disorders (43.1%) compared to the other subgroups.

The *many concerns* subgroup (SG5), i.e., with overall a lot of concerns, compared to the other subgroups, contained the most respondents who scored high on the social distance items (ranging from 72.8% for not wanting to work with a coworker with MHI who they work intensively with to 77.8% not wanting to work for a higher ranking manager with MHI). Respondents in this subgroup found it much harder to work with a coworker with MHI (60.1%), compared to the other subgroups. Around half of SG5 would like to learn more about how they could best deal with coworkers with MHI (53.6%). SG5 contained most respondents who associated a coworker with MHI other (more severe) disorders (51.3%), and the most respondents, but still a relatively small percentage, with a negative experience with interacting with coworkers with MHI (20.5%).

4. Discussion

The aims of this study were to examine (1) Dutch workers' knowledge and attitudes towards having a coworker with MHI, especially concerning the desire for social distance, (2) to identify distinct subgroups of workers based on their potential concerns towards having a coworker with MHI, and (3) to characterize these



*** Figure 1 compares the mean score per subgroup per item (blue bar) with the overall mean score per item (orange dot), this resulted in a profile for each subgroup.**

FIGURE 1
Profiles of the five subgroups based on potential concerns about having a coworker with MHI.

subgroups in terms of knowledge, attitudes, and background characteristics. First, concerning the desire for social distance, nearly half of the respondents did not want to have a coworker with MHI who they would have to work with intensively and about two-thirds did not want to work for a higher-ranking manager who had MHI. Almost half of the respondents showed willingness to learn more about how to communicate and deal with coworkers with MHI. Very few workers had negative personal experiences with interacting with coworkers with MHI. The most frequently reported concern was that a coworker with MHI would not be able to handle the work. For the second research aim, five distinct subgroups of respondents were identified based on their concerns about having a coworker with MHI: two subgroups with few concerns (SG1 and SG2), one subgroup with average concerns (SG3), and two subgroups with more concerns (SG4 and SG5). Third, these subgroups were characterized by significant differences in knowledge, experience, and attitudes. Four out of five subgroups showed a high tendency towards the desire for social distance. Even in the subgroups with average and more concerns (almost) half of the respondents were willing to learn more about how to best deal with coworkers with MHI. The subgroups with more concerns contained most respondents who associated a coworker with MHI with other (more severe) disorders. No significant differences were found between the subgroups on background characteristics.

This study showed overall a high tendency towards the desire for social distance. When differentiated in subgroups, even higher rates were found for the subgroups with average or more concerns. This is worrying, and in line with previous research which reported that respondents did not want to work with or for people with MHI due to stigma (11). As 92.6% did not have negative personal experiences with interacting with coworkers with MHI, this tendency to the desire for social distance is not likely to be based on personal experiences. Our analyses showed that even in the subgroup with the most concerns (SG5) only 20.5% of the respondents had actual negative experiences with interacting with coworkers with MHI in the workplace. Moreover, the tendency towards exclusion without having negative experiences was also found in a study among Dutch line managers, where 64% was reluctant to hire a job applicant with a mental health issue, despite

TABLE 4 Characteristics of the subgroups in terms of knowledge, experience, attitudes, and background variables.

			SG1 Personal concerns (*N*=330)	SG2 Few concerns (*N*=304)	SG3 Incompetence concerns (*N*=278)	SG4 Damage and incompetence concerns (*N*=212)	SG5 Many concerns (*N*=103)	*p*-value
Knowledge and experience	Knowledge	Estimated prevalence of MHI in organization						0.690
		<15%	54.3%	53.4%	35.3%	46.1%	45.5%	
		15–25%	21.9%	19.7%	23.7%	18.1%	19.8%	
		25%>	23.8%	26.9%	41.0%	35.8%	34.7%	
		Association MHI: work related disorders						0,000
		Yes	78.1%	53.7%	84.4%	66.8%	79.6%	
		Association MHI: common disorders						0.040
		Yes	51.4%	37.0%	37.4%	53.8%	77.1%	
		Association MHI: other disorders						0.000
		Yes	25.4%	18.7%	16.5%	43.1%	51.3%	
	Experience	General familiarity with MHI						0.170
		Not familiar	29.1%	41.9%	20.7%	13.1%	21.8%	
		Little familiar	19.0%	18.4%	20.1%	17.5%	10.6%	
		Very familiar	51.1%	38.6%	58.1%	68.6%	67.4%	
		Personal experience with interacting with coworkers with MHI						0.035
		Negative	4.5%	2.0%	8.5%	11.7%	20.5%	
		Neutral	22.8%	26.5%	33.5%	36.0%	34.6%	
		Positive	31.7%	29.5%	40.9%	30.2%	22.4%	
		None	41.1%	42.0%	17.1%	22.2%	22.5%	
Attitudes	Desire for social distance	Want to have a coworker with MHI, who you hardly work with						0.760
		No	16.0%	9.2%	23.8%	32.2%	40.2%	
		Neutral	70.5%	62.7%	62.8%	58.0%	50.6%	
		Yes	11.2%	14.2%	11.5%	8.6%	7.1%	
		Want to have a coworker with MHI, who you will work with intensively						0.000
		No	38.5%	12.0%	47.3%	57.7%	72.8%	
		Neutral	50.3%	58.7%	36.4%	36.6%	16.6%	
		Yes	9.2%	15.6%	15.1%	5.1%	9.6%	
		Want to work for a higher-ranking manager with MHI						0.014

(Continued)

TABLE 4 (Continued)

			SG1 Personal concerns (*N*=330)	SG2 Few concerns (*N*=304)	SG3 Incompetence concerns (*N*=278)	SG4 Damage and incompetence concerns (*N*=212)	SG5 Many concerns (*N*=103)	*p*-value
		No	67.2%	28.8%	70.2%	79.8%	77.8%	
		Neutral	27.1%	47.4%	18.6%	15.7%	15.9%	
		Yes	4.4%	10.9%	9.8%	3.9%	4.0%	
	Willingness to support	Free up extra time for a coworker with MHI, so we can talk about his/her problems						0.540
		No	8.3%	8.5%	13.5%	11.1%	28.4%	
		Neutral	25.8%	39.5%	26.0%	19.5%	22.3%	
		Yes	65.8%	52.0%	60.1%	69.0%	49.2%	
		I am happy to offer practical support to a coworker with MHI						0.580
		No	4.9%	13.0%	15.5%	14.7%	31.6%	
		Neutral	28.2%	38.6%	24.8%	20.8%	19.6%	
		Yes	66.8%	48.4%	59.3%	64.2%	48.6%	
		I would like to learn more about MHI in general						0.036
		No	19.6%	20.7%	32.5%	34.8%	27.2%	
		Neutral	41.5%	49.8%	31.4%	31.6%	37.5%	
		Yes	38.8%	29.5%	35.8%	33.2%	35.3%	
		I would like to learn more about how I can best deal with coworkers with MHI						0.000
		No	9.7%	19.3%	21.5%	22.2%	25.6%	
		Neutral	22.9%	47.0%	32.7%	30.4%	20.7%	
		Yes	67.4%	33.8%	45.5%	47.1%	53.6%	
		Want to know if coworker has MHI						0.006
		No	9.2%	6.1%	2.0%	7.8%	9.7%	
		Neutral	24.1%	44.3%	23.8%	18.8%	22.0%	
		Yes	65.6%	37.6%	73.4%	72.7%	66.1%	
		I do not find it hard to work with a coworker with MHI						0.000
		No	24.8%	11.0%	28.7%	26.4%	60.1%	
		Neutral	46.5%	42.4%	34.1%	35.6%	23.9%	
		Yes	28.6%	46.6%	36.9%	37.7%	15.9%	

(Continued)

TABLE 4 (Continued)

			SG1 Personal concerns (*N*=330)	SG2 Few concerns (*N*=304)	SG3 Incompetence concerns (*N*=278)	SG4 Damage and incompetence concerns (*N*=212)	SG5 Many concerns (*N*=103)	*p*-value
	Responsibility	People are mainly personally responsible for their MHI						0.190
		No	18.4%	14.6%	24.5%	30.8%	37.1%	
		Neutral	20.1%	34.3%	22.1%	17.5%	22.0%	
		Yes	61.4%	51.1%	53.1%	51.4%	40.8%	
Background characteristics	Personal	Current or past MHI						0.110
		Yes	30.9%	25.1%	28.3%	29.8%	21.8%	
	Sociodemographic	Age (in years)						0.230
		Mean	44.0	46.4	43.0	46.9	41.2	
		Gender						0.250
		Male	50.9%	43.1%	32.6%	44.8%	40.5%	
		Female	49.1%	56.9%	67.4%	55.2%	59.5%	
		Educational level						0.110
		Low	13.6%	27.7%	11.7%	13.9%	18.1%	
		Secondary	34.3%	43.9%	36.8%	47.0%	42.7%	
		High	52.2%	28.4%	51.5%	39.1%	39.2%	
		Marital status						0.220
		Unmarried	53.2%	44.1%	50.0%	44.2%	66.4%	
		Married	46.8%	55.9%	50.0%	55.8%	33.6%	
	Work-related	Income (in Euros)						1.000
		Mean	4,872,76	4,592,50	5,077,28	4,962,71	4,628,07	
		Sector						0.074
		Private	52.6%	51.2%	32.5%	41.5%	38.5%	
		Public	26.1%	31.6%	45.6%	38.0%	38.5%	
		Company size						0.770
		Small	26.6%	28.6%	28.9%	29.6%	25.3%	
		Medium or large	35.4%	30.6%	32.2%	34.2%	31.1%	
		Workplace atmosphere						0.220
		Negative	12.2%	4.8%	14.8%	10.1%	17.4%	
		Neutral	27.1%	46.0%	19.0%	30.6%	33.8%	
		Positive	60.7%	49.2%	65.9%	58.9%	48.6%	

*Wald statistic. $p < 0.05$.

the fact that only 7% of them had actual negative experiences with such workers (6). Also, it is noteworthy that this present study showed that the tendency towards the desire for social distance is higher when respondents were asked about having to work for a higher-ranking manager with MHI compared to having to work with a coworker with MHI. A qualitative study also showed that negative disclosure outcomes were more likely to be expected for people with MHI in higher positions (1). More research is needed to understand this difference. The results concerning the high tendency towards the desire for social distance underline the importance of an adequately prepared disclosure decision. The high desire for social distance towards coworkers with MHI might also be partly due to the Dutch context. The Extended Payment of Income Act states that employers pay at least 70% of the income for the first 2 years of sickness absence. This might create an incentive for employers to be more careful during the hiring process, which can stimulate a culture of social distancing and exclusion.

To design an effective intervention it is important to understand what the focus needs to be, as stigma has three dimensions the focus can be on problems of: knowledge (misinformation or ignorance), attitudes (prejudice), and behaviour (discrimination) (21). Anti-stigma interventions in the workplace like increasing knowledge can lead to helping behaviour mediated by the change in attitudes, since these three dimensions are interrelated (15). This present study indicates that anti-stigma interventions in the workplace should focus on increasing knowledge, as there was a need among respondents to learn how to best deal with coworkers with MHI and to learn more about MHI in general. As the present study found no differences in background characteristics between the subgroups, this indicates that anti-stigma interventions in the workplace do not need to differentiate in background variables of workers.

4.1. Strengths and limitations

A strength of this study is the use of a large representative sample of Dutch workers. The workers were selected from population registers based on a true probability sample and participated anonymous to prevent the respondents' possible tendency to underreport socially undesirable responses and overreport more socially desirable responses. Furthermore, this is one of the first datasets that focuses on workplace stigma in Netherlands which provides important new insights in the attitudes of workers. Another strength is that in this study coworkers were not seen as one homogenous group, but that heterogeneity was taken into account reflecting individual differences better which is needed for designing interventions. Latent Class Analysis, an increasingly popular method, is strong in identifying subgroups and it uses a model-based technique which enables researchers to have more flexibility and accuracy when looking into the subgroups and the associated variables (34). Although this study generated valuable insights, there are a few limitations. Self-reported data were used which were based on perceptions, rather than on actual behaviour. Nevertheless, perceptions have been linked to actual behaviour (35). Additionally, this study focused on concerns, which might reflect a more negative view of the reality because this study did not simultaneously focus on positive attitudes. Future studies should also focus on the positive attitudes in order to add more knowledge on both the positive and negative attitudes towards coworkers with MHI, because knowledge about such attitudes may also be helpful in designing interventions to create more inclusive workplaces.

5. Conclusion

This representative sample of Dutch workers showed a high tendency towards the desire for social distance of coworkers with MHI. As much as 41.9% did not want to have a coworker with MHI who they would work with intensively. The desire for social distance was even much higher towards managers with MHI: 64.1% did not want to work for a higher-ranking manager with MHI. Interestingly, despite these high percentages, over 92.6% of workers did not personally have negative experiences with interacting with coworkers with MHI. Workers differed in their concerns about having a coworker with MHI, five distinct subgroups were identified. Differences between these subgroups were found in knowledge, experience, and attitudes towards having a coworker with MHI. This study found that anti-stigma interventions in the workplace which focus on increasing knowledge are needed. This study found that anti-stigma interventions in the workplace which focus on increasing knowledge are needed, because (almost) half of the workers indicated they would like to learn more about MHI. These interventions should especially focus on increasing the knowledge of workers about how to best communicate and deal with coworkers with MHI and about MHI in general in order to create more inclusive workplaces to improve sustained employment of people with MHI.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by The Ethics Review Board of the School of Social and Behavioral Sciences of Tilburg University (registration number: RP606). The patients/participants provided their written informed consent to participate in this study.

Author contributions

EB, MB, MJ, GS, and IB designed the study. MB assisted IB with the statistical analysis of the study. IB and GS wrote the manuscript. EB, MB, MJ, GS, CD, JW, and CH contributed to reviewing and revising of the manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2023.1212568/full#supplementary-material

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Stigma and related factors among renal dialysis patients in China

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Background: Stigma is an important psychological concept that is being studied in many diseases. However, there have been few studies on stigma in renal dialysis patients in China. This study aimed to investigate the level of stigma and its potential influencing factors among Chinese renal dialysis patients.

Methods: A cross-sectional study was conducted among renal dialysis patients in two Chinese dialysis centers between April 2022 and July 2022. Two hundred four renal kidney patients were interviewed with a questionnaire on demographic variables using the Social Impact Scale (SIS), Resilience Scale-14 (RS-14), Herth Hope Index(HHI), Multidimensional Scale of Perceived Social Support (MSPSS), Revised Life Orientation Test(LOT-R), Perceived Stress Scale (PSS-4) and Fear of Progression (FoP). T-test/univariate one-way ANOVA, Pearson's R, and hierarchical linear regression analysis were used to investigate the factors that influence stigma.

Results: Renal dialysis patients in China experienced a moderate level of stigma (52.36 ± 8.16). Stigma was negatively correlated with resilience, hope, and perceived social support, whereas it was positively associated with perceived stress and fear of progression. However, it showed no significant relationship between optimism and stigma. Hierarchical linear regression analysis showed that hope (β = -0.318, $P < 0.001$), social support (β = -0.193, $P < 0.01$), perceived stress (β = 0.197, $P < 0.01$), and fear of progression (β = 199, $P < 0.01$) were found to be associated with stigma among the renal dialysis patients. All four variables in the model could explain 34.6% of the variance in stigma among renal dialysis patients in China.

Conclusion: According to this study, renal dialysis patients in China face a moderate level of stigma. Stigma was found to be negatively related to hope and social support but positively associated with perceived stress and fear of progression. Future research on the stigma of renal dialysis patients should include hope-based interventions, proper and specific social support strategies, stress management interventions, and more disease-related information.

KEYWORDS

renal dialysis, stigma, fear of progression, hope, social support

1. Introduction

End-stage kidney disease, which is the fifth stage of chronic kidney disease, is the most severe stage of chronic kidney failure caused by various factors (1). The patient's renal function is completely or nearly completely lost, which seriously threatens the patient's life (2). It was reported that the number of patients requiring renal replacement therapy ranged from 4.902 to 9.701 million worldwide and that this figure would more than double by 2030 (3). Similar conditions can be found in America (4), Europe (5), China (6), and other countries.

Renal dialysis is the most commonly used treatment for patients with end-stage kidney disease, with more than 90% receiving it. The therapy provides those patients with a potentially longer life span. However, the adverse effects of therapy include low quality of life (7), fatigue (8), sleep disorders (9), anorexia, nausea/vomiting, pruritus, sleepiness, difficulty concentrating, pain (10), which cannot be ignored. In addition to the physical effects, the psychological effects should be considered. It is reported that when patients decide on renal dialysis, they tend to avoid the therapy due to thinking that dialysis is the most stressful part of the disease (11). In addition to distress (12), loss (13), well-being (14), negative coping (15), anxiety (16), depression (17), and so on cannot be ignored as patients on dialysis. Many studies have found that renal dialysis patients' experience feeling of passivity and restriction (18). They can hardly do their original jobs anymore (19), and their lives must be entirely re-planned to adapt to dialysis. Dialysis patients have low self-esteem, believe they are a burden on their family members and do not contribute to the family. They expose themselves to uncertain future and are hesitant to interact with others (20). These changes are visible and life-long and may result in the absence of individuals from full social acceptance, and patients themselves may have thoughts of escaping society, which corresponds to the concept of stigma.

Stigma describes a deeply discreditable attribute or characteristic, conveying a spoiled social identity and a sense of disgrace in a particular social context, disqualifying the individual from social recognition (21). Stigma is a psychological stress response. Patient's self-assessment plays a crucial role in the production and formation of stigma (22, 23). Stigma increases the psychological burden of patients, causing them to be labeled, stereotyped, isolated, lose their status, and even face discrimination (24). It will affect the patient's quality of life and follow-up treatment and even lead to adverse consequences such as social escape and suicide (25). Studies have also shown that stigma reduces self-esteem, self-efficacy, and belief in own abilities (26). Stigma has widely been used in patient populations such as cancer (27), chronic diseases (28), psychiatric disorders (29), addiction diseases (30), obesity (31), and geriatric diseases (32), and so on to provide many new perspectives and findings.

Stigma is an important concept in psychology and has been a research topic for many diseases. Surprisingly, little information is currently available about stigma in renal dialysis patients. Considering such immense pressure and its effect on renal dialysis patients and its importance, stigma should be approached from different perspectives. Therefore, the present study aimed to fill this knowledge gap. Studies examining the stigma associated with other diseases have revealed that, in addition to demographic and clinical characteristics, resilience (33), optimism (34), social support (35, 36), hope (37), perceived stress (38) were all related factors to stigma. Furthermore, renal dialysis was a life-long treatment with multiple complications. Many patients in the chronic kidney disease stage reported their fear of disease progression (39). Excessive fear of disease progression may cause patients to label the disease even more and devalue themselves. Thus, we would explore the relationship of the aforementioned factors in renal dialysis patients from the Chinese population. The hypothesis proposes that stigma is positively associated with stress and fear of progression and negatively associated with resilience, hope, social support, and optimism among renal dialysis patients. Accordingly, we will test this hypothesis in the current study. This study aimed to investigate the level of stigma and its potential influencing factors among Chinese renal dialysis patients. We hope that the findings of our study, particularly the identification of stigmatizing factors, will be useful and shed new light on the management of renal dialysis patients.

2. Materials and methods

2.1. Study settings

This is a cross-sectional designed study that was carried out at two renal dialysis centers in China. Data was collected between April 2022 and July 2022. The Ethics Committee of China Medical University approved this study (2022PS153K).

2.2. Subjects

Patients receiving renal dialysis therapy who understood and completed the questionnaire were invited to participate in the study under their consent, while patients in severe conditions were excluded. The study size was arrived at following the below formula: $n = \frac{z_{\alpha}^{2}\sigma^{2}}{\delta^{2}}$. The parameters in the study were set as follows: $\alpha = 0.05$, $Z\alpha = 1.96$, $\sigma = 10.58$ (which was arrived via pre-test), $\delta = 1.5$; therefore, $n = 1.962{*}10.58^{2}/1.52 = 191.1$. The sample size was increased by 10%～20%, considering invalid questionnaires, resulting in a final sample size of 211～230.

2.3. Data collection

The entire research process was anonymous, and the patients were voluntary. The researchers of the study uniformly trained the five investigators. After the patients agreed to participate, the paper questionnaires were filled out in a separate and undisturbed space in the hospital to prevent patients from influencing each other while filling out questionnaires. The investigator is responsible for interpreting the questionnaire items without any incentive. Another trained investigator performed quality control on site. Epidata software (version 3.1) was used for data entry and review.

2.4. Tools

Questionnaires including demographic and clinical characteristics were self-developed in the study. The demographic section included age, gender, education level, job status, religious belief, income, family structure, and medical payments. Also, the clinical variables section included the approach and the course of dialysis of the patient (how long the dialysis lasted).

2.4.1. Stigma

The stigma of the respondents was measured using the Social Impact Scale (SIS) (40). SIS consists of 24 items divided into four categories: social rejection, financial insecurity, internalized shame, and social isolation. Each scale item has a four-point scale, with a total score ranging from 24 to 96. Cronbach's α of stigma was 0.871 in this study.

2.4.2. Resilience

Resilience was assessed using the Resilience Scale-14 (RS-14) (41). The RS-14 consists of 14 items on a 7-point scale, with an overall score ranging from 14 and 98. In the current study, Cronbach's α of resilience was 0.863.

2.4.3. Hope

The level of hope was assessed by the Herth Hope Index (HHI) (42). The HHI consists of 12 items, and each item is scored on a 4-point scale. The total HHI score ranges from 12 to 48, and a higher total score reflects a higher level of hope. In the present study, Cronbach's α of hope was 0.866.

2.4.4. Social support

The Chinese version of the Multidimensional Scale of Perceived Social Support (MSPSS) was used to assess perceived social support (43). The MSPSS comprises ten items scored on a 7-point scale; the total score ranges from 12 to 84, with a higher score indicating more social support. Cronbach's α of social support was 0.935 in the present research.

2.4.5. Optimism

The 10-item Revised Life Orientation Test (LOT-R) was used to assess optimism (44). The LOT-R uses a 5-point rating system. A higher score indicates a higher level of optimism. Cronbach's α of optimism was 0.621 in this research.

2.4.6. Perceived stress

The 4-item Perceived Stress Scale (PSS-4) was used to assess perceived stress (45). PSS-4 is scored using a 5-point scale, with a total score ranging from 0 to 16. Higher scores indicate a higher level of perceived stress. Cronbach's α of perceived stress was 0.764 in this study.

2.4.7. Fear of progression

The Fear of Progression Questionnaire-Short Form (Fo P-Q-SF) was used to assess the Fear of Progression (FoP) (46). The Fo P-Q-SF is a 12-item scale with a 5-point rating and a total score ranging from 12 to 60. A higher score indicates a greater fear of disease progression. Cronbach's α for fear of progression was 0.895 in the present study.

2.5. Statistical analyses

Data analysis was performed using the statistical software package for social sciences (SPSS 20.0). The significance for all statistical tests was 0.05 (2-tailed). Each continuous variable is first tested for normality and homogeneity of variance. Independent-samples t-tests and one-way ANOVA were used to describe the distribution of stigma for categorical demographic and clinical variables in renal dialysis patients. Pearson's R-test was used to assess the correlations between resilience, hope, social support, optimism, stress, fear of progress, and stigma. Hierarchical linear regression analysis was used to assess the research hypotheses. To avoid overfitting the regression model, the one-way ANOVA/t-test variable with $P < 0.2$ was entered as the control variable in the first step of the hierarchical regression analysis (47). Then, the independent variables (resilience, hope, perceived social support, perceived stress, fear of progress) also entered the second step of the hierarchical regression. Diagnostic tests for multicollinearity were performed using tolerance and variance inflation factor (VIF). The data provided by the regression model include standardized regression coefficient (β), R^2, adjusted R^2 (Adj. R^2), R^2-change, and F value.

3. Results

3.1. Descriptive statistics

A total of 230 questionnaires were distributed in this study. Twenty patients refused to participate in the survey, and six invalid questionnaires. There were 204 valid questionnaires with an effective response rate of 88.7%.

Out of the 204 respondents, 126 (61.8%) were male, and 78 (38.2%) were females. Nearly half of them (46.1%) were above 60 years old. All the patients had medical insurance. Only 12 (5.8%) patients had a regular employee. In terms of clinical variables, most respondents (96.1%) used an autogenous arteriovenous fistula to access dialysis. More than half of the respondents had dialysis for less than five years. **Table 1** presents the details.

3.2. Stigma level

Table 2 depicts the level of stigma and its dimensions among renal dialysis patients.

3.3. Correlation among continuous variables

Table 3 depicts the correlation analysis results of resilience, hope, perceived social support, optimism, perceived stress, fear of progression, and stigma among renal dialysis patients. Stigma was negatively correlated with resilience ($r = -0.386$, $P < 0.001$), hope ($r = -0.448$, $P < 0.001$), perceived social support ($r = -0.393$, $P < 0.001$), and positively associated with and perceived stress ($r = 0.255$, $P < 0.001$), fear of progression ($r = 0.314$, $P < 0.001$).

TABLE 1 Demographic and clinical characteristics and the level of stigma among renal dialysis patients (n = 204).

Variables	*N* (%)	Mean (SD)	T/F	*P*
Gender			0.463	0.644
Male	126(61.8)	52.57 (7.22)		
Female	78 (38.2)	52.03 (9.54)		
Marriage			0.345	0.731
Single/divorced/widow	47 (23.0)	52.72 (9.98)		
Married/cohabitation	157 (77.0)	52.25 (7.57)		
The course of dialysis in the patient (Year)			3.036	0.050
<5	104 (51.0)	51.05 (8.71)		
5~10	70 (34.3)	53.37 (7.53)		
≥10	30 (14.7)	54.57 (6.96)		
Ageof patients			0.078	0.925
≤40	27 (13.2)	52.81 (8.36)		
41–60	83 (40.7)	52.13 (8.08)		
>40	94 (46.1)	52.44 (8.26)		
Education of patients			0.256	0.775
Middle school or lower	82 (40.2)	52.63 (9.45)		
High school or secondary school	60 (29.4)	52.63 (5.84)		
College or university or above	62 (30.4)	51.74 (8.34)		
Job status			0.293	0.746
Unemployed	178 (87.3)	52.53 (8.22)		
Regular employee	12 (5.8)	51.00 (6.95)		
Temporary employee	14 (6.9)	51.43 (8.75)		
Religious belief			1.818	0.071
No	196 (91.3)	52.57 (8.17)		
Yes	68 (8.7)	47.25 (6.48)		
Income (RMB, yuan)			3.204	0.043
<3,000	51 (25.0)	52.86 (8.38)		
3,000–6,000	117 (57.4)	53.09 (8.76)		
>6,000	36 (17.6)	49.28 (4.46)		
Family structure			1.483	0.229
Live with unmarried child (ren)	32 (15.7)	54.34 (9.16)		
Live with married child (ren)	57 (27.9)	51.25 (8.28)		
Live alone/or with spouse	115 (56.4)	52.37 (7.77)		
Smoking			0.671	0.513
No	139 (68.1)	52.19 (8.77)		
Yes	57 (28.0)	51.67 (7.00)		
Stopped smoking	8 (3.9)	56.75 (2.87)		
Drinking			1.129	0.261
No	176 (86.3)	52.73 (8.24)		
Yes	28 (13.7)	50.07 (7.67)		
Approach of dialysis			0.580	0.561
Autogenous arteriovenous fistula	196 (96.1)	52.24 (7.92)		
Long- term deep vein catheterization	6 (2.9)	55.83 (15.56)		
Temporary catheterization	2 (1.0)	53.50 (3.54)		

N, number.

Besides, it showed no significant relationship between optimism and stigma ($P > 0.05$).

3.4. Hierarchical linear regression analysis

The influencing factors of stigma in renal dialysis patients were investigated using hierarchical linear regression analysis. Multiple regression analysis included variables significantly related to stigma in univariate analysis and variables related to the psychological status of renal dialysis patients. This study included demographic variables (the course of dialysis in the patient, religious belief, and income), resilience, hope, perceived social support, perceived stress, and fear of progression in the regression analysis. Hope (β = -0.318, $P < 0.001$), social support (β = -0.193, $P < 0.01$), perceived stress (β = 0.197, $P < 0.01$), fear of progression (β = 199, $P < 0.01$) were associated with stigma in renal dialysis patients, with all four variables in the model explaining 34.6% of the variance in stigma in renal dialysis patients. There is no collinearity between the variables (Tolerance > 0.5, VIF < 2). **Table 4** lists the details.

4. Discussion

4.1. Stigma levels among renal dialysis patients

There have been a few studies on stigma in dialysis patients. We found that the level of stigma in the study was higher (48) than

TABLE 2 The levels of stigma among renal dialysis patients (*N* = 204).

Variables	Items	Mean ± SD	Actual scoring range	Average item score
Social rejection	9	19.09 ± 3.51	9∼30	2.12
Financial insecurity	3	6.13 ± 1.40	3∼9	2.04
Internalized shame	5	11.83 ± 2.14	7∼17	2.37
Social isolation	7	15.31 ± 2.90	7∼23	2.19
Stigma	24	52.36 ± 8.16	27∼79	2.18

TABLE 3 Descriptive statistics and correlations in continuous variables among renal dialysis patients (*N* = 204).

	Means	SD	Stigma	Resilience	Hope	Social support	Optimism	Perceived stress
Resilience	68.55	12.93	−0.386***	1				
Hope	35.00	4.54	−0.448***	0.471***	1			
Perceived social support	64.92	12.15	−0.393***	0.534***	0.540***	1		
Optimism	15.28	2.67	−0.124	0.209**	0.397***	0.337***	1	
Perceived stress	6.83	3.08	0.255***	−0.168*	0.033	0.031	−0.340***	1
Fear of Progression	31.50	9.69	0.314***	−0.256***	−0.086	−0.057	0.000	−0.354***

*$P < 0.05$; **$P < 0.01$; ***$P < 0.001$ (two-tailed).

TABLE 4 Hierarchical linear regression analysis on stigma among renal dialysis patients (*N* = 204).

Variables	Resilience					
	β	*P*	β	*P*	Tolerance	VIF
Step 1						
course of dialysis						
<5(reference)						
5 10	0.140	0.054	0.114	0.058	0.903	1.107
ł10	0.139	0.056	0.089	0.142	0.885	1.131
Income						
<3,000 (reference)						
3,000–6,000	0.014	0.861	0.039	0.576	0.677	1.487
>6,000	−0.162	0.048	−0.092	0.184	0.673	1.485
Religious belief	−0.105	0.129	−0.075	0.197	0.956	1.046
Step 2						
Hope			−0.318	0.000	0.702	1.424
Social support			−0.193	0.005	0.690	1.449
Perceived stress			0.197	0.002	0.838	1.193
Fear of Progression			0.199	0.001	0.846	1.182
F	3.070*		14.421***			
R^2	0.058		0.372			
adjR^2	0.039		0.346			
R^2-change	–		0.314			

***$P < 0.001$ (two-tailed); *$P < 0.05$ (two-tailed).

in previous studies of renal dialysis patients in limited studies. We speculate that this is due to age differences in the target population. Furthermore, we found that the level of stigma among renal dialysis patients was lower than that of some cancer patients (49–51), which could be attributed to the age and job status of patients in the study. In this study, nearly half of the patients (46.1%) were above 60 years old, and only 12 (5.8%) were regular employees. The conditions mentioned above may weaken the social stigma of renal dialysis patients. However, it does not mean that stigma on renal dialysis patients is insignificant. A recent study in Japan quantitatively elucidated dialysis-related stigma in patients on dialysis (52). Renal dialysis patients are subjected to long-term continuous treatment that may last until the end of their lives, disrupting their routines, social interactions, quality of life, mental health, and family life (7) as stigma is impossible to avoid. Some researchers reported that patients with dialysis (53) and chronic kidney disease (54–56) had an unspoken stigma, reminding us that we should pay more attention to stigma among patients with this disease. In terms of dimensions, we found that internalized shame scored highest. Previous studies showed that stigma could be most harmful when internalized (57), which could devalue themselves (58). Besides, the most stigma dialysis patients experienced were internalized shame and social isolation, which were consistent with patients with COPD (59) and diabetes (60). This implies that it is critical to change patients' inner beliefs, values, idea and give them support in order to reduce the stigma associated with renal dialysis patients.

4.2. Factors associated with stigma among renal dialysis patients

In the present study, hope, social support, perceived stress, and fear of progression were potentially related to stigma among renal dialysis patients.

According to the results of hierarchical linear regression analysis, hope may have the strongest effect on stigma among renal dialysis patients, similar to previous studies on patients with other diseases (37, 61). It has been reported that hope is related to almost all health outcomes (62) for two reasons. Rather, hope is a vital positive psychological variable. Hope is a dynamic life force to expect a good future when facing uncertainty (63). Patients with a high level of hope have a promising attitude to the disease, which is beneficial to avoid devaluing themselves. Conversely, hope has been reported to have a positive effect on resilience (64), quality of life (65), stress (66, 67), anxiety (66), and depression (66) which may reduce the level of stigma indirectly. Furthermore, interventions based on Snyder's hope theory have been reported effective in reducing the stigma level (68, 69). Therefore, we can take interventions based on hope of reducing the level of stigma in patients.

In the study, perceived social support was another variable that had a positive effect on decreasing the level of stigma among renal dialysis patients; a similar condition has also been found in previous related studies (70, 71). Social support is a vital strength for the patients. It is important to have a high level of social support due to the long-term, uninterrupted nature of the disease. And previous studies have also shown that social support had an important effect in deciding whether patients with end-stage kidney disease should receive dialysis (72). In the literature, social support is divided into instrumental support and emotional support (73). The supports mentioned above were both critical to the patients. However, some studies suggest that dialysis patients' personal views about their illness can provide insight into whether patients could benefit from support (18, 74). It reminds us that we should pay attention to the thinking, and value of patients. It is in line with some research about social support, which has shown that social support works through hope and resilience (75). Given the preceding discussion, we should focus on using personalized combined with group intervention for dialysis patients in future work to improve the level of social support of patients. The content of the intervention is comprehensive, and the content of the intervention is what the patients need.

It was not surprising that perceived stress was an essential factor in the stigma among renal dialysis patients confirmed in previous studies on other diseases (76, 77). The levels of perceived stress are not the real level of stress but rather the stress that the patient perceives as an event. For the same event, different people may have different stress. The right amount of pressure is beneficial. However, if the patient's stress perception level is excessive, it means that the disease has a significant impact on them. They usually look at the disease negatively and even look at themselves negatively. The patients may not believe in their future and themselves. The feelings mentioned above may make them more shamed. In this case, the stigma is more likely to arise. Not to mention that the severe disease was taboo and easily associated with uniformed and misinformed social impressions (78). Therefore, managing stress and maintaining it is a crucial issue. A study about stress management training has shown that stigma was reduced after the training (79), suggesting that stress management interventions can be implemented in dialysis patients.

Finally, fear of progression was identified as a significant potential influencing factor of stigma in dialysis patients. The fear of progression has been reported in patients with chronic kidney disease (39) without data on renal dialysis patients. Fear of progression (FoP) is a feeling of worry and fear caused by disease and its treatment that is different from traditional psychological dysfunction (80). The fear of progression in disease has been proved to related to quality of life (81), social function (82), happiness (83), well-being (84), and so on. Patients who are afraid of disease progression are unable to recognize and accept it. Even minor changes in illness can cause emotional panic. The abovementioned factors are detrimental to patients and would cause them to undervalue themselves. For renal dialysis patients, the possibility of disease cure is low. And, to some extent, the development of the disease in a negative direction is known. A high level of fear during the disease development process will make the patient more reluctant to reveal to others and make the patient look down on himself. It will also harm the patient's treatment and quality of life. In the previous studies, group-based intervention (82) and illness perception (85) have been reported to be effective. Thus, actions and interventions aimed at increasing renal dialysis patients' knowledge of disease-related information aided in the formation of a good group intervention.

However, in the study, some results were inconsistent with our hypotheses, such as optimism and resilience showed no significant relationship. Therefore, the exact mechanism of action of these two variables still needs further research.

5. Strength and limitations

This study aimed to identify potential factors related to stigma in renal dialysis patients. In this regard, our research provided some new information. The results showed that stigma in kidney dialysis patients were associated with hope, social support, perceived stress, and fear of progression. It emphasizes the significance of changing patients' inner beliefs, values and ideas. Future work to reduce stigma among renal dialysis patients should include hope-based intervention, proper and specific strategies to improve social support, stress management interventions, and more disease-related information. This result indicated that stigma should be a major focus when dealing with renal dialysis patients.

Causation could not be established in this study due to the cross-sectional design. Future studies should assess whether the intervention can reduce stigma levels in renal dialysis patients. Furthermore, we focused only on the associations between stigma and resilience, hope, perceived social support, optimism, perceived stress, and fear of progress, whereas other factors that might affect stigma have been disregarded. Moreover, larger samples are required to improve representativeness. And the number of questions may limit the quality of the responses. The last but not the least, stigma is multifaceted in nature, dialysis patients experience stigma for multiple reasons, thus additional qualitative studies could be explored in the future research. Despite some limitations, our study provides important new information on stigma in renal dialysis patients with useful clinical implications.

6. Conclusion

According to this study, renal dialysis patients in China face a moderate level of stigma. Stigma was found to be negatively related to hope and social support but positively associated with perceived stress and fear of progression. Future research on the stigma of renal dialysis patients should include hope-based interventions, proper and specific social support strategies, stress management interventions, and more disease-related information.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by Committee of China Medical University (2022PS153K). The patients/participants provided their written informed consent to participate in this study.

Author contributions

BL and PX were responsible for conception and design of the study. BL, DL, and YZ performed data extraction. BL did the data analysis and wrote the manuscript. PX contributed to the revision of the manuscript. All authors have reviewed the manuscript and given final approval of the version to be published.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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A sociocultural perspective of mental health stigma in Malta

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mental health stigma, mental health in Malta, sociocultural perspective, service evolution, stigma reduction, stigma attitudes

Introduction

Epidemiological research depicting the overall prevalence of mental health disorders in Malta is sparse. With a population of over 535,000 inhabitants, it is estimated that around 120,000 individuals have a mental disorder (1). The reported local percentage prevalence stands at 6.6% for depression; 7.8% for anxiety, and for schizophrenia, at 0.026% for the general population and 0.4% for asylum seekers (2, 3). Approximately 25.2% of individuals under the age of 14 are at risk of developing a mental disorder, which is higher than that estimated in Europe (3, 4).

Stigma, or the negative judgement toward individuals with a mental illness (5), is a prevailing concern that has been on local and international agendas for years. Research worldwide depicts that stigma affects various dimensions, including treatment adherence, family dynamics, employment, social inclusion, and the occurrence of other mental health illnesses (5–8). Individuals having mental illnesses in Malta also experience stigma (9), and an exploration of this phenomenon requires immersion in a Mediterranean cultural context, due to its influence on Maltese society**.** Such cultural beliefs are of significance as they influence how disorders are understood, described, and managed, how help is sought and how treatment is received (10). Malta, being at the center of the Mediterranean Sea, and having been under the governance of Arabic, Central and Southern European territories, has been inspired to develop into what it is today, with Mediterranean values remaining prominent. Familial support, honor, religion, shame, and strong family values are factors shaping overall wellbeing in a Mediterranean culture, possibly affecting how Maltese society views and behaves when confronted with mental illness (7).

Despite efforts to shift institutional care to community care, discussing mental health disorders is still not a customary practice and many refrain from admitting to any pertinent mental health challenges. Conversely, discussing mental health wellbeing in general is becoming more acceptable, possibly due to the ever-increasing mental wellbeing awareness campaigns, focusing on the importance of creating a healthy work-life balance. The association between Maltese cultural and societal norms and public attitudes toward mental health poses concern, particularly when trying to curb stigmatizing behaviors. This article aims at raising awareness on the impact of this relationship and offers views on the effectiveness of current stigma reduction movements and initiatives.

Stigma on an individual level

Locally, stigma has been perceived as affecting the wellbeing of people with mental illnesses, often leading to discrimination, marginalization, and a general label that they are harmful to society (11). One area which stigma affects deeply is the self, as individuals with mental illnesses come to believe stereotypes and stigmatizing attitudes, such as being weak, unworthy, or incapable of succeeding in life. The internalization of such beliefs is referred to as self-stigma (11–13), and often results in feelings of hopelessness, low self-esteem and low self-efficacy. This lack of self-belief has long been recognized as having a negative impact on recovery processes, independent living, empowerment, and the development of social interactions (14), creating a vicious cycle that further validates public stigma.

It is crucial to interpret the impact of self-stigma alongside sociocultural and sociopolitical contexts of a specific population (13). Different populations develop different forms of stereotypes, however growing up with conceptualized ideas of mental illness increases the risk of self-stigma (14). For instance, the importance of upholding family honor by avoiding familial shame, remains prominent in a Maltese sociocultural context and hinders many from seeking the required help (15). Experiences of mental illness are often denied and not spoken about, especially within communities harboring strong stereotypes, for fear of familial exclusion or deterioration in relationships. In fact, locals take an average of 6.25 years before seeking help, with fear of isolation, embarrassment, and shame being significant contributing factors (16, 17).

Self-stigma is also reported to negatively impact interactions with professionals and relatives alike (18). Health professionals may perceive self-stigma in people with mental disorders, as triggering a sense of powerlessness and avoidance of situations where they encounter discrimination (13). They may also view self-stigma as a choice rather than customary practice. This phenomenon, better known as iatrogenic stigma, can exacerbate structural stigma, in that forms of discrimination and downgrading are often transferred onto the workplace. With Malta being a small island, this problem is further intensified, as many inhabitants are related or know each other personally. Galea (19) details how structural stigma manifests in Malta, highlighting issues of maltreatment, lower wages, lower advancement opportunities and an inability to find jobs that they are qualified in, attesting the cycle of self-stigma. Such issues often lead to poverty, and generally relatives feel duty-bound to support their relative with mental health challenges financially, causing further emotional and physical strain on relatives, who may need to work multiple jobs to make ends meet.

Stigma on a communal level

Overall Maltese society still endorses the importance of maintaining close family networks, from which support, be it emotional, moral or financial can be received. In neighborhoods sustaining the sense of traditional community, support may also be sought from neighbors and other members of that community, who are often considered as extended family. This support can easily be shattered if people with mental illnesses are ostracized for fear of bringing shame to the family or the community. Such disregard can further deteriorate mental wellbeing, increase dependence on social welfare and increase self-stigma (7).

Nonetheless, one still finds families who choose to walk the recovery journey with their relatives. Fenech and Scerri (20) describe the emotional turmoil of caring for a relative with a mental illness, as well as the potential negative impact on the caregivers' well-being due to lifestyle changes and added responsibilities. This study highlights the family's role in caring, providing support and assisting with coping, a value deeply endorsed by Mediterranean cultures and still present in Malta today. As participants hereby stated, it is often either the parents or a person (such as a sibling) perceived as having the least commitments who take on the caring role, and a shift in responsibilities onto other relatives tends to be done with hesitancy. The impact of stigma upon social inclusion, acceptance and employment was also emphasized, noting how full integration into society presents a significant challenge. This study further depicts the financial strain imposed upon caregivers as a result of their relative's difficulty in finding employment.

Derogatory comments toward people with mental illness remain common, affecting not just self-perception, but also help-seeking attitudes. The Maltese term “mignun” has been repeatedly used to refer to someone experiencing a mental illness (21). It is not uncommon for locals to feel unsafe when seeking professional help, out of fear that even professionals might show stigmatizing and condemnatory approaches. Locally, iatrogenic stigma, manifests in various forms, for instance the diagnostic labeling of individuals with mental illness, and the notion that individuals with certain conditions, such as substance misuse, are inclined toward aggression or service manipulation. In the study by Galea (19), participants who experienced iatrogenic stigma recounted how professionals delimit people with mental illness, believing that they cannot do much on their own, and exhibit paternalistic and patronizing behaviors. Consequently, many locals interpret that symptoms of a psychological nature have a primary physical cause, compelling them to first seek medical help, unconsciously or deliberately avoiding psychological support. Furthermore, this may be attributed to the locals' close link and faith in primary healthcare, particularly their family doctor, who is often their sole point of reference for anything medically related.

Cachia (21) also emphasized stigma endured by children and adolescents. School-based professional services, aimed at promoting help-seeking attitudes and increasing mental health literacy from a young age are on the rise. Nevertheless, such services can have a rebound effect and discourage use, out of fear of being discovered by peers and possibly social group exclusion (19). Discordance between children and their parents has also been considered as barriers to help-seeking (22). Further misconceptions and negative prejudice toward mental health in general may reflect the population's dearth of mental health literacy.

The evolution of services

Mental healthcare in Malta remains somewhat hospital-based and medically driven, with comparatively less attention given to alternative/complimentary therapies. Geographically, Malta is an archipelago of small islands, and there is one psychiatric hospital that caters for the mental health needs of the population. Having been built in the 19th century, this building is still referred to by a stigmatizing term, that continues to fuel the everyday stigma experienced by individuals requiring hospitalization (19). The lack of sufficient investment in maintaining and improving human and infrastructural resources has created challenges in offering quality mental healthcare (3).

Over the years, however, there has been much investment allocated to developing community-based mental health services such as mental health clinics and outreach teams, that offer services closer to people and that help reduce stigma (23). These clinics are distributed across the island and hence vary in relation to catchment area and the number of persons being cared for. They also provide better access to mental health services, as requests for mental healthcare are directly referred to them, without having to unnecessarily go through the inpatient pathway. Despite this, the increasing demand for human resources in community-based services poses a challenge to provide adequate support, leading to unnecessary prolonged hospital stays. In fact, the average length of stay in Malta is one of the highest in Europe and has increased over the past few years (3).

In 2012, a New Mental Health Act came into effect. This law provided people having a mental illness with civil, political, economic, social, religious, educational, and cultural rights, which were previously unheard of, such as the right to actively participate in care and the right to select a responsible carer of one's own choice. This law significantly reduced the length of stay for involuntary care, such that an involuntary admission for treatment order was reduced from one year to 10 weeks (24).

The Office of the Commissioner for Mental Health (OCMH) was also subsequently established to safeguard clients' rights and ensure that the commitment toward advancement of mental health services remains (25). In 2019, this Office pushed for a 10-year Mental Health Strategy. Regardless of governmental commitment toward this strategy, investment remains primarily focused on improving medical care. It is difficult to determine whether this is due to stigma, or the impact of the COVID-19 pandemic, with a focus on prevention, containment, and management. Nonetheless, the percentage of Members of Parliament participating in annual debates organized by the OCMH, remains at an average low of 10% or less (17, 25, 26). Such statistics may provide a twofold indication; primarily of how governmental bodies perceive mental wellbeing; and the persistent stigma surrounding mental health.

The total number of trained mental health professionals remains amongst the lowest in Europe. The Maltese Association of Psychiatrists highlighted the low number of trained professionals and the large discrepancy between current and recommended practicing numbers (25, 27). The low number of prospective students also reflects the fear of stigmatizing attitudes by peers and colleagues. This inclination has recently started shifting, with more nurses working in specializations other than mental health, recognizing the importance of mental health literacy and engaging in specialized training.

Mental health promotion

The relationship between low mental health literacy and stigma has long been investigated (5, 6). Recent research examining the likelihood of individuals seeking support following social media promotion has instigated the commencement of several movements and campaigns, aiming at increasing mental health literacy (28).

Locally, World Mental Health Day is now being celebrated yearly, with the OCMH organizing events to promote mental wellbeing. Throughout the year, the OCMH frequently discusses current affairs having a direct or an underlying mental health theme at different media houses. Similarly, several professionals participate in debates on local media, discussing stigma, services offered, mental illnesses, and holistic factors that contribute to mental wellbeing. In 2018, the #StopStigma national campaign endeavored to normalize and equalize mental health care. This campaign saw the OCMH, academics working within the University's mental health department and students undertaking the mental health nursing course create a series of informative posters that were distributed nationally.

Promotion is also being done within the education system. Children are being informed about the importance of maintaining mental wellbeing, accepting peers from diverse cultural or socioeconomic status, and sheering away from behaviors that can precipitate addiction. There is also increased awareness about the importance of early identification of autism, ADHD and other mental health disorders. Nurture classes and support zones have been developed in primary and secondary schools respectively, whereas students at tertiary-level education can access mental health services on campus (22).

One local non-governmental organization commenced training on "Mental health first aid," with the aim of increasing knowledge and providing participants with skills to support individuals experiencing mental health issues. Following an initial target of students and educators, it is nowadays tailormade to various sectors including businesses, healthcare, and disciplined corps.

Public self-disclosures, previously considered implausible and taboo, have recently increased in settings such as media houses, self-help groups, seminars, and schools. Most self-help groups, as those for substance misuse, anxiety, depression and psychosis, are delivered by individuals on the path to mental health recovery. Others have developed their own nongovernmental organization, such as that for bipolar disorder, named "Be Positive, Bipolar Self-Help Malta." Public disclosure, however, has its challenges. Instances whereby individuals were dismissed from work or long-term unemployment have been reported, making it difficult for them to live a flourishing and fulfilling life. Fears for public disclosure are recently being challenged by the contribution of foreigners experiencing mental health problems, whose own culture may possibly view this as an opportunity to influence a wider audience.

Co-production and service-user movements are still in their infancy in Malta, but initiatives are being made. The voices of experts by experience in relation to the formulation and delivery of some courses and care provision are now being sought. Nonetheless, further efforts are required for their inclusion in the formulation, implementation, and evaluation of policies. Two factors possibly affect co-production, iatrogenic stigma, and structural stigma (29, 30). People with mental health challenges still need to face the daily reality of lack of adjustment and understanding from employers, hindering full and active participation within society, including co-production movements. Despite this, the Alliance for Mental Health (A4MH), which consists of various mental health stakeholders, has discussed, and documented at length the need for service improvement, delivery, and access. Well-intentioned improvements, it states, can only be generated by prioritizing the involvement of clients and caregivers (31).

Discussion

Mental health stigma remains a debilitating issue worldwide, the extent and intensity of which is affected by cultural and societal factors. Within the Maltese context there is still a dearth of local research highlighting the multifactorial considerations and complications of stigma. Although local promotion campaigns have multiplied, their impact is yet to be measured. Concern over society's unaddressed mental health needs due to stigma, and the consequent effect on the population's general health have also been highlighted (27).

Mental health stigma can be reduced, but it must be targeted in a systematic manner (6). One cannot change society's views on mental health without tackling iatrogenic stigma first. Incentives to increase professionals' interest in furthering related education need to be devised and implemented. Recruitment within mental health has become a global phenomenon, and enrollment efforts are being dampened by stigmatizing attitudes. Despite this, recruitment efforts have intensified and evolved in an attempt to reach a wider population. Adequate and quality person-centered care cannot be delivered if professionals keep demonstrating stigmatizing attitudes and authoritarian approaches to care.

Continuous education and public campaigns normalizing mental wellbeing need to become standard, as does professional support, particularly in school-based, university and workplace settings (30). Education needs to be further strengthened through the practice of informal interaction between service-users and general public (6).

Despite a shift in favor of normalization, mental health stigma remains prominent and tangible within the Maltese context. It is hoped that by targeting mental health stigma, the fear, shame, and negative beliefs surrounding mental health decrease.

Author contributions

JS, AS, and JA contributed to concept, design of work, and wrote sections of the manuscript. All authors contributed to manuscript revision, read, and approved the submitted version.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Physical and sexual victimization of persons with severe mental illness seeking care in central and southwestern Uganda

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Purpose: This study established the prevalence of physical and sexual victimization, associated factors and psychosocial consequences of victimization among 1,201 out-patients with severe mental illness at Butabika and Masaka hospitals in Uganda.

Methods: Participants completed structured, standardized and locally translated instruments. Physical and sexual victimization was assessed using the modified adverse life events module of the European Para-suicide Interview Schedule. We used logistic regression to determine the association between victimization, the associated factors and psychosocial consequences.

Results: The prevalence of physical abuse was 34.1% and that of sexual victimization was 21.9%. The age group of $> = 50$ years (aOR 1.02;95% CI 0.62–1.66; $p = 0.048$) was more likely to have suffered physical victimization, while living in a rural area was protective against physical (aOR 0.59; 95% CI 0.46–0.76; $p = <0.001$) and sexual (aOR 0.48, 95% CI 0.35–0.65; $p < 0.001$) victimization. High socioeconomic status (SES) (aOR 0.56; 95% CI 0.34–0.92; $p = <0.001$) was protective against physical victimization. Females were more likely to have been sexually victimized (aOR 3.38; 95% CI 2.47–4.64; $p = <0.001$), while being a Muslim (aOR 0.60; 95% CI 0.39–0.90; $p = 0.045$) was protective against sexual victimization. Risky sexual behavior was a negative outcome associated with physical (aOR 2.19; 95% CI 1.66–2.90; $p = <0.001$) and sexual (aOR 3.09; 95% CI 2.25–4.23; $p < 0.001$) victimization. Mental health stigma was a negative outcome associated with physical (aOR 1.03; 95% CI 1.01–1.05; $p < 0.001$) and sexual (aOR 1.03; 95% CI 1.01–1.05; $p = 0.002$) victimization. Poor adherence to oral anti-psychotic medications was a negative outcome associated with physical (aOR 1.51; 95% CI 1.13–2.00; $p = 0.006$) and sexual (aOR 1.39; 95% CI 0.99–1.94; $p = 0.044$) victimization.

Conclusion: There is a high burden of physical and sexual victimization among people with SMI in central Uganda. There is need to put in place and evaluate complex interventions for improving detection and response to abusive experiences within mental health services. Public health practitioners, policymakers, and legislators should act to protect the health and rights of people with SMI in resource poor settings.

KEYWORDS

physical victimization, sexual victimization, mental illness, seeking care, Uganda

Introduction

Much of the research on violence and severe mental illness (SMI) has focused on violence committed by individuals with mental illness with their victimization experience receiving little attention (1). This has contributed in a large measure to the stereotyping of persons with SMI as 'violent and unpredictable' helping to drive the stigma associated with the mental illness label (1). Contrary to this perception, emerging literature indicates that individuals with SMI are at significantly higher risk of violent victimization compared to the general population (2–5).

In a systematic review by Latalova et al. (4), the prevalence of violent victimization in the last 1 year was reported to range between 7.1 and 56% (4). Risk factors for both sexual and physical victimization have been reported to include: socio-demographic factors (male/female gender-depending on the study, homelessness, residence in a poor neighborhood); psychiatric illness factors (severity of psychiatric symptomatology, comorbid personality disorder); and psychosocial factors [engagement in criminal activity, stress (for men), history of victimization in childhood and adolescence and recent history of violence perpetration] (1, 3, 5–7).

Three theories suggested by Siegel (8) seem to apply to victimization of persons with SMI (8); the first victim perception theory suggests that some people may actually initiate the confrontation that eventually leads to their injury or death. For example, through pursuit of a relationship with the perpetrator or through personality traits such impulsivity that might render them abrasive or obnoxious. The second theory states that people may become crime victims because their lifestyle increases their exposure to criminal offenders, for example members of high risk groups such as the homeless and drug users. The third theory states that the more often victims visit dangerous places, the more likely they will be exposed to crime and violence for example if they reside in socially disorganized high-crime areas (8). Violent victimization of persons with SMI is of public health concern because of its known negative impact on the course and outcomes of mental disorder (9). Violent victimization of persons with SMI has been associated with increased severity of psychiatric symptoms, self-harm behavior, chronicity, increased risk of homelessness, reduced quality of life, impaired community functioning and greater caregiver financial burden (4, 10, 11). While considerable research has been undertaken to elucidate this problem in western countries, there is a paucity of research from developing country settings such as those in sub-Saharan Africa. In this paper we investigate the prevalence, risk factors and psychosocial consequences of physical and sexual victimization of persons with severe mental illness seeking care at two psychiatric facilities in central and south-western Uganda.

Materials and methods

Study design and site

This is a cross-sectional analysis from the longitudinal study entitled, '*HIV clinical trials preparedness studies among patients with severe mental illness in HIV endemic Uganda-the SMILE Study*' (12, 13). Baseline recruitment included 1,201 individuals with severe mental illness (SMI) who were enrolled from the out-patient departments of Butabika National Referral Mental Hospital (urban central) and the Department of Psychiatry, Masaka Regional Referral Hospital (rural southwestern) Uganda between January–March 2018. Butabika National Referral Mental Hospital offers general and specialized mental health services both to in-patients and out-patients. Butabika National Referral Mental Hospital has a current psychiatric bed occupancy of 1,100 in-patients and sees about 30,000 psychiatric out-patients annually (personal communication from the Executive Director, Butabika National Psychiatric Referral Hospital, 23rd September 2022). Masaka Regional Referral Hospital offers all services expected of a regional referral health facility, including psychiatric services. The Psychiatric Department at Masaka Regional Referral Hospital has a 30-bed capacity in-patient service and an out-patient service. In the period between July 2018 to June 2019, the psychiatric department at Masaka Regional Referral Hospital attended to 8,260 out-patients (14, 15).

Eligibility criteria

Serious Mental Illness (SMI) was operationalized as a condition whereby someone over the age of 18 years has (or had within the past year) one or more of the following diagnosable mental disorders: schizophrenia, bipolar affective disorder and recurrent major depressive disorder that caused serious functional impairment leading to at least one admission. The diagnosis was confirmed by a review of the clinical records by a psychiatrist (member of the research team). At the time of enrollment into the study, the study participant must have been in remission and attending the out-patient departments of either Butabika National Referral Mental Hospital or Masaka Regional Referral Hospital. Additional eligibility criteria included speaking either English or Luganda (the local language spoken in the study areas). Exclusion criteria were concurrent enrollment in another study, in need of immediate medical attention, and unable to understand the study assessment instruments for whatever reason.

Recruitment and data collection

Participants were randomly selected from over 3,000 recovering mentally sick people attending out-patients' departments (OPDs) at Butabika National Referral Mental Hospital and Masaka Regional Referral Hospital between January–March 2018 (study flow chart is below).

The trained research assistants (Psychiatric Clinical Officers and Psychiatric Nurses) gave potential participants information about the study before obtaining informed consent and assent to enroll into the study. Research assistants collected the data using structured, standardized, and locally translated assessment instruments (16–19). Participants with predetermined high risk criteria (as determined by the MINI criteria) or severe psychiatric symptomatology were referred to attending clinicians in the out-patient departments of the two participating hospitals.

Measures

SMIs were established using the MINI International Neuropsychiatric Interview version 7.2. The variables reported in this paper were organized under the sub-headings based upon the conceptual framework developed by the 'SMILE study team' (Figure 1) (12, 13): (i) socio-demographic factors (study site, gender, age category, religion, socio-economic status, and marital status), (ii) psychosocial factors (social support, mental health stigma, childhood physical victimization, childhood sexual victimization, physical victimization in adulthood and sexual victimization in adulthood), (iii) psychiatric illness factors (family history of psychiatric illness, past depressive episode, past manic episode, past psychotic episode, lifetime suicide attempt), (iv) psychotropic drugs (Antiparkinsonian medication, mood stabilizers, 1st generation neuroleptics, 2nd generation neuroleptics, tri-cyclic anti-depressants, selective serotonin reuptake Inhibitors) and (v) maladaptive behaviors (alcohol use, use of tobacco, alcohol drinking problem, use of marijuana or use of khat).

Statistical analysis

In this study, we had two sets of dependent variables; namely, adulthood physical and sexual victimization variables and clinical and behavioral outcome variables (risky sexual behavior, poor adherence to oral anti-psychotic medications). Frequencies of socio-demographic characteristics (study site, gender, age, socio-economic status, marital status, employment status, religion and education level) were described with frequencies and percentages for the categorical variables and median (IQR) for the continuous variables.

For each of the two outcome categories on adulthood victimization namely, physical and sexual victimization, three derived outcome variable were constructed from the relevant sections of the Uganda modified life events and histories module of the European Parasuicide Study Interview Schedule I (EPSIS I) (16, 20). The three derived outcome categories were: '*past adulthood physical or sexual victimization*' (between 18 years of age to 12 months before interview date); '*recent adulthood physical or sexual victimization*' (in the last 12 months before the study); and '*ever suffered physical or sexual victimization in adulthood*' (between 18 year of age to interview date). The first two categories were derived from the relevant section of the life events and histories module of EPSIS I while the last category was a combination of the two former categories.

Prevalence of each of the three derived outcome variables for both physical and sexual victimization was calculated with 95% confidence intervals. To assess for factors associated with the derived outcome variables of '*ever suffered physical victimization in adulthood*' (between 18 year of age to interview date) and '*ever suffered sexual victimization in adulthood*' (between 18 year of age to the interview date) the following approach was employed.

To undertake multivariate analyses, the approach recommended by Victora et al. (21) was used based on the conceptual framework. Firstly, the association of socio-demographic factors was investigated through the use of a backward elimination logistic regression model, choosing the candidate variables based on prior knowledge and plausibility, and using a liberal p-value (15%) for removal, in order to ensure that all variables that could have a possible confounding effect on the ultimate risk factors were included, as recommended by Royston et al. (22). At second stage of model building, psychiatric illness factors and psychosocial factors were included into the model at a liberal value of p of 15%.

To investigate the association between clinical and behavioral outcome variables with physical and sexual victimization, the following approach was employed. For continuous outcomes ordinal logistic regression models were fitted while for the binary outcomes (risky sexual behavior, adherence to oral anti-psychotic medications), logistic regression models were fitted. At each of these model building stages, the likelihood ratio approach was used to determine the best fit for the final models. The following covariates were also controlled for as design variables: age, gender and study site. A two-sided $p < 0.05$ was considered statistically significant. STATA version 15.0 was used for all statistical analyses.

Ethical consideration

The study obtained ethical approvals from the Uganda Virus Research Institute's Research and Ethics Committee (GC/127/19/10/612) and the Uganda National Council of Science and Technology (HS 2337). Participants were given information about the study by trained study psychiatric nurses and informed consent and assent sought before enrolment into the study. Participants found to have a SMI were provided healthcare and supported at the out-patient departments (OPDs) of their respective hospitals.

Results

Characteristics of study participants

Out of the 1201 participants enrolled into the study, 54.5% were female and 58.4% lived in urban areas (Table 1). The average age of the participants was 36 years ±11.9, the majority (81.3%) were Christians and over 95% had attained at least primary education. Participants who were HIV seropositive were 7.2%, while those who were syphilis seropositive were 4.4% as indicated in Table 1.

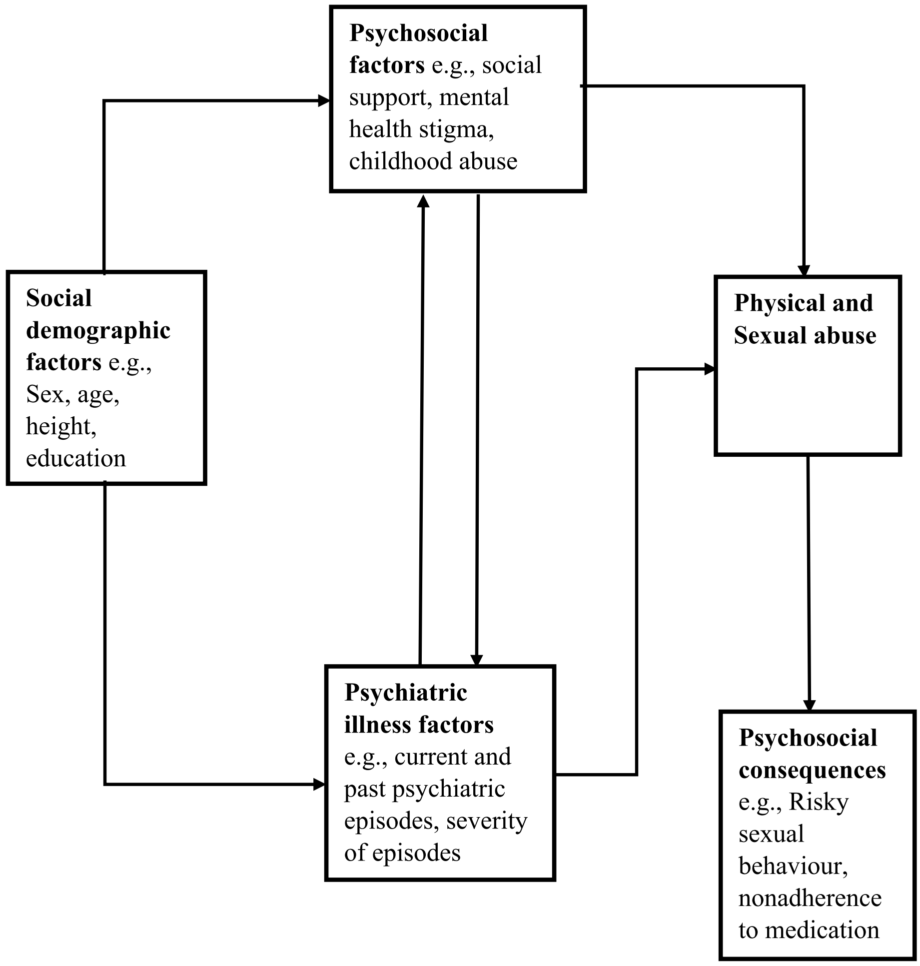

FIGURE 1
Conceptual framework for physical and sexual abuse among people with severe mental illness.

Prevalence of physical and sexual victimization

Four hundred and nine (34.1%) participants met criteria for 'ever suffered adulthood physical victimization' with 'recent adulthood physical victimization' (in the last 12 months) reported by 13.6%, while 'past physical victimization in adulthood' (from 18 years up to 12 months before study) was reported by 31.1%. Two hundred and sixty-three (21.9%) participants met criteria for 'ever suffered adulthood sexual victimization' with 'recent adulthood sexual victimization' (in the last 12 months) reported by 8.6%, while 'past sexual victimization in adulthood' (from 18 years up to 12 months before study) was reported by 19.6% (Tables 2, 3).

Socio-demographic and psychosocial factors associated with physical and sexual victimization

Age (>=50) of the respondent was found to be associated with physical victimization ($p = 0.048$). Residing in rural residences (Masaka) was found to be protective against physical (aOR 0.59, 95% CI 0.46–0.76; $p < 0.001$) and sexual (aOR 0.48, 95% CI 0.35–0.65; $p < 0.001$) victimization. Socio-economic status was also found to be associated with physical victimization; participants with a higher socio-economic status were less likely to suffer physical victimization compared to those with lower socio-economic status.

Sex of the respondent was found to be associated with sexual victimization. Female respondents reported three times more likely to suffer sexual victimization compared to their male counterparts (aOR 3.38; 95% CI 2.47–4.64; $p < 0.001$). Religion (being Muslim) was protective by 40% against sexual victimization ($p = 0.045$) (Table 4). Childhood trauma was associated with both physical (aOR 1.04; 95% CI 1.03–1.05; $p < 0.001$) and sexual (aOR 1.05; 95% CI 1.04–1.06; $p < 0.001$) victimization. Social support was protective against both physical (aOR 0.95; 95% CI 0.94–0.97; $p < 0.001$) and sexual (aOR 0.96; 95% CI 0.94–0.98; $p < 0.001$) victimization.

Association between physical and sexual victimization with negative outcomes

Risky sexual behavior was associated with both physical (aOR 2.19; 95% CI 1.66–2.90; $p < 0.001$) and sexual (aOR 3.09; 95% CI 2.25–4.23; $p < 0.001$) victimization. Mental health stigma (Per unit increase) was associated with physical (aOR1.03; 95% CI 1.01–1.05; $p < 0.001$)

and sexual (aOR 1.03; 95% CI 1.01–1.05; $p = 0.002$) victimization. Missed taking of oral psychiatric medications in last 3 days was associated with both physical (aOR1.50; 95% CI 1.12–2.00; $p = 0.006$) and sexual (aOR 1.39; 95% CI 1.00–1.93; $p = 0.044$) victimization. Poor adherence to oral anti-psychotic medications was associated with both physical (aOR 1.51; 95% CI 1.13–2.00; $p = 0.006$) and sexual (aOR 1.39; 95% CI 0.99–1.94; $p = 0.044$) victimization (Table 5).

TABLE 1 Baseline characteristics.

Factor	Level	*N* = 1,201 *n* (%)
Site	Butabika(urban)	701 (58.4%)
	Masaka(rural)	500 (41.6%)
Gender	Male	547 (45.5%)
	Female	654 (54.5%)
Age	Median(IQR)	36 (29,45)
Socio-economic status(grouped)	0–2	189 (15.7%)
	3–4	409 (34.1%)
	5–6	486 (40.5%)
	8-Jul	117 (9.7%)
Marital status	Currently married	384 (32.0%)
	Widowed	57 (4.7%)
	Separated/divorced	295 (24.6%)
	Single	464 (38.7%)
Employment status	Farmer/fisherman	304 (25.4%)
	Professional	139 (11.6%)
	Informal employment	206 (17.2%)
	Unemployed	549 (45.8%)
Religion	Christian	977 (81.3%)
	Muslim	212 (17.6%)
	Others	10 (0.83%)
Education level	No formal education	37 (3.1%)
	Primary	476 (39.6%)
	Secondary	460 (38.3%)
	Tertiary	227 (18.9%)
Primary diagnosis	Schizophrenia	314 (26.1%)
	Bipolar affective disorder	787 (65.5%)
	Major Depressive disorder	83 (6.9%)
Missed taking oral psychiatric medications in last 3 days	Yes	260 (21.7%)
	No	912 (75.9%)
HIV status	Positive	87 (7.2%)
Syphilis (VDRL)	Positive	53 (4.4%)

Discussion

This study demonstrates a high prevalence of physical and sexual victimization, associated factors and negative outcomes among patients with severe mental illness (SMI) attending out-patients' departments (OPDs) at Butabika and Masaka hospitals in Uganda. The prevalence of physical victimization was 34.1%, while sexual victimization was 21.9%. Associated risk factors for both physical and sexual victimization were, living in a rural area, childhood trauma, and social support; Age group of >=50 and high social economic status (SES) were associated with physical victimization, while female gender and religion (being a Muslim) were associated with sexual victimization. Negative outcomes associated with both physical and sexual victimization were risky sexual behaviors, mental health stigma, having missed to take oral psychiatric medications in last 3 days, and poor adherence to oral anti-psychotic medications.

Prevalence of physical and sexual victimization

According to this study, the prevalence of physical victimization among people with SMI (34.1%) was similar to the rate of 31% established by Frueh et al. (23, 24) but much higher than the rate of 20.7% (in women) and 17.8% (in men) that was established by a recent review of 30 studies about victimization against people with SMI (25); the prevalence of physical victimization established by this study relates to the national prevalence of physical victimization among women (34%) and men (45%) in the general population in Uganda (26). Compared to people with SMI versus those without SMI, the odds of physical victimization happen to be elevated with a range of 2–22-fold higher odds (with a recent study reporting a pooled estimate of 5-fold relative odds for any physical victimization among people with SMI compared to those without SMI) (25); similarly, a previous systematic review by Hughes et al. (27) established a 4-fold risk for any physical victimization among people with disabilities compared to those without disabilities. This study established a prevalence of sexual victimization (21.9%) which was much higher than the established rate of 8% by Frueh et al. (23) and higher than 9.9% (in Women) and 3.1% (in men) established by a recent review of 30 studies that focused upon victimization among people with SMI (25); the prevalence of

TABLE 2 Prevalence of physical and sexual victimization.

	n	Prevalence	95%CI
Ever suffered adulthood Physical victimization (between 18 year of age to interview date)	409/1201	34.1%	(31.4–36.8%)
Past physical victimization in adulthood (*from 18 years up to 12 months before study*)	373/1200	31.1%	(28.5–33.8%)
Recent adulthood physical victimization (in the last 12 months)	163/1199	13.6%	(11.8–15.6%)
Ever suffered adulthood Sexual victimization (between 18 year of age to interview date)	263/1201	21.9%	(19.7–24.3%)
Past sexual victimization in adulthood (*from 18 years up to 12 months before study*)	237/1200	19.6%	(17.5–22.1%)
Recent adulthood sexual victimization (in the last 12 months)	103/1095	8.6%	(7.1–10.3%)

TABLE 3 A prevalence of sexual and physical victimization by severe mental illness diagnosis.

	Prevalence 95%CI		
	Schizophrenia	Bipolar affective disorder	Major depressive disorder
Sexual victimization	22.3 (18.0; 27.2)	21.6 (18.9; 24.6)	22.9 (15.0; 33.3)
Physical victimization	36.6 (31.4; 42.1)	33.8 (30.6; 37.2)	25.3 (17.0; 35.9)

TABLE 4 Socio-demographic and psychosocial factors associated with physical and sexual victimization.

Factor	Level	Physical victimization	*p*–value	Sexual victimization	*p*-value
		Adj. OR		Adj. OR	
Age	<25	1			
	25–34	1.55 (1.01,2.38)		–	
	35–49	1.46 (0.96,2.23)			
	> = 50	1.02 (0.62,1.66)	0.048		
Sex	Female	0.85 (0.67,1.08)		3.38 (2.47;4.64)	<0.001
	Male	1	0.188	1	
Urban/rural residence	Butabika	1		1	
	Masaka	0.59 (0.46,0.76)	<0.001	0.48 (0.35;0.65)	<0.001
Religion	Christian			1	
	Muslim	–		0.60 (0.39;0.90)	0.045
	Others			1.32 (0.27;6.51)	
Marital status	Currently	1			
	Widowed	0.96 (0.49,1.87)		–	
	Separated	1.48 (1.07,2.05)			
	Single	1.09 (0.80,1.49)	0.091		
Socio-economic status	2-January	1			
(number of items possessed)	4-March	0.68 (0.48,0.98)		-	
	6-May	0.43 (0.30,0.62)			
	8-July	0.56 (0.34,0.92)	<0.001		
Employed/unemployed	Farmer			1	
	Professional	–		1.10 (0.66;1.84)	0.079
	Informal			0.57 (0.34;0.97)	
	unemployed			1.01 (0.69;1.49)	
Childhood trauma	Per unit increase	1.04 (1.03,1.05)	<0.001	1.05 (1.04;1.06)	<0.001
Social support	Per unit increase	0.95 (0.94,0.97)	<0.001	0.96 (0.94;0.98)	<0.001
Primary diagnosis	Schizophrenia	1		1	
	Bipolar affective disorder	1.01 (0.76; 1.34)		1.09 (0.77; 1.53)	
	Major depressive diosrder	0.67 (0.38; 1.17)	0.301	1.05 (0.57; 1.93)	0.882

All analyses adjusted for study site, sex and age.

sexual victimization established by this study was much higher than the national prevalence of sexual victimization among women (5%) and men (2%) in the general population in Uganda (26). The prevalence of physical and sexual victimization established by this study relates to the prevalence of physical and sexual intimate partner violence (IPV) among women living with HIV (WLWH) (29%) (28), but higher than the national prevalence of both physical and sexual victimization among women (18%) and men (6%) in Uganda (26). Several mechanisms have been suggested to explain the high prevalence of physical and sexual victimization among people with SMI; living in socially deprived neighborhoods (with its social and economic conditions) fosters physical and sexual victimization among people with SMI (25, 29), but such deprived neighborhoods (with such social and economic conditions) also foster physical and sexual victimization among people without SMI (25, 29). Another mechanism suggests that some people with SMI (acutely ill patients) display disturbed or psychotic behavior, which may evoke hostile reactions and attempts at social control from others, often results into

TABLE 5 Association between physical and sexual victimization with negative outcomes.

Factor		Any physical victimization	*p*-value	Any sexual victimization	*p*-value
		Adj. OR		Adj. OR	
Behavioral outcomes					
Risky sexual behavior	Yes	2.19 (1.66; 2.90)	<0.001	3.09 (2.25;4.23)	<0.001
Mental health stigma	Per unit increase	1.03 (1.01,1.05)	<0.001	1.03 (1.01;1.05)	0.002
Clinical outcomes					
Missed taking oral psychiatric medications in last 3 days	Yes	1.50 (1.12; 2.00)	0.006	1.39 (1.00; 1.93)	0.044
Poor adherence to oral anti-psychotic medications	Yes	1.51 (1.13; 2.00)	0.006	1.39 (0.99;1.94)	0.044

All analyses adjusted for study site, sex and age.

conflict and mutual victimization (30). Exposure to institutional victimization (i.e., coercive measures such as being taken down by police or psychiatric staff, being committed against own will, forced medication, seclusion, or restraint) within the mental health care system has been shown to lead to physical victimization (sometimes sexual victimization, especially when a 'staff contact person' is absent or treatment by staff happens to be dismissive and derogatory) (31–33). Similarly, homelessness among people with SMI is highly associated with increased physical and sexual victimization (25, 34, 35); possibly, the poor development of mental health facilities, poor staffing levels [with increased use of 'informally trained low-level staff' ('local security-guards') to offer clinical services, e.g., use of batons to manage aggressive/violent patients], poor 'qualified staff-to-patient-ratios (especially during the night shifts)', poor infrastructure of the mental health services, coupled with inadequate sensitization could partly be responsible for the increased prevalence of physical and sexual victimization among people with SMI in Uganda compared to other parts of the world.

Socio-demographic and psychosocial factors associated with physical and sexual victimization

Result from this study indicate that the age category of >=50 years was associated with physical victimization ($p = 0.048$), contrary to a previous study which established that victimization rates among adults with SMI decrease with age (4); increased physical victimization with age established by this study possibly relates to the increased illness severity (number of hospitalizations, number of symptoms) with increasing age, coupled with lack of meaningful social roles for the majority of people with SMI which makes them vulnerable to victimization (25). According to this study, age of the respondent was not associated with sexual victimization; findings from this study were similar to a previous study which established that people with severe mental illness experience victimization, regardless of their age (25), but contrary to findings from a study which established that younger age is associated with sexual victimization, while victimization rates appeared to decrease with age (4). This study established that female respondents were three times more likely to suffer sexual victimization compared to their male counterparts; findings from this study were similar to a previous study which established that the prevalence of sexual victimization was three times higher in women [9.9% (IQR ¼ 5.9–18.1%)] as compared to men [3.1% (IQR ¼ 2.5–6.7%)] (25); results from this study were in agreement with previous studies which suggest that women are more likely to be victims of sexual abuse (4, 25). Similarly, other studies from high-income countries suggest that women with SMI are at an increased risk of sexual victimization both within and outside intimate relationships (34, 36–38). Female patients are significantly more likely to be sexually victimized than male patients (4, 39), because being female is associated with an increased risk of victimization (4). In sub-Saharan Africa, access to mental health treatment is limited, thus women with inadequately treated psychiatric symptoms constitute 'suitable targets' for sexual victimization (34, 40). According to this study, residing in rural residences was found to be protective by 41% against physical victimization, which rhymes with a previous study which revealed that living in rural areas is significantly associated with lower risk of reporting severe mental illnesses and happens to be associated with better overall mental health (41); additionally, subjective safety for people with SMI is clearly worse in cities than in rural areas (42), while other related studies established that living in socially deprived neighborhoods fosters physical victimization among people with SMI (25, 29). This study further established that residing in rural residences was found to be protective by 52% against sexual victimization, which rhymes with a previous study which revealed that subjective safety for people with SMI is clearly worse in cities than in rural areas (42), while other related studies established that living in socially deprived neighborhoods fosters sexual victimization among people with SMI (25, 29). Based upon results from this study, religion (being Muslim) was protective by 40% against sexual victimization; findings from this study relates to a previous study which suggest that religion is a protective factor against sexual and gender-based violence (SGBV) (43); similarly, a previous study established that trauma related to sexual victimization is shaped by religious beliefs relating to forgiveness, sacrifice and salvation; possibly, people with SMI use religion to cope with the 'after-effects of sexual abuse'; contrary to findings from this study, a previous study established that manifestation of victimization (including sexual victimization) happens to be more influenced by religion (44).

This study established that participants with a higher socio-economic status (an individual's position in a society which is determined by wealth, occupation, and social class and is a measure of an individual's or group's standing in the community) were found to be less likely to suffer physical victimization compared to those with lower socio-economic status, thus the findings happen to be in agreement with previous studies which suggest that poor social and economic conditions fosters physical victimization among people with

SMI (25, 29); most people with SMI happen to be socioeconomically disadvantaged compared to the general population (45), hence more likely to suffer physical victimization than other people without SMI. Similarly, other previous studies have established that socio-economic disadvantage makes persons with severe mental illness to be more vulnerable beyond the effects of the mental illness itself (34, 46).

According to this study, childhood trauma was associated with physical victimization; results from this study are in agreement with previous studies which suggest that increase in the risk of adult physical victimization is associated with previous childhood abuse (47, 48). Similarly, a high prevalence of previous childhood abuse has been previously reported among people with SMI (48–50). It has been suggested that abuse in childhood increases the odds of adulthood violent victimization in both women and men (48). Previous studies established that experiences of childhood maltreatment are associated with more severe psychiatric symptoms and more complex clinical manifestations among people with SMI (48, 51, 52). Possibly, broader stressful childhood experiences may affect the life trajectory negatively in terms of complex social and behavioral outcomes which may increase vulnerability to victimization, rather than there being a specific abusive experiences in childhood that makes people more vulnerable to similar abusive experiences in adulthood (48). Relatedly, experiences of victimization in early life influence risk of later victimization in this causal manner, via changes in social and psychological development and the severity of illness; while on the other hand, the association may simply reflect continuity of adversity across the life course, with early victimization as a marker of social disadvantage that is still present in adulthood, thus increasing risk of victimization (48). Relatedly, this study established that childhood trauma was associated with sexual victimization; findings from this study are in agreement with previous studies which suggest that increase in the risk of adult sexual victimization is associated with history of previous childhood abuse (47, 48). Similarly, other previous studies have reported a high prevalence of previous childhood abuse among people with SMI (48–50, 53). A previous study looking at men and women with SMI found that patients who had been sexually victimized as adults were more likely to have been sexually abused as children, but physical abuse in childhood was not associated with physical victimization in adulthood (39). Relatedly, other previous studies suggest that sexually victimized people with SMI were significantly more likely to report a history of sexual abuse during childhood (4, 39). Among mentally sick people, abuse in childhood increases the odds of adulthood violent victimization (48). Since the cause of sexual victimization is always ultimately the behavior of the perpetrator, it can be difficult to clarify the mechanisms by which a person's negative childhood experiences increase their vulnerability to later victimization. Grauerholz uses an ecological framework, proposing that personal, interpersonal and sociocultural factors associated with childhood abuse may increase the risk of exposure to potential perpetrators, or increase the likelihood that potential perpetrators will act aggressively (54). Factors associated with childhood abuse in the general population such as lack of resources, social isolation, drug and alcohol abuse, psychiatric symptoms and stigmatization (55–57), may all increase the risk of a perpetrator acting aggressively, due to the perception of the victim as an easier target and feeling more justified in behaving aggressively, as well as decreasing the ability of the victim to respond assertively (54).

According to this study, social support was protective against physical victimization; findings are in agreement with previous studies which suggest that social support happens to be protective against physical victimization among mentally sick people (58); mentally sick people with poorer social support experience greater exposure to traumatic events, while better social support helps ensure a better quality of life for people with mental illness (59). This study further established that social support was found to be protective against sexual victimization; findings are in agreement with a previous study which suggests that good social support lowers the risk of victimization and lessens suffering from exposure to traumatic events (59). Similarly, it has been established that social support networks may serve to buffer the psychological effects of stress and victimization (60).

Association between physical and sexual victimization with negative outcomes

This study established that risky sexual behaviors (aOR 2.19 95%CI 1.66–2.90; $p < 0.001$) were associated with physical victimization; relatedly, previous studies established that risky sexual behaviors (RSBs) are common among people with SMI (9, 12). Patients in the acute phase of severe mental illness are more likely to practice RSBs, largely associated with the general impairment of reality testing and judgment common among this population (12, 55); since some people with SMI (acutely ill patients) display disturbed behavior which evokes hostile reactions, attempts to control such patients often leads to conflict and physical victimization (23); thus a possible association between RSBs and physical victimization. Risky sexual behaviors were found to be associated with sexual victimization; findings from this study relate to a previous study which suggested a complex link between childhood sexual abuse and adult risky sexual behaviors among persons with SMI (61). Similarly, a previous study established that people with sexual abuse history are significantly more likely to engage in risky sexual behavior than people without sexual abuse history (62). Similarly, a previous research with community-based samples indicated that childhood sexual abuse is associated with increased engagement in risky sexual behaviors during adulthood (63). It has been hypothesized that childhood sexual abuse impacts subsequent risky sexual behavior via three pathways: (1) psychopathology, including PTSD, depression, and dissociation; (2) drug use; and (3) adverse sexual adjustment including an obsession with sexual activities, an inability to sustain intimate relationships, and participation in destructive sexual relationships (64). It has been suggested that for persons with SMI, childhood sexual abuse serves as a threshold for engaging in risky sexual behavior as adults (61). Risky sexual behaviors among patients with a severe mental disorders are highly prevalent and happens to be associated with many negative outcomes (65).

According to this study, mental health stigma was associated with physical victimization; findings rhyme with previous studies which suggest that stigma is associated with prior experience of trauma (59), exceeds the effects of mental illness itself, thus makes people with mental illness to be extremely vulnerable (46); stigma co-occurs with both victimization and serious mental illness (38); obviously, individuals exposed to traumatic events/victimization often feel stigmatized because of their experiences (59). As a possible mechanism, stigma toward vulnerable people can increase the risk of a perpetrator acting aggressively, due to the perception of the victim as an easier target and feeling more justified in behaving aggressively, as well as decreasing the ability of the victim to respond assertively (54).

This study established that mental health stigma was associated with sexual victimization; results from this study rhyme with a previous study which established that sexual victimization among people with SMI is associated with social stigma, shame, guilt, dehumanization and increased vulnerability (66); people with SMI who experience sexual victimization suffer the double burden of stigma from both mental illness and sexual victimization (38, 59, 66). In low-and middle-income countries, lack of psychiatric services and widespread mental illness stigma are structural factors that exacerbate the social vulnerability of persons with SMI (34, 67, 68); stigmatizing attitudes against persons with SMI are widespread in sub-Saharan Africa (40). Relatedly, a previous Ugandan study established that some female participants reported being sexually exploited due to economic and emotional dependence by persons intimate to them (34, 69); economic dependence on intimate partners contributes to Ugandan women's low negotiating power in decision-making about sex (34, 69). Arguably, the same environmental factors [living in socially deprived neighborhoods, where social and economic conditions foster abusive norms (29)] that are responsible for sexual victimization, trigger/manifest psychiatric symptoms and social stigma since they subject people with SMI to be more vulnerable (25).

Missed taking of oral psychiatric medications in last 3 days was associated with physical victimization (aOR1.50; 95% CI 1.12–2.00; $p = 0.006$), which probably relates to the greater treatment resistance observed among psychiatric patients (70, 71); possibly, administration of treatment against the will of individuals with severe mental illness (23, 72) results into physical victimization. Similarly, missed taking of oral psychiatric medications in last 3 days was associated with sexual victimization, possibly due to the impending relapse associated with non-adherence to antipsychotic medication (73), thus this could have subjected people with SMI to be more vulnerable to sexual victimization.

Poor adherence to oral anti-psychotic medications was associated with physical victimization; findings from this study rhyme with previous studies which established that violent victimization in people with SMI is associated with being unresponsive to treatment and non-adherent with medication (44); greater treatment resistance has been observed among psychiatric patients (70, 71). Relatedly, other previous studies established that lifetime exposure to assault was associated with administration of treatment against the will of individuals with severe mental illness within the mental health care system (23, 72). Poor adherence to oral anti-psychotic medications was associated with sexual victimization; probably, poor adherence to antipsychotic medication increases the risk of relapse and hospitalization and reduces the quality of life (74), thus mentally sick people (with poor adherence to oral anti-psychotic medications) were more vulnerable since they were more likely to relapse and become sexually victimized.

Strengths and limitations

This study used a large sample size (1,201 participants), established the prevalence of physical and sexual victimization, associated risk factors and their psychosocial consequences among patients with severe mental illness (SMI) in rural and urban Uganda. This study incorporated and determined other very important variables through a variety of standardized tools. In addition, recruiting participants after screening for their insight [recognition of one's own mental illness and need for treatment; a person's capacity to understand the nature, significance, and severity of his or her own illness (75)] is a plus strength of the study since inviting and including participants having poor insight might have affected the findings. Limitations of this study are inherent to the cross-sectional study design which did not allow for conclusions about causal pathways but this will be addressed during the longitudinal part of this study. Because of the cross-sectional nature of this study, it is unclear whether potential risk factors were (already) present at the time of physical and sexual victimization; In the future, a prospective design (which is part of the larger study) will be utilized to investigate the risk factors and to capture causal trajectories of physical and sexual victimization among people with SMI in urban and rural Uganda. This study used measures of physical and sexual victimization that were based on self-report, which is unfortunately more apt to be influenced by memory or reporting bias (76); however, recall bias was minimized by obtaining collateral information from significant people to the participants. Similarly, use of self-report was more adequate (especially for this group) than Police reports because people with SMI are less likely to have an official police report about physical and sexual abuse (77). Another limitation was the absence of a neighborhood matched control group. Although results of this study revealed that physical and sexual victimization prevalence is high, it is unknown how much higher these rates are compared with the general population that lives in the same neighborhood or circumstances. To gain more knowledge about the risk factors, it is important to investigate the mediating and moderating factors that influence the risk of physical and sexual victimization. Relatedly, it is important to conduct a study to understand why people with SMI are more prone to physical and sexual victimization, thus more information is needed about lifestyles and related routine activities, type of incidents, the context (e.g., where was it, who was the offender), and the process of cause and effect. Despite the limitations, this study provides additional understanding of the difficult life situation of persons living with SMI in resource-poor settings, documents the physical and sexual victimization by 'people significant to those with SMI', community members, Police officers (security personnel), health workers and hospital security guards (especially when people with SMI are admitted in psychiatric settings) during illness episodes. Our findings suggest that it is important for clinicians to assess for physical and sexual victimization among people with SMI in sub-Saharan Africa, in order to provide appropriate support/mental health care.

Conclusion

People with severe mental illness are victims of physical and sexual abuse. The age group of >= 50 years was more likely to have suffered physical victimization; living in a rural area was protective against physical and sexual victimization; high socioeconomic status (SES) was protective against physical victimization; socioeconomic status (SES) refers to a person's economic and social position in relation to others, based on income, education, and occupation (78), including possession of commonly available household items/resources (12, 18). Females were more likely to have been sexually victimized; being a Muslim was protective against sexual victimization.

Risky sexual behaviors, mental health stigma, missed taking of oral psychiatric medications in the previous 3 days and poor adherence to oral anti-psychotic medications were negative outcomes associated with physical and sexual victimization.

Implication of these findings; practitioners need to consider introducing questions about prior experience of physical and sexual victimization in routine anamnesis which may help uncover physical and sexual abuse among people with SMI to improve upon service delivery. The risk for patients may vary depending on the community in which they live (urban versus rural setting). Physical and sexual victimization among people with SMI is public mental health problem, thus it is important to understand the risk pathways for different types of abuses within a developmental framework. Given the high burden and excess risk of physical and sexual victimization among people with SMI, future research should evaluate complex interventions for improving detection of and response to abusive experiences within mental health services. It is important to conduct studies to guide clinical practice and policy on 'gender sensitive preventive measures for physical and sexual victimization among people with SMI'.

Data availability statement

The datasets presented in the study are included in the Supplementary material, further inquiries can be directed to the corresponding author/s.

Ethics statement

The studies involving human participants were reviewed and approved by the study obtained ethical approvals from the Uganda Virus Research Institute's Research and Ethics Committee (GC/127/19/10/612) and the Uganda National Council of Science and Technology (HS 2337). The patients/participants provided their written informed consent to participate in this study.

Author contributions

RM, WS, GR, PA, CB, RR, CT, KG, AK, VP, MN, and EK have made substantial contributions to conception, design, acquisition of data, drafting the manuscript, revising it critically, and gave the final approval of this version to be published. WS did the analysis and interpretation of the data. All authors participated sufficiently in this work and takes public responsibility for appropriate portions of the content.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1167076/full#supplementary-material

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Arabic validation of the "Mental Health Knowledge Schedule" and the "Reported and Intended Behavior Scale"

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Objectives: Mental illness affects one in eight people in the world according to the WHO. It is a leading cause of morbidity and a major public health problem. Stigma harms the quality of life of people with mental illness. This study aimed at validating the Arabic version of the Mental Health Knowledge Schedule (MAKS) and the Reported and Intended Behavior Scale (RIBS) in a sample of Tunisian students and determining socio-demographic and clinical factors correlated with stigma.

Methods: This cross-sectional study was conducted on 2,501 Tunisian students who filled in the MAKS, the RIBS, and a sociodemographic and clinical questionnaire. The validation of the questionnaires in Arabic was carried out using the validity criteria: face and content validity, reliability, and construct validity. Next, the associations between stigma and sample characteristics have been studied using multivariate linear regression.

Results: Face and content validity of the measures MAKS and RIBS were satisfactory, with adequate internal consistency. There were significant positive correlations between the items and scales, and test–retest reliability was excellent. The internal validity showed that the items were well-aligned with the intended factors, and the external validity revealed a significant positive relationship between the MAKS and RIBS. Besides, gender, the field of study, psychiatric history, and contact with someone with a mental illness were all contributing factors to mental illness stigma. Additionally, men performed better than women in terms of behavior toward people with mental illness, while women had a greater level of knowledge about mental health.

Conclusion: The Arabic versions of the MAKS and RIBS have appropriate psychometric properties, making them effective tools for evaluating mental illness stigma. With multiple factors contributing to this issue, these instruments can help focus anti-stigma efforts and promote a more inclusive society.

KEYWORDS

stigma, mental illness, validation, students, surveys and questionnaires

1. Introduction

Stigma against mental illness is a universal issue considered to be the main barrier to access mental health care (1). It significantly harms the quality of life of people with mental illness and its negative effects can be seen in various areas of their life, including difficulty finding and maintaining housing and employment, limited social connections, and finances (2).

Stigmatization can arise because of several attributes of a person, namely differences in visible physical manifestations (deafness, blindness), origins (ethnicity, religion, race…), or behaviors (3). However, compared to these, mental illnesses are often more stigmatized, which has been called the ultimate stigma (4).

Worldwide, the burden of mental illness continues to grow significantly with significant health impacts and major socioeconomic and human rights consequences according to WHO in 2019. Indeed, mental illness nowadays affects about 970 million people around the globe (5).

To better understand stigma, it is important to consider its three constructs: knowledge (ignorance), attitudes (prejudice), and behavior (discrimination) (6, 7). Surprisingly, when it comes to knowledge, the public understanding of the biological underpinnings of mental illness does not seem to lead to greater social acceptance of these individuals. Indeed, these individuals are still described as "dangerous" and "unpredictable," which increases social distance (8).

Several studies have shown that mental health knowledge specific to symptom recognition, treatment efficacy, and help-seeking can facilitate understanding when communicating with clinicians and decrease fear and embarrassment when interacting with people with mental illness (9, 10). Thus, it can play a key role in influencing behaviors and attitudes (11).

Rates of anticipated and experienced discrimination among people with mental illness are consistently high (12). Not only do they have to deal with the handicap inflicted by the symptoms of the disease, but they must face the harsh judgments made by society in their daily lives (13). In a cross-sectional study comparing public beliefs and attitudes toward schizophrenia in Central Europe (Germany) and North Africa (Tunisia), individuals with schizophrenia in Tunisia were found to be more accepted in distant relationships, such as being a neighbor or colleague, but faced stronger rejection in culturally significant family roles, such as marrying into the family or taking care of children, risking exclusion (14).

Enhancing the public's understanding of mental health can have a positive effect on reducing stigma and social exclusion, increasing willingness to seek help, and ultimately improving individuals' adherence to treatment in the future (15).

Although the number of studies assessing stigma and testing interventions to reduce stigma is continually growing in the Arab world, their number is still low compared to Western countries. In addition, there is a lack of contextually adapted and validated instruments to measure stigma and assess the efficacy of anti-stigma interventions in the Arab world.

The Mental Health Knowledge Schedule (MAKS) and the Reported and Intended Behavior Scale (RIBS) were adapted to Arabic in the context of the "INDIGO" partnership research program whose aim is to increase the understanding of mechanisms behind stigma and to develop interventions to reduce stigma toward individuals with mental health issues in low-and middle-income countries (LMICs) (16).

Unlike previous measures that focused on evaluating knowledge and behavior within specific populations or for specific diagnoses, the MAKS and RIBS were developed as part of the UK Time To Change (TTC) anti-stigma campaign 2008–2012 to evaluate the contribution of interventions to knowledge and behavior change of the general public and to allow the comparability of results (17). This study aimed at validating the Arabic versions of the MAKS and the RIBS in a sample of Tunisian students and identifying socio-demographic and clinical factors associated with stereotypes and stigmatizing behavior in this student sample.

2. Materials and methods

2.1. Sample

We conducted a descriptive and validation study on 2,501 Tunisian students enrolled in public and private universities in different regions of Tunisia during the academic year 2020–2021. Our study did not include foreign students, medical students, and participants who had completed their university studies.

2.2. Methods of recruitment

We asked the student delegates of each institution to distribute the form via the mailing lists of students of each institution. Thus, we were able to target students from different fields of study (Arts, Economics and Management, Literature, and Sciences) enrolled in both public and private sector institutions in all regions of Tunisia between July and November 2021. The form was accompanied by a description containing information on the purpose and content of the study, as well as on the confidentiality of the data and its use for purely scientific purposes. Accessing the form and answering the questionnaire indicated the consent of the candidate. Each student could only access the questionnaire once to avoid data redundancy. If a student answers "No" to the question "Are you a student?," he/she will be automatically directed to the end of the questionnaire. Candidates could not send their answers if they did not complete the questionnaire. We have also invited 110 subjects to participate in the test–retest study after a random selection. Their responses were combined with their initial results to compare them. The time to answer the form varied between 5 and 10 min. All results were automatically recorded in an excel file accessible only to the author of the form.

2.3. Measurement

2.3.1. MAKS

This questionnaire was designed by S. Evans-Lacko and published in 2010 (15). It contains two sub-scales each consisting of six items scored on a Likert scale. The first six items refer to mental health knowledge. Items 7–12 assess whether participants qualify the following conditions: depression, stress, schizophrenia, bipolar disorder, drug addiction, or grief as mental illness (15). It has already been validated in French, Italian, Persian, and Kiswahili languages (18–21).

2.3.2. RIBS

The RIBS was developed to enhance the assessment of anti-stigma interventions by encouraging the integration of behavioral outcomes (22) and has been validated in French, Italian, Japanese, Chinese, and Brazilian (18, 23–26). It consists of two sub-scales exploring four different areas: living with, working with, living near, and pursuing a relationship with someone with a mental health problem. It contains eight items, the first four of which explore the prevalence of reported or actual behavior with three possible responses "No," "Yes," and "I do not know," and the second sub-scale with four items evaluates future intentions in the four areas described above and are scored on a Likert scale (22). This distribution enables us to understand how reported behavior may influence intended behavior.

2.3.3. Items coding

All items which were assessed using the Likert Scale were coded from 1: "Strongly disagree" to 5: "Strongly agree." "Do not know" was coded as neutral (i.e., 3). Items 6, 8, and 12 of the MAKS were reverse-coded. No score value was assigned to items 1–4 of RIBS because they only calculate the prevalence of behaviors. The total score was calculated by summing the values of the responses. A higher score of responses to MAKS and/or RIBS reflects a better understanding of mental illness and a higher willingness to engage in positive behaviors toward people with mental illness (15, 22).

2.4. Procedure

2.4.1. Data analysis

Data analysis was performed using SPSS version 26.0 statistical software after importing the data from the Excel document that was recorded from the form responses.

We proceeded to a descriptive study of the population according to the different criteria: quantitative variables were studied using means (M) or medians, and qualitative variables were described using percentages (%) and standard deviations (SD). Determinants of mental illness stigma were analyzed using multivariate linear regression. In all statistical tests, the threshold of statistical significance was "$p < 0.05$."

2.4.2. Translation

We translated the MAKS and the RIBS from the original version to easily understandable standard Arabic based on the "back-translation "method. The first step was the translation from English to standard Arabic. Then, this version was evaluated by a committee of experts composed of psychiatrists, psychologists, and psychiatric nurses from Razi Hospital as well as of service users. Second, we realized back-translation from Arabic to English. Finally, the original and back-translated versions were subjected to a comparative analysis. The purpose of this step was to verify the adequacy of the translation and the adaptation of the items to the socio-cultural context. The preliminary version obtained at the end of this stage was studied by the committee of experts who evaluated the clarity, discrimination, and relevance of the MAKS and RIBS items. The resulting version was pre-tested with a sample of 30 individuals from the target population.

2.4.3. Validity study

2.4.3.1. Reliability

We analyzed the reliability of the two scales using "Cronbach's alpha" coefficient, whose value can vary between 0 and 1. Internal consistency is considered satisfactory starting from 0.7; however, above 0.9, it could indicate a certain redundancy of the items (27). To strengthen our study, we studied the inter-item and total inter-item correlation using the Pearson coefficient. This step assesses the strength of the link between the items within the same scale (27).

We also studied the test–retest reliability using the "intra-class coefficient" (ICC) and the "paired samples" to verify the consistency of the results over a 1 month interval.

2.4.3.2. Construct validity

To establish internal construct validity, we opted for a confirmatory factor analysis (CFA): we set a number of factors according to the number of dimensions we wanted to identify, and the proposed model was retained or not according to the "fit measures" obtained (28). Then, we associated a step studying the factorial solutions of each questionnaire. This step was carried out using two tools: the "Kayser-Meyer-Olkin" (KMO) measure which should exceed 0.6 for factorability (29) and the "Barlett sphericity test" which requires at least five individuals per variable given its high sensitivity to the number of individuals (30).

To test convergent validity and as, at the time of the study, no validated scales in Arabic assessing the stigma of mental illness in the general population existed, we studied the correlation between the MAKS and the RIBS using the Pearson coefficient after having validated each of the two scales.

TABLE 1 General characteristics of the participants included in the study (*N* = 2,501).

Participant's characteristic	M	SD
Mean age	21.57	2.55
Sex-ratio male/female	0.37	
	N	%
Family psychiatric history	428	17
Personal psychiatric history	440	17.6
Tobacco use	522	20.9
Considers him/herself as religious	1,892	75.6
Field of study		
Science and technology	1,468	58.7
Literature	436	17.4
Economics and management	381	15.2
Arts	120	4.8

TABLE 2 Distribution of participants' responses to the MAKS.

MAKS	Strongly disagree	Disagree	Neither agree nor disagree/ I do not know	Agree	Strongly agree
1. Most people with mental health problems want to have paid employment.	5.30%	10.40%	60.20%	15.40%	8.70%
2. If a friend had a mental health problem, I know what advice to give them to get professional help.	1.20%	3.10%	12%	31.20%	52.50%
3. Medication can be an effective treatment for people with mental health problems.	7.70%	16.90%	18.30%	38.50%	18.60%
4. Psychotherapy (e.g., counseling or talking therapy) can be an effective treatment for people with mental health problems.	0.90%	3.20%	5.90%	25.30%	64.70%
5. People with severe mental health problems can fully recover.	4%	8.90%	18.40%	35.30%	33.50%
6. Most people with mental health problems go to a healthcare professional to get help.	17.40%	21.60%	29.70%	21.70%	9.70%
7. Depression	1.40%	4.20%	3.60%	17.20%	73.60%
8. Stress	5.10%	11.30%	12.50%	30.80%	40.30%
9. Schizophrenia	0.60%	1.50%	3.50%	8.80%	85.60%
10. Bipolar disorder (maniac depression)	0.70%	3.30%	7.50%	13.50%	75.10%
11. Drug addiction	6.60%	11.10%	19.40%	24.80%	38.20%
12. Grief	10.20%	15.90%	21%	27.20%	25.70%

3. Results

3.1. Sample characteristics

We included 2,501 participants. Their sociodemographic and clinical characteristics are presented in Table 1.

3.2. Distribution of participants' responses

The median MAKS score was 45 out of 60 with a range of 30–56. The distribution of participants' responses to the MAKS is detailed in Table 2.

The first four items of the RIBS are not part of the behavioral assessment. However, they provide information about the prevalence of behaviors in each of the four contexts. Thus, the median RIBS score was calculated using the scores of items 5–8, and it was equal to 15 out of 20 ranging from 4–20. The distribution of participants' responses to the RIBS is illustrated in Table 3.

3.3. Validity study

3.3.1. Content validity

Among the 12 items of the MAKS scale, 4 items were discussed by experts: items 9 ("Schizophrenia"), 10 ("Bipolar disorder"), and 12 ("Grief") were reworded to make them more understandable and item 4 ("Psychotherapy (e.g., counseling or talking therapy) can be an effective treatment for people with mental health problems.") was reworded with a version more adapted to the Arabic and Tunisian context. For RIBS, the title was reworded with terms better understood by the local context. At the pre-test stage, only item 1 ("Most people with mental health problems want to have paid employment.") of the MAKS was ambiguous for one participant, and we remedied this problem by adding an explanation to the questionnaire statement ("Most people with mental health problems want to have paid employment, just as anybody").

3.3.2. Reliability

The internal consistency of the two questionnaires was evaluated by "Cronbach's alpha," which was 0.56 for MAKS and 0.83 for RIBS. The "inter-item," "item-total" and "inter-dimensional correlation" studies showed a significantly positive correlation between the different items of each scale and the totals of each sub-scale, indicating good overall reliability. Regarding test–retest reliability, the intra-class coefficient was 0.882 and 0.996 for the MAKS and RIBS total scores, respectively, indicating excellent concordance and thus good stability of responses over time. This result was supported by the paired samples *T*-test for each of the two questionnaires (Table 4).

3.3.3. Construct validity

The KMO index was 0.632 for the MAKS and 0.763 for the RIBS. The total variance explained by the two factors was 31.58% for the MAKS and 52.28% for the RIBS. All items saturated in the expected factor of each scale as for the original version. Thus, the same distribution was maintained for both the MAKS and the RIBS. Regarding the convergent validity study, Pearson's coefficient was 0.154 between the scores of the RIBS and the MAKS (Table 4).

3.4. Determinants of mental health stigma

Multivariate linear regression analysis showed that gender, psychiatric history, contact with a person with mental illness, and the artistic field of study were found to be independently associated with mental health knowledge and intended behavior toward people with mental illness (Table 5).

TABLE 3 Distribution of participants' responses to the RIBS.

RIBS (Reported behavior)	Yes	No/ I do not know			
Are you currently living with, or have you ever lived with, someone with a mental health problem?	40%	60%			
Are you currently working with, or have you ever worked with, someone with a mental health problem?	24%	76%			
Do you currently have, or have you ever had, a neighbor with a mental health problem?	34%	66%			
Do you currently have, or have you ever had, a close friend with a mental health problem?	51%	49%			
RIBS (Intended behavior)	**Strongly disagree**	**Disagree**	**Neither agree nor disagree/ I do not know**	**Agree**	**Strongly agree**
In the future, I would be willing to live with someone with a mental health problem.	14%	11.80%	24.50%	30.10%	19.60%
In the future, I would be willing to work with someone with a mental health problem.	13.20%	11.90%	21.50%	30.90%	22.50%
In the future, I would be willing to live nearby to someone with a mental health problem.	10.60%	9.80%	21.70%	31.60%	26.40%
In the future, I would be willing to continue a relationship with a friend who developed a mental health problem.	3.10%	3.30%	10%	23%	60.70%

TABLE 4 Validity tests of both MAKS and RIBS.

Scale	Internal consistency	Inter-dimension correlation	Test–retest reliability		Internal validity		Convergent validity
	Cronbach's alpha	Pearson's coefficient	Intra-class correlation coefficient	Paired samples *T*-tests (*p*)	KMO index	Percentage of total variance explained	Pearson's correlation between MAKS and RIBS
MAKS	0.56	0.170*	0.882	0.456	0.632	31.58%	0.154*
RIBS	0.83	0.112*	0.996	0.059	0.763	52.28%	

*The correlation is significant at the 0.05 level (two-tailed).

TABLE 5 Multivariate regression analysis of the determinants of mental health stigma.

Determinants	MAKS Score as a dependent variable		RIBS Score as a dependent variable	
	β	*p*	β	*p*
(Constant)	44.623	0.000	13.783	0.000
Male gender	−0.635	0.000	0.409	0.033
Personal psychiatric history	0.273	0.158	1.677	0.000
Family psychiatric history	0.297	0.140	0.478	0.034
Artistic field of study	−0.748	0.044	−0.201	0.628
Psychoactive substance use	0.158	0.386	0.372	0.068
Considers him/herself as religious	−0.036	0.858	−0.292	0.198
Contact with a person with a mental illness	0.450	0.005	0.736	0.000

4. Discussion

4.1. Validity study

The MAKS and RIBS have recently been validated in multiple languages (18–21, 23–26). However, no measurement tool assessing knowledge and behavior toward mental illness in the general population has been validated in Arabic, except for a questionnaire assessing attitudes toward patients with schizophrenia entitled "Attribution Questionnaire" which has been validated in Arabic in a population of Tunisian university students (31). Our validation study will add two valuable tools to assess mental health related knowledge and behavior in Arabic-speaking general population samples. In addition, the MAKS and RIBS differ from the previously validated measurement tool in that they address mental health problems in general, without specifying a diagnosis.

In our study, Cronbach's alpha was equal to 0.56. While certain authors argue that a reliability score of at least 0.7 is necessary (32, 33), the threshold of 0.56 remains acceptable based on the standards established by George and Mallery (34), especially since the MAKS is not considered a scale, and each of its items evaluates knowledge on a specific domain. This has already been discussed in previous versions. The MAKS was therefore considered more as an indicator of trends in responses (15). Thus, the alpha coefficient in the original version was 0.65. Indeed, it is important to keep in mind that the results of the various statistical tests may be less strong than those of the original version due to the linguistic and cultural differences between the two versions. Moreover, the inter-item correlation coefficients of the MAKS were low, which was also explained by the heterogeneity of the set of items (15).

Regarding the RIBS, our translated Arabic version had an internal consistency very similar to that of the original version (0.85) (22). The inter-item and inter-dimension correlation studies showed a significantly positive correlation between the different items of the MAKS and the RIBS and between the two subscales of each scale.

The ICC of the MAKS and RIBS total score indicated excellent concordance and thus good stability of responses over time.

Pearson's correlation between the MAKS and the RIBS was comparable to the one of the French and Kiswahili versions (18, 21).

4.2. Mental health stigma in Tunisian students

Our sample size was 2,501, largely exceeding that of the original validation study which included a total of 403 students (15, 22) and that of other validation studies (18–21, 23–26), with a good representativeness of the sample. However, as our study targeted only adolescents and young adults, it would be useful to study "knowledge" and "behavior" using MAKS and RIBS in all age groups. The online questionnaire allowed us to maximize the number of participants in a shorter time, target both public and private institutions from different regions of Tunisia, ensure anonymity, and limit social desirability bias.

The responses obtained for each of the items of the MAKS and the RIBS were close to those of the original version, except for item 1 of the MAKS where 60.2% answered "do not know" or "neither agree nor disagree." In Tunisian society, there could be a lack of understanding or education about mental illness and its effects on individuals' ability to work. Indeed, this item was removed from the French validation study of the MAKS (18). However, we decided to keep it in our study as we believe it is relevant in the Tunisian social context given that work is considered as a means of upward social mobility. Therefore, we should think about studies and discussion forums that are relevant to employment among people with mental illness.

Women tended to have significantly higher scores on mental health knowledge ($\beta = 0.635$; $p < 0.001$), such as employment among people with mental illness, the effectiveness of treatments, help-seeking, and the classification of various mental health conditions compared to men. On the other hand, men tended to have higher scores on intended behavior ($\beta = 0.409$; $p = 0.033$), which suggests that they are less discriminating than women and may engage in more positive interactions with individuals with mental illness. This relation has not been clearly addressed in the literature. Nevertheless, a significant association between attitudes toward mental illness and the female gender has been explained by the fact that women are more empathetic, open-minded, and positive thus showing less stigma (35, 36), but may also be more fearful and avoidant, of people with mental illness, than men (37).

Besides, participants who studied "Art" had lower scores on mental health knowledge ($\beta = -0.748$; $p = 0.044$). Indeed, the scientific and literary fields in Tunisian institutions offer training that provides a minimum of knowledge about mental health, unlike the "Art" disciplines, which leads us to think about the importance of integrating educational content related to mental health.

In addition, the results show less discrimination toward the mentally ill among participants with a personal ($\beta = 1.67$; $p < 0.001$) or family ($\beta = 0.478$; $p = 0.034$) psychiatric history. Participants who have been in contact with someone with a mental illness had also higher scores on both mental health knowledge ($\beta = 0.450$; $p = 0.005$) and behavior ($\beta = 0.736$; $p < 0.001$) toward people with mental illness. This result is consistent with several prior studies which suggested that contact with individuals with mental illness can help reduce stigma (38–41).

These findings emphasize the advantages of having personal interactions and experiences with individuals who have a mental illness, as well as the importance of providing information about mental illness. These factors had a positive impact on the participants' knowledge and behaviors toward people with mental illness. It is worth considering the statement of Professor Sartorius that successful campaigns can be implemented in any country or region, regardless of its size, economic status, or level of development (42).

4.3. Strengths of the study

Significant merits of our study encompass a large sample size of 2,501 participants, outstripping the original version (15, 22) and other validation studies (18–21, 23–26), representing diverse fields of study and institutions across Tunisia. We excluded medical students to limit knowledge bias. We conducted the study online to reach our technologically proficient target population, ensuring a fast response rate, wide regional coverage, anonymity, and reduced social desirability bias.

Additionally, our study suggests valuable tools for assessing mental health knowledge and behavior in all Arabic-speaking general population samples.

Our research would be of great interest in advancing the ongoing assessment of stigma, providing a solid foundation for the development of anti-stigma strategies. Notably, the MAKS and RIBS differ from previously studied measurement tools in that they target the general public and include a broader range of mental health problems, unlike existing tools that focus on specific diagnoses (31).

This greatly enhances the significance of our research for reducing stigma and developing effective strategies.

4.4. Limits of the study

The study is cross-sectional, which does not provide information on possible changes over time and on the influence of certain factors on the responses of the same individual.

Our study might have an inherent selection bias, given that it clearly indicated the subject of mental health at the beginning of the online questionnaire. Therefore, it could have attracted a particular profile of individuals that are less stigmatizing or discriminating against mental illness and pay more interest to stigma, hence the relatively high rate of people with personal psychiatric history (17.6%). Furthermore, an online questionnaire does not allow us to estimate the proportion of refusals compared to those who agreed to participate in our study. Thus, the overall scores of mental health knowledge and intended behaviors may be overestimated. Moreover, declarative bias may contribute to the overestimation of the scores.

In addition, our study population is limited to students and findings can therefore not be extrapolated to all of Tunisia's population. Although an online questionnaire limits social desirability, students may tend to answer Likert scale questions in the same direction to obtain a higher score due to the competitive nature of the student population.

On another note, the MAKS intentionally incorporates items with a multidimensional structure to assess various types of mental health knowledge. As a result, internal coherence and inter-item and item-total correlation are low. This issue has also been discussed in validation studies of previous versions (15).

Finally, in the absence of validated measurement instruments in Arabic that assess mental health stigma in the general population, we assessed external validity by correlating the MAKS and RIBS scales, a methodology previously used in the French, Italian, and Kiswahili versions (18, 19, 21).

5. Conclusion

The MAKS and RIBS validated in standard Arabic show good psychometric properties and could therefore be used in all Arabic-speaking populations to compare results and to study common determinants of mental illness stigma.

Mental illness stigma is influenced by multiple factors, including gender, field of study, psychiatric history, and contact with someone with a mental illness.

This study should be extended to the general population with more representative groups by carrying out on-site studies in public spaces or door-to-door to ensure representative samples of the Tunisian population, i.e., wider age groups and more varied intellectual and socio-professional levels.

Further research on mental illness attitudes is necessary to explore potential correlations. Using objective measures can help to track changes in knowledge, attitudes, and behavior over time, which would strengthen and guide efforts to decrease stigma.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by Ethics Committee of Razi Hospital. Accessing the form and answering the questionnaire indicated the consent of the candidate.

Author contributions

MB and YZ designed the study. YZ, AA, EB, AM, and UO evaluated the Arab versions of the MAKS and RIBS. Data were collected and interpreted by MB, YZ, and UO who have drafted the work, which was reviewed by all authors. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2023.1241611/full#supplementary-material

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Cultural adaptation and validation of the mental illness associated stigma scale for Arabic-speaking population in Saudi Arabia

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Objective: This research aimed to culturally adapt and validate the MIAS scale for Arabic-speaking individuals within the Saudi Arabian general population, with an emphasis on cultural, societal, and individual nuances.

Methods: An initial pilot testing with a small group ensured the scale's clarity. Subsequently, two cross-sectional studies involving 189 participants to assess structural validity of the Arabic MIAS scale, and 38 participants to assess the test-retest reliability. Descriptive statistics, Cronbach's α, Intraclass Correlation Coefficient (ICC), and Confirmatory Factor Analysis (CFA) were employed for data analysis.

Results: The Arabic MIAS scale demonstrated good internal consistency and acceptable test-retest reliability (ICC $\alpha = 0.631$). A three-factor model emerged ($CFI = 0.890$, $TLI = 0.845$, $RMSEA = 0.094$), including "Outcomes," "Negative Stereotypes," and "Recovery," closely mirroring the original study's structure. one item was excluded from the model since it didn't align with any of the three factors.

Conclusion: The study contributes a culturally adapted, validated, non-condition-specific tool to gauge public attitudes toward mental health stigma in an Arabic context. It highlights the need for culturally sensitive stigma research and interventions and underscores the importance of improving such tools for cross-cultural applicability and comparability.

KEYWORDS

mental illness, stigma, validation, MIAS scale, Arabic, Saudi Arabia, cultural adaptation

Background

Mental health stigma refers to the negative attitudes, misconceptions, and stereotypes that individuals and society hold toward individuals with mental illnesses (1). This stigma can manifest in several ways, including social exclusion, discrimination, and prejudice (2). Individuals suffering from mental health disorders often feel marginalized, misunderstood, and feared by society due to such stigma (3).

Measuring mental health stigma in the general population is crucial to understand the extent and prevalence of these negative attitudes and misconceptions (4). It offers a comprehensive overview that aids in identifying the factors contributing to the stigma and provides data to develop effective public health strategies to combat it (5). Furthermore, it allows policymakers to address stigma within the broader social context and promotes inclusive health services (6).

Measuring mental health stigma in the general population helps to improve the mental health outcomes of individuals suffering from mental disorders. It supports the development of stigma reduction interventions and promotes public understanding and empathy (7). Moreover, it assists in identifying the social and cultural factors that perpetuate stigma, providing valuable insights for tailoring mental health advocacy and education programs (8).

Condition-specific tools for measuring mental health stigma focus on the stigma associated with specific mental health conditions, such as schizophrenia or depression (9). They provide detailed insights into the unique stigma experiences related to individual disorders (10). On the other hand, assessments of public attitudes toward mental health stigma provide a broad understanding of societal attitudes and beliefs about mental illnesses (11). These assessments measure the general public's knowledge, beliefs, and attitudes toward mental health, which can inform public health initiatives and policies (12). While both are essential, condition-specific tools offer a more nuanced understanding of stigma, and assessments of public attitudes provide an overview of societal attitudes toward mental health (13).

However, accurately measuring mental health stigma in the general population poses a significant challenge. This is primarily because stigma is a complex, multidimensional construct, influenced by various factors such as culture, personal beliefs, experiences, and societal norms (3). Thus, a validated scale adapted to the local community is essential for accurately measuring mental health stigma. This entails considering the specific cultural, societal, and individual factors that influence stigma in the community. The process of cultural adaptation ensures that the scale is relevant and sensitive to the local context, thus enhancing its validity (14).

Saudi Arabia, under the guidance of the National Center for Mental Health Promotion (NCMH), has established several programs to monitor mental health indicators at the national level. These include the Saudi Mental Health Surveillance system and an ongoing project aimed at measuring national mental health literacy (15, 16). Additionally, the NCMH is planning to monitor the stigma associated with mental illness within the Saudi general population, which is directly related to the research project presented in this article.

This study aims to adapt and validate the Generic Scale for Public Health Surveillance of Mental Illness Associated Stigma (MIAS) (17) for Arabic-speaking individuals within the general population of Saudi Arabia. This includes translation, assessing the psychometric properties, establishing reliability, and conducting a test-retest reliability.

Methods

Selection of a stigma instrument

The study criteria for selecting a tool were based on the need to choose an instrument that measures attitudes toward mental illnesses. We prioritized tools that are concise and have been used nationally, ensuring their validation for international comparisons.

Design

This study entailed translating the original English version of the MIAS into a culturally and linguistically suitable Arabic version specific to Saudi Arabia. This adaptation was then subjected to a validation study, utilizing two separate cross-sectional sets of self-reported data collected from samples that completed the translated scale.

Measures

Demographic variables

Participants in the study were asked to provide basic demographic details such as their age, sex, and level of education.

MIAS scale

Afterward the participants were instructed to complete the MIAS, which encompasses 11 items. Respondents were asked to indicate level of agreement on a 5-point Likert scale, where 1 = strongly disagree, and 5 = strongly agree. The MIAS score varies from 11 to 55, where a higher score signifies higher stigma (17). Note that items 5, 6, 8, 9, 10, and 11 are reversed. Table 1 shows the MIAS items.

Translation of the MIAS and scale adaptation

In compliance with the recommendations made by Sousa et al. (18) for culturally transferring healthcare research tools, we started the translation process with the forward-backward method, and subsequently had our preliminary draft reviewed and approved by a board of mental health and research professionals. The initial pre-final Arabic version was then test-piloted with a group of 10 individuals. Participants were instructed to review the scale's directions and elements utilizing a binary clarity assessment (clear or unclear). If any aspect of the tool was deemed unclear, feedback and suggestions for revisions were actively solicited from the participants to enhance clarity. Any component that was identified as unclear by a minimum of 20% of the sample required further scrutiny (18). Our results showed that all the 11 items reached a consensus level of 80% or more.

Participants and data collection

Sample 1: test re-test reliability

The accepted norm for sample size in test-retest reliability studies, as evidenced by existing literature, suggests a participant count ranging from 20 to 40 (19, 20). In June 2023, an electronic questionnaire was presented to a randomly chosen group of 55 Arabic-speaking adults from the general population of Saudi Arabia. The ZDataCloud data collection system was employed to automatically determine eligibility (21, 22), which was based on being 18 years or older and using Arabic as a primary language. Qualified individuals from our participant database were notified via SMS to complete the survey through unique survey links. The decision to administer online SMS was driven by several factors. Online surveys provide accessibility and convenience, crucial for sensitive topics like attitude toward mental illness, ensuring higher participation rates and more honest responses. The anonymity of online responses is particularly vital in attitude toward mental illness research, as it encourages openness and honesty among participants, who might otherwise feel uncomfortable discussing such topics in person. Additionally, the online format allows for a wider demographic reach, essential for capturing diverse perspectives on attitude toward mental illness. This method also aligns with current social distancing norms, ensuring participant safety amidst ongoing health concerns. Up to three reminders were sent to each prospective participant within a 1 week period. It was imperative that participants fully complete all questions prior to submitting the questionnaire. The ZDataCloud system, equipped with integrated eligibility and sampling modules, was employed to maintain sample eligibility, manage distribution, avoid sampling bias linked to human error, and ensure data quality and integrity. Each response had to be fully answered for successful submission to the database. All gathered data were coded and securely housed within the ZDataCloud database.

Sample 2: structural validity

The suggested sample size for testing structural validity typically falls between a minimum of 2 and a maximum of 20 individuals per item. Given the presence of 11 items in the MIAS, the lower limit for our sample size was calculated to be 165 participants, based on the requirement of at least 15 participants per item (21, 23).

In June 2023, we selected a total of 300 Arabic-speaking adults from Saudi Arabia randomly to complete the digital questionnaire, considering potential non-responses. The completion of all questions was mandatory prior to submitting the questionnaire. The criteria for eligibility and the recruitment approach mirrored those implemented during the test-retest phase.

Data analysis

We employed descriptive statistics to provide an overview of the sample and the corresponding MIAS scores. The internal consistency of the instrument was evaluated using Cronbach's α, while the test-retest reliability was gauged via the Intraclass Correlation Coefficient (ICC). The previously identified 2-factor structure from the original study was evaluated using Confirmatory factor analysis (CFA).

The appropriateness of conducting factor analysis was determined through an examination of the correlation amongst scale items, utilizing the Kaiser–Meyer–Olkin measure of sampling adequacy (with non-significant results indicating the data's suitability for factor analysis) and the Bartlett test (significant results indicating data appropriateness for factor analysis) (23, 24).

In order to scrutinize the factorial structure of the scales, an exploratory factor analysis was executed using the principal factor extraction technique. The oblimin rotation, principal axis

TABLE 1 The MIAS items.

Item 1 (St1)	I believe a person with mental illness is a danger to others
Item 2 (St2)	I believe a person with mental illness is unpredictable
Item 3 (St3)	I believe a person with mental illness is hard to talk with
Item 4 (St4)	I believe a person with mental illness has only himself/herself to blame for his/her condition
Item 5 (St5)	I believe a person with mental illness would improve if given treatment and support
Item 6 (St6)	I believe a person with mental illness feels the way we all do at times
Item 7 (St7)	I believe a person with mental illness could pull himself/herself together if he/she wanted
Item 8 (St8)	I believe a person with mental illness can eventually recover
Item 9 (St9)	I believe a person with mental illness can be as successful at work as others
Item 10 (St10)	Treatment can help people with mental illness lead normal lives
Item 11 (St11)	People are generally caring and sympathetic to people with mental illness

TABLE 2 Demographics of sample.

Social-demographics	*n* (%)
Sample 1	
Age (Mean) (range 18–75)	36.1 years
Gender	
Male	19 (50.0%)
Female	19 (50.0%)
Sample 2	
Age (Mean) (range 18–75)	36.5 years
Gender	
Male	89 (47.1%)
Female	100 (52.9%)
Education	
Less than bachelor	76 (40.2%)
Bachelor and above	113 (59.8%)

TABLE 3 Confirmatory factor analysis (CFA) with a two-factor solution based on the original study.

Factor	Indicator/Item	Estimate	SE	*Z*	*P*	Standard estimate
Negative stereotypes	St1	0.749	0.1240	6.04	<0.001	0.573
Negative stereotypes	St2	0.738	0.1159	6.37	<0.001	0.573
Negative stereotypes	St3	0.842	0.1220	6.91	<0.001	0.693
Negative stereotypes	St4	0.388	0.1075	3.61	<0.001	0.350
Negative stereotypes	St7	−0.380	0.1309	−2.90	0.004	−0.276
Recovery and Outcomes	St5	0.815	0.0828	9.84	<0.001	0.692
Recovery and Outcomes	St6	0.588	0.1075	5.47	<0.001	0.420
Recovery and Outcomes	St8	0.993	0.0800	12.41	<0.001	0.832
Recovery and Outcomes	St9	0.723	0.0918	7.88	<0.001	0.576
Recovery and Outcomes	St10	0.898	0.0890	10.08	<0.001	0.703

extraction, and parallel analysis methods were employed to derive coherent factorial structures and facilitate a comparison with the original study.

Results

Study samples

Sample 1

Of the 38 participants in sample 1 (test-retest reliability), 19 (50.0%) were male and the mean age was 36.1 years (range 18–75). In the analysis of test-retest reliability, the ICC was $\alpha = 0.631$.

Sample 2

The dataset comprises 189 subjects. The sample is relatively balanced, with 100 females (52.9%) and 89 males (47.1%). Respondents range in age from 18 to 70 years, with a mean age of 36.5 (SD = 13.1). Regarding the level of education, 59.8% hold a bachelor's degree or above and 40.2% have less than bachelor's degree. All participants completed the 11-item scale, thereby leaving no missing data. The overall scale consistency is good (Cronbach's alpha: 0.663). Table 2 showed the Social-Demographics of sample 2.

Validation results

The original validation study (17) posited that the instrument could adhere to a two-factor or three-factor structure. However, they favored the two-factor structure. The authors of the original study reported that the two factors explain 32% of the common variance among items. The structure has a Cronbach's alpha of 0.69 for Factor 1 (labeled Negative Stereotypes) and 0.66 for Factor 2 (labeled Recovery and Outcomes).

A Confirmatory factor analysis (CFA) was performed following the original validation study with two factors. The CFA model does not show a good fit with CFI = 0.685, TLI = 0.583, RMSEA = 0.156. One item (item 7) in factor 1 has negative loading (Table 3). This suggests that the factor structure might differ or possibly be unidimensional.

TABLE 4 EFA results.

Item	Factor			Uniqueness
	1	2	3	
St1		0.520		0.578
St2		0.493		0.634
St3		0.755		0.435
St4	0.444	0.452		0.641
St5	0.684			0.490
St6			0.537	0.592
St7			−0.784	0.350
St8	0.731			0.372
St9			0.492	0.525
St10	0.785			0.397
St11	0.428			0.798

To identify a suitable dimensional structure in the data, exploratory factor analysis (EFA) was performed. All 11 items were included into EFA model. Sample size is sufficient for EFA based on Kaiser-Meyer-Olkin test (value 0.755). Bartlett's test of sphericity $[\chi^2 (55) = 575, p < 0.001]$ is statistically significant, which further confirms that items correlate with each other to the sufficient degree for EFA to be performed.

The initial EFA model (oblimin rotation, principal axis extraction, parallel analysis) has 3 factors (Table 4). However, there is one item (item #4) that shows cross-loading between factor 1 and 2. Only the first two factors have eigenvalue > 1 (eigenvalue for factor 3 is 0.612). Three-factor model explains 47.2% of common variance and has a reasonably acceptable fit (TLI = 0.934, RMSEA = 0.057). Item 7 also have a negative loading in factor 3 (Figure 1).

According to Defne et al. (25), the optimal number of components for the model was determined using a scree plot (Figure 2), which suggested a clear 'elbow' at the third component, indicating that additional factors contributed minimally to the explanation of variance within the data.

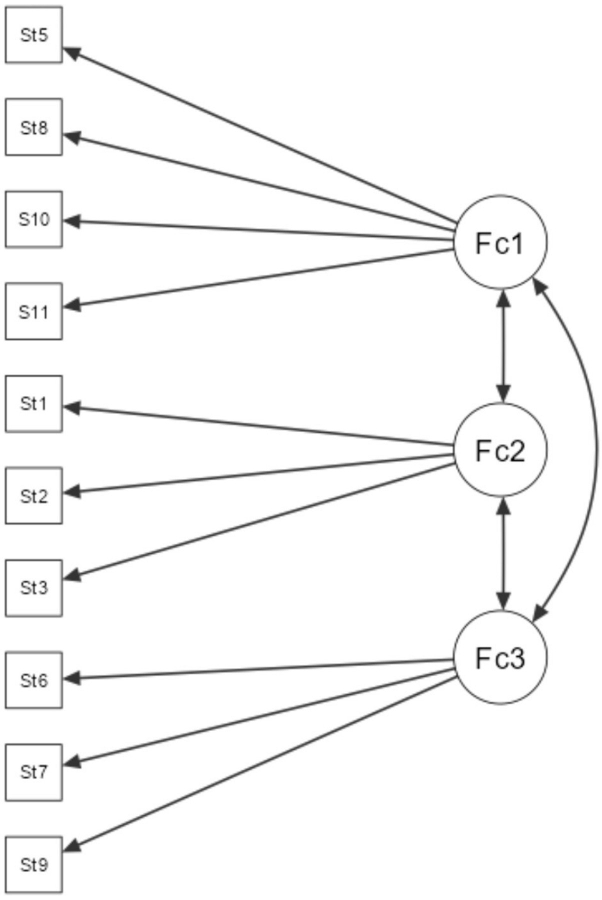

FIGURE 1
Exploratory factor analysis model.

To determine three-factor model has a better fit, separate CFA model was built. Three-factor CFA model (Table 5) has a reasonably good fit (CFI = 0.890, TLI = 0.845, RMSEA = 0.094) and all items having significant loadings into the factors. Item 4 was excluded from the model as it does not fit with any of the three factors. Factor 1 includes 4 items (5, 8, 10, 11), has reliability of Cronbach's $\alpha = 0.77$ and can be labeled as Outcomes. Factor 2 includes 3 items (1, 2, 3), has reliability of Cronbach's $\alpha = 0.65$ and can be labeled as Negative Stereotypes. Factor 3 includes 3 items (6, 7, 9), but item 7 has negative coefficient. This is reflected with negative Cronbach's $\alpha = -0.87$. Factor 3 can be labeled as Recovery. Significant strong positive correlation was found between factor 1 and factor 3, $r = 0.659$, $p < 0.001$. Factor 2 does not have significant correlation with factors 1 or 3. Nevertheless, it appears that three-factor model has a better fit and thus better reflects the dimensional structure of the instrument.

Discussion

Results summary

This study focused on translating, validating, and psychometrically testing the Arabic version of the MIAS Scale within the Saudi Arabian general population. The Arabic MIAS exhibited good internal consistency, acceptable test-retest reliability, and produced a three-factor model. Each of the three factors showed good internal consistency. Our factor categorization is similar to that of the original study. However, unlike the original study which combined the "outcomes" and "recovery" factors into one, our study distinctly separates these two factors. Item 4 "I believe a person with mental illness has only himself/herself to blame for his/her condition" was excluded from the model since it didn't align with any of the three factors. Despite having a negative coefficient in the model, item 7 suggests a need for reverse coding. However, the logic behind the item implies that stigma increases if the participant strongly agrees with the statement: "I believe a person with mental illness could pull himself/herself together if he/she wanted."

Results interpretations

In terms of the internal consistency of the Arabic MIAS compared to the original English version the results are closely similar for of the sub-factors. It's noteworthy that the original MIAS scale study did not provide any test-retest reliability data or overall scale reliability which limited our comparison.

In considering the issues with items 4 and 7, it appears to be more a cultural and knowledge-based challenge in interpreting the meaning of the item, rather than a translation issue. Upon closer examination of item 4, the attribution of mental health conditions to the individual, and the view of such conditions as being subject to personal blame, can greatly vary across cultures, societies, and even within communities.

In the case of Saudi Arabia, which is largely a collectivist and spiritual society, several scientific studies exploring attitudes toward mental health have found these attitudes to be varied and complex. Some research does suggest that beliefs related to spiritual or supernatural causes, personal weakness, and divine punishment do exist within the society (26–28).

With the relatively low level of mental health awareness in Saudi Arabia, this interpretation is further complicated. For instance, one study found that 67.3% of participants believed depression was caused by a lack of faith, and 45.5% believed depression was caused by "the evil eye" or black magic. Consequently, this item could be interpreted bidirectionally, depending on individual beliefs, rather than as a general attitude (29).

A similar argument could be applied to item 7. Although this item fits within the model, it has been negatively interpreted by the participants. This item, too, pertains to the individual's responsibility for their mental health conditions. It appears that due to the cultural belief that an individual is solely responsible for their mental health condition, the item was logically linked to the "recovery" factor in the analysis, rather than the intended "Negative Stereotypes" factor, which also explains the negative coefficient.

This study is limited by several factors. First, there is a lack of other validated scales potentially usable for routine monitoring of stigma in population surveys. Second, due to the non-condition specific nature of this scale, no specifications regarding the type of mental illness were made (e.g., a person with dysthymia vs. a person with schizophrenia). As such, respondents were expected to self-define the construct of mental illness (30, 31). In theory,

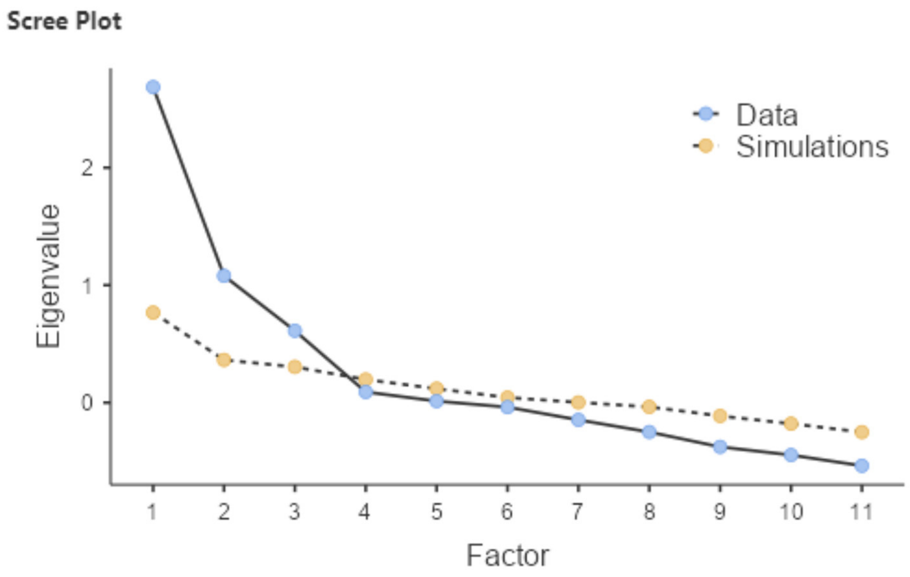

FIGURE 2
Scree plot.

TABLE 5 Confirmatory factor analysis with 3 factors (following EFA).

Factor	Indicator/Item	Estimate	SE	Z	p	Standard estimate
Factor 1: Outcomes	St5	0.827	0.0819	10.09	<0.001	0.702
Factor 1: Outcomes	St8	0.978	0.0797	12.27	<0.001	0.819
Factor 1: Outcomes	St10	0.925	0.0884	10.46	<0.001	0.724
Factor 1: Outcomes	St11	0.619	0.1017	6.09	<0.001	0.462
Factor 2: Negative Stereotypes	St1	0.859	0.1490	5.76	<0.001	0.657
Factor 2: Negative Stereotypes	St2	0.817	0.1404	5.82	<0.001	0.635
Factor 2: Negative Stereotypes	St3	0.651	0.1156	5.63	<0.001	0.536
Factor 3: Recovery	St6	0.757	0.1125	6.73	<0.001	0.541
Factor 3: Recovery	St7	−0.898	0.1094	−8.21	<0.001	−0.652
Factor 3: Recovery	St9	0.946	0.0965	9.81	<0.001	0.754

respondents' attitudes can vary based on their beliefs and feelings about the cause, nature, treatment, and prognosis of mental illness (32).

On the positive side, the translated scale demonstrated good validity. This contributes to the literature on non-condition-specific tools that can be used in assessing public attitudes toward mental health stigma, providing a broad understanding of societal attitudes and beliefs about mental illnesses. Further research is still needed to develop and improve such tools, enhancing their validity and cross-cultural applicability, to facilitate comparisons across countries and cultures.

Conclusions

Our study supports the validity and reliability of the Arabic MIAS Scale among the Saudi population. However, cultural interpretation challenges related to personal blame and responsibility for mental health conditions emerged. The diversity of attitudes and beliefs about mental health in Saudi Arabia, compounded by low mental health awareness, further complexified the interpretation. Future research should focus on enhancing the validity of non-condition-specific tools and their cross-cultural applicability to advance understanding of mental health stigma across diverse contexts.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by the Ethics Committee of the Sharik Association for Health Research. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

NB: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Software, Supervision, Validation, Writing – original draft, Writing – review & editing. NA: Data curation, Funding acquisition, Project administration, Supervision, Validation, Writing – review & editing. SA-L: Conceptualization, Writing – review & editing. MA: Conceptualization, Writing – review & editing. SS: Conceptualization, Writing – review & editing. HA: Conceptualization, Writing – review & editing. AS: Validation, Writing – review & editing. RA-D: Writing – review & editing. AA: Writing – review & editing.

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Conflict of interest

AS was employed by the UZIK Consulting Inc.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Cultural adaptation of INDIGO mental health stigma reduction interventions using an ecological validity model in north India

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Background: The International Study of Discrimination and Stigma Outcomes (INDIGO) Partnership is a multi-country international research program in seven sites across five low- and middle-income countries (LMICs) in Africa and Asia to develop, contextually adapt mental health stigma reduction interventions and pilot these among a variety of target populations. The aim of this paper is to report on the process of culturally adapting these interventions in India using an established framework.

Methods: As part of this larger program, we have contextualized and implemented these interventions from March 2022 to August 2023 in a site in north India. The Ecological Validity Model (EVM) was used to guide the adaptation and contextualization process comprising eight dimensions.

Findings: Six dimensions of the Ecological Validity Model were adapted, namely language, persons, metaphors, content, methods, and context; and two dimensions, namely concepts and goals, were retained.

Conclusion: Stigma reduction strategies with varied target groups, based on culturally appropriate adaptations, are more likely to be acceptable to the stakeholders involved in the intervention, and to be effective in terms of the program impact.

KEYWORDS

indigo, cultural adaptation, mental health, stigma reduction, discrimination, India

1 Introduction

Stigma and discrimination towards people with mental health conditions are universally reported across the world (1). People with mental health conditions experience stigma, prejudice, and discrimination from a variety of different sources and settings. Such stigma can come, for example, from the public and local communities where people with mental health conditions live (2, 3), from primary care workers and the healthcare system (4, 5), or from specialist mental health professionals (6). Stigma has wide-ranging consequences on people with mental health conditions, who have described stigma as worse than the mental health condition itself (1, 7). Stigma from different sources can have a range of deleterious impacts on people with mental health conditions, who can be excluded from social participation, with negative impacts on wellbeing, reduced employment opportunities, greater risk of poverty, difficulties in maintaining personal relationships (8), and limited access to health care because of barriers to help seeking (9, 10).

There is limited research conducted in low-and middle-income countries (LMICs) that evaluates the effectiveness of interventions to reduce mental health stigma and discrimination among groups that have the potential to stigmatize (11–14). There are studies in some of these countries that have shown an increase in the uptake of mental health services following an anti-stigma and awareness campaign (15, 16). There is also emerging evidence that basic mental health services can be provided by trained non-specialists (e.g., primary care providers and community health workers, peers, and other lay persons) in LMICs (17, 18). However, there is an absence of studies on anti-stigma interventions that target mental health professionals in LMICs (12), with relevant studies mostly taking place in high-income countries (19, 20). Recent studies and systematic reviews examining interventions to reduce mental health stigma and discrimination have shown that there is an increasing number of effective interventions being reported from LMICs (11–14). There is more evidence on interventions to change mental health knowledge, but fewer that addresses the critical areas of attitudes and behavior (11, 12). Extant evidence on stigma interventions has shown the effectiveness of social contact-based interventions in reducing mental health stigma, with regard to changes in discriminatory behaviors across different target groups (1). However, this evidence is less robust from LMICs (4, 11, 21) where the cultural contexts and stigmatizing groups can be very diverse.

The ways in which stigma and discrimination are expressed by different groups at the community, primary healthcare, and mental health system levels, as well as how they are experienced by people with mental health conditions, varies a great deal across countries and cultures (22–25). Dominant local beliefs about mental health conditions co-exist along with western biomedical models in LMICs with a pluralistic health system (26, 27). Labels, stereotypes, and causal attributions attached to mental health conditions vary considerably across different cultures (22, 28), and may mediate the extent to which people with mental health conditions are stigmatized and seek treatment (29). A study conducted in North India showed that the most commonly used labels for people with severe mental illness were *“Aalsi”* (lazy), *“sustt”* (lethargic), *“paagal”* (mad), and *“darpok”* (coward). About one third of the participants with these illnesses reported experiencing these labels were significantly associated with discontinuing treatment or a desire to do so (29). Despite such cultural variations, promising research shows that evidence-based psychological interventions are effective for the treatment of mental health conditions among diverse populations (30, 31). A recent review that examined incorporating cultural elements into anti-stigma programs in LMICs found that only a fifth of the studies considered cultural values, meanings, and practices in their interventions with healthcare professionals, community members and people with lived experiences (32).

In this context, the International Study of Discrimination and Stigma Outcomes (INDIGO) Partnership is a multi-country international research program in seven sites across five LMICs in Africa and Asia to develop, test and contextually adapt mental health stigma reduction interventions among a variety of target populations (33). The three interventions that are being piloted target community members and community health workers (CHWs) (Indigo-Local) (34), primary care providers (PCPs) (Indigo-Primary) (35), and mental health professionals (Indigo-READ) (36). As part of this larger program, we have contextualized and implemented these interventions in a site in north India. The aim of this paper is to report the process of culturally adapting these interventions using an established framework.

2 Methods

2.1 Study implementation and design

Implementation of the Indigo-Primary intervention among PCPs was the first of the three interventions to be implemented. This included two site staff (MD and SK), i.e. researchers involved in mental health projects, being trained in the RESHAPE (REducing Stigma among HealthcAre ProvidErs) manual (35, 37), a social-contact based stigma reduction intervention, in which five mental health service users (MHSUs) and two caregivers were trained in the photovoice technique over a period of two-and-a-half months. This is a participatory photography narrative technique to visually develop and narrate recovery stories and testimonials (38). The intervention included training primary health care providers on mental health where social contact of photovoice trained MHSUs was integrated. Two health workers were trained in the WHO mhGAP-Intervention Guide (depression and suicide modules) (39) where the two MHSUs and their caregivers narrated their recovery stories using the photovoice technique, along with a model aspirational figure (primary healthcare facility doctor) who had experience of managing people with common mental disorders. The aspirational figure shared her reflections and learnings from providing treatment for common mental disorders in a primary health care setting.

The Indigo-Local intervention comprised of a community-based, multi-component, public awareness-raising activities designed to reduce stigma and discrimination and to increase referrals of people with mental health conditions. Implementation of the intervention among community members and CHWs involved organizing two stakeholder meetings where a total of more than 50 participants were present, comprising local administrative officials of different political parties, schoolteachers, CHWs, health workers, and community members. Eleven CHWs and two MHSUs participated in the intervention trainings. A media campaign for this study was rolled out in the community using printed materials and lived experience videos developed as a part of the SMART mental health study, where a large anti-stigma campaign was implemented in a similar setting (40). This campaign as a part of INDIGO Local, was implemented for three months and covered 1185 community members with majority (70%) being women.

The Indigo-READ intervention assesses the feasibility, potential effectiveness and costs of responding to experienced and anticipated discrimination training for health professionals working in mental health care. This intervention included in-person training of six mental health professionals of the district mental health program comprising of two psychiatric nurses, one psychologist, one psychiatrist, a data entry personnel, and an intern. In addition to a service user who presented her personal testimony as an expert by experience, a short video of a person with lived experience was screened in the training.

All three interventions employed an uncontrolled design with evaluations pre-and post-intervention, and a later follow up point at three, six- or 12-months' time. These are small scale feasibility studies that test a particular proof-of-principle largely employing mixed methods approaches (41). Box 1 describes the different program details and key components of each of the Indigo interventions. Table 1 provides further details on the methodological aspects of each intervention in the North Indian site. All the three interventions have been completed and there is a plan to bring out separate site-specific publication following the main and combined publication of each of these interventions by the work package leads.

2.2 Setting

The interventions were conducted in and around two Urban Primary Health Centres (UPHCs) of Atmadpur and Mewla Maharajpur, covering the areas of Rajeev nagar, Harkesh nagar, Santosh nagar, Dheeraj nagar part 1, Dheeraj nagar part 2, under the former UPHC and Mewla Maharajpur, Ghandhi colony, Fatehpur Chandela, under the latter UPHC. These UPHCs fall under the district of Faridabad, Haryana state where the intervention with mental health professionals took place at the district hospital. The UPHCs and district hospital were chosen as they were near the central office and

BOX 1 Program details and key components of Indigo interventions.

Indigo-Local

- **Aim**- to develop, implement, and evaluate a community-based, multi-component, public awareness-raising intervention designed to reduce stigma and discrimination and to increase referrals of people with mental health conditions for assessment and treatment.
- **Key components**- stakeholder group workshop; a stepped training programme of CHWs and MHSUs with repeated supervision and booster sessions; awareness raising activities in the community; and a media campaign.
- Social contact and service user involvement are instrumental to all components.
- **Evaluation**- mixed-methods pre-post design; quantitative assessment of stigma outcomes measuring knowledge, attitudes, and behaviour; quantitative evaluation of mental health service utilization rates; qualitative assessment of effectiveness and impact of the intervention; process evaluation; implementation evaluation; and evaluation of implementation costs.
- **Sample size**- 11-86 CHWS, 3-5 MHSUs, and 5-20 stakeholders. Participants were sampled purposively and based on feasibility and availability of local resources and size of the site.

Indigo-Primary

- **Aim**- to adapt and evaluate cross-cultural feasibility and acceptability of a social contact-based primary healthcare intervention.
- **Key components**- collaboration MHSUs with lived experience of mental health conditions, their family members, and aspirational figures (PCPs who have demonstrated high motivation to integrate mental health services). MHSUs and their family members are trained in a participatory technique, PhotoVoice, to visually depict and narrate recovery stories. Aspirational figures conduct myth busting exercises and share their experiences treating MHSUs.
- **Evaluation**- uncontrolled before-after study design; outcomes among PCPs will include stigma knowledge, explicit and implicit attitudes, and mental healthcare competencies; qualitative interviews with MHSUs, family members, and aspirational figures, PhotoVoice trainers, mental health specialists co-leading the primary care trainings, and PCPs receiving mental health training; generate evidence regarding feasibility, acceptability, recruitment, retention, fidelity, safety, and usefulness of the intervention.
- **Sample size**- 6-20 MHSUs, 1-8 aspirational figure, and 2-36 PCPs. The sample size were determined by the number of participants available and feasibility to include them in the study.

Indigo-READ

- **Aim**- assess feasibility, potential effectiveness, and costs of Responding to Experienced and Anticipated Discrimination training for health professionals working in mental health care.
- **Key components**- training draws upon evidence bases for stigma reduction, health advocacy and medical education and is tailored to sites through situational analyses; content, delivery methods and intensity were agreed upon through a consensus exercise with site research teams; delivered to health professionals working in mental health care.
- **Evaluation**- uncontrolled pre-post mixed methods feasibility study; baseline data collection; outcome measures at post-training and 3 months post-baseline, followed by qualitative data collection; fidelity rated during intervention delivery; data on training costs; qualitative data to identify feedback about training methods and content, including the implementability of the knowledge and skills learned; pooled and site-specific training costs per trainee and per session.
- **Sample size**- 4-30 mental health professionals. As this is a feasibility study without any control group the sample size is not designed to determine effectiveness.

TABLE 1 Study design, sample size, follow-up evaluations and methods for Indigo interventions in North India.

Interventions (Work Package)	Study design	Sample characteristics and size	Follow-up evaluations and methods
Reducing stigma and improving access to care for people with mental health conditions in the community (Indigo-Local)	Feasibility pilot	11 Accredited Social Health Activists (ASHAs); 3 service users.	Quantitative- pre, post, 6 and 12 months Qualitative- 6 months
Contact-based intervention to reduce mental health related stigma in primary healthcare setting (Indigo-Primary)	Uncontrolled before-after proof-of-principle	5 service user, 3 primary care provider (PCP)	Quantitative- pre, post, 3 and 6 months Qualitative- 6 months
Mental health professionals responding to experienced and anticipated mental health related discrimination (Indigo-READ)	Uncontrolled pre-post feasibility	5 mental health professionals	Quantitative- pre, post and 3 months Qualitative- post and 3 months

field offices of the implementing site of Delhi, and we had a well-established relationship with the state and district health departments. Study participants across all interventions were selected using a qualitative technique akin to convenience sampling as they were easily accessible, and such a technique is generally applied for pilot testing (41).

The activities across all the three anti-stigma interventions started in July 2022 with the integrated training of PCPs beginning first. However, the preparation for this intervention started much before in March 2022 with the training of service users on the photovoice technique. All intervention activities have been completed with a final quantitative evaluation of CHWs done in late August 2023.

2.3 Cultural adaptation framework

Each of the Indigo interventions went through a process of adaption. The adaptations were specifically made keeping in mind the local cultural context in which the interventions were implemented. The Ecological Validity Model (42) was used to document the adaptation and contextualization process. This documentation took place either during the preparatory phase of planning the interventions or during and after certain intervention activities were completed. The EVM outlines eight contextualization dimensions, with operational definitions provided in Table 2.

Across each of these dimensions six domains of contextualization were recorded: 1) original content changed, 2) pages/location in the intervention manual or materials, 3) description of contextualization, 4) rationale of change and what it would accomplish, 5) evidence for change, and 6) the source of this evidence. Characteristics of team members who conducted the contextualization procedure were also recorded. This included indicating relevant educational qualifications and work experience of the team members, and any other relevant demographic information. Additionally, it was critically important to mention whether team members spoke the local language and had experience working in settings where the intervention was rolled out.

TABLE 2 Operational definitions of EVM dimensions.

Dimensions	Definitions
1. Concepts	Concepts refer to how the intervention material is thought of and communicated to the facilitators, intervention participants, community members, and other stakeholders. The programs' and the facilitators' credibility may be reduced if the communication of concepts and the concepts themselves do not match the local culture.
2. Methods	Methods are the procedures followed to achieve treatment goals. These methods and procedures should be congruent with the participants' culture and use of language.
3. Goals	Goals are the agreement between participants and facilitator in what participants would like to achieve during the course of the intervention. These goals must be realistic and fit with the participants' values and personal motivations.
4. Context	Context refers to the participants' economic, social, political and cultural environment. This should look beyond just the participant as an individual and focus on outside factors, such as socialization, discrimination, and family history, that could influence the intervention.
5. Content	The knowledge, values, customs, and traditions shared by the participants should be integrated into all elements of the intervention. This can be seen as a starting point for culturally adapting the recruitment process, assessments, and the treatment itself.
6. Metaphors	Culturally appropriate symbols or concepts should be embedded within the intervention that support participants in absorbing the intervention's core mechanisms of action. Metaphors used may be pictorial, idioms, commonly used phrases or item and symbols.
7. Persons	A culturally appropriate intervention must consider the role of ethnicity, race, gender, class and other relevant social constructs in the relationship between the participants and facilitators. This relationship should respect expectations and limitations that are reflective of the local culture.
8. Language	Language is inherently attached to culture and is related to the expression of emotional experiences. The intervention should be in the language most comfortable and accessible to the participants and should also use appropriate terminology based on the education levels of the facilitators and participants.

2.4 Characteristics of team conducting cultural adaptation and contextualization

A total of three staff members were involved in the cultural adaptation process with diverse educational qualifications, experience, genders, and capability of speaking in the local language of study participants. The educational qualifications of the team members varied from Masters to Post-doctoral level in social work or public health. Experience of working in the field of mental health also varied among the team members between 5-20 years. All the members involved in the cultural adaptation process had varying capabilities of reading, writing, and speaking the local language of study participants. Two of the team members (SK and SC) could read, write, and speak the local language and were involved in the translation of training materials from English to Hindi and conducting the training sessions.[1] MD adapted the training materials as per the need and context of the interventions that were provided in English by the work package leads. These were then handed over to SC who was primarily involved in translating the materials to Hindi. This was then cross checked and finalized by SK. If any disagreements on the translation arose, then it was consensually decided by both SC and SK. One team member (MD) who could speak the local language was involved in conducting the training sessions.[1] All team members had the experience of directly engaging with MHSUs from an ongoing project (40, 43).

3 Results

3.1 Cultural adaptation and contextualization

The processes of culturally adapting the interventions are documented and presented in a matrix under each contextual dimension and across the different domains (Table 3). All materials used in the training of MHSUs and CHWs that were presented in the form of power point slides were originally developed in English and then translated into Hindi (the local vernacular language spoken in the area). These changes have been indicated in the pages of the original training manuals and the adapted manuals or power point slides. Training materials for mental health professionals (MHPs) were however retained in the original English language and used as such, though much of the discussion around the content of the training were done in the local Hindi language.

3.2 Language

The adaptation of *language* in the training and intervention materials included terms used for mental health and mental illness, severe mental disorders, depression and anxiety, stigma, and discrimination. The translated Hindi terms used for these are further described in Table 3. The contextualization process considered previous research that was conducted in similar geographical locations and cultural context (40, 45) to where the Indigo interventions were implemented. Additionally, MHSUs were asked to elucidate derogatory terms used for people with mental health conditions that either they have been referred to or have heard somewhere. These terms were *"besahoor"* (creep), *"chatka huaa"* (cracked), *"paagal"* (mad), *"nasamaj"* (foolish), *"budhiheen"* (brainless), mental, *"ganwar"* (uneducated), *"bewakoof"* (idiot). It was necessary to bring out culturally dominant and derogatory stereotypes that MHSUs experienced to provide alternative destigmatizing terms to challenge these. These terms were adapted to the local context as they are more relatable to ASHAs and MHSUs and convey the desired meaning in the local context.

3.3 Persons

Participants who were recruited for the interventions were CHWs known as Accredited Social Health Activists (ASHAs) in India. As this was a pilot intervention, only few ASHAs who worked in select areas serviced by two UPHCs were included. ASHAs are an all women cadre of primary health workers and act as a link between the community and the health system (40, 46). The project team had experience working with ASHAs for a considerable period in mental health projects that also utilized an anti-stigma campaign (16, 40). The research team had experience working with MHSUs (40, 43). MHSUs with depression, anxiety, and suicide risk who were receiving treatment from either a public or private facility and those from an ongoing project were included in the interventions. Doctors from the UPHCs and mental health professionals who are a part of the District Mental Health Program (DMHP) at the district hospital were included in the trainings.

3.4 Metaphors

Culturally adapted materials in a lay local language that were used in an ongoing mental health study were used for the training of CHWs and MHSUs to orient them on mental health, types of mental disorders, causes of mental disorders, identifying mental disorders, treatment of common mental disorders (like depression, anxiety and suicide risk), ways to manage people with CMDs and ways to overcome stigma (45, 47). As part of a media campaign for the intervention with community members (Indigo Local), we used existing culturally adapted materials like a flipbook and a video of a person with lived experience. The flipbook included simple illustrations of what CMDs are and what can be done to overcome and live with CMDs. In the training with MHPs, we used materials in English as training participants and trainers spoke both English and Hindi. However, the discussions during the training were done in the local language, where for example local metaphors were used to explain the idea of empathy in a culturally relevant way by one of the participants.

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TABLE 3 Cultural adaptation of Indigo study interventions using an ecological validity model matrix.

Adaptation Dimension	Original Content	Pages/Location	Contextualization Strategy	Rationale	Evidence	Source
Language	• Terms used for mental health and mental illness, severe mental disorders, depression and anxiety, stigma, discrimination and CHWs	• Sections in original training materials • Adapted training manual • Adapted PPT training slides	Terms adapted: • Mental health= *"mansik swasth"* • Mental illness= *"mansik rog"* • Severe mental disorders= *"gambhir mansik rog"* • Depression= *"udasi"* • Anxiety= *"ghabrahat"* • Stigma=*"kalank"* • Discrimination= *"bhedbhaw"* • CHWs= ASHAs	• These terms are locally relatable to study participants and conveys the intended meaning in the north Indian context	• Situational analysis in north Indian site • Cultural adaptation work of Indigo study • Literature review	• Kaur et al., 2023 (44) • Internal documents of Indigo study • Daniel et al., 2023 (45)
People	• Selection of CHWs, MHSUs, PCP, and MHPs	• Sections in original training materials • Adapted training manual	• Recruited ASHAs who work in areas serviced by two UPHCs • Doctors from these UPHCs • MHSUs with depression, anxiety and suicide risk who were women and from local or neighboring areas • MHPs (psychiatrist, psychologist, community, and psychiatric nurse) who work in DMHP and are posted at district hospital	• The site team had experience working with ASHAs • Some MHSUs was part of an existing project • There is a dearth of MHPs in district • Team of MHPs of DMHP, some of whom we have been working with in other mental health projects were available and accessible	• Situational analysis in north Indian site • Literature review	• Kaur et al., 2023 (44) • Internal documents of Indigo study. • Daniel et al., 2021 (40) • Daniel et al., 2023 (45)
Metaphors	• Introduction to mental health and mental illness	• Sections in original training materials • Adapted training manual • Adapted PPT training slides	• An in-house developed culturally adapted IEC material in lay local language with illustrations to orient CHWs and MHSUs was used • Similar materials were used for media campaign	• There were readily available materials adapted to the local context with simple and culturally relevant illustrations	• Literature review	• Kaur et al., 2021 (12) • Daniel et al., 2021 (40) • Daniel et al., 2023 (45)
Content	• Human Rights and mental illness • Service user rights and movement • Common myths surrounding mental illness • Aspirational figure presentation • Case studies	• Sections in original training materials • Adapted training manual • Adapted PPT training slides	• Case studies were adapted with changes in names and places, and existing context of the district health system • An example of successfully treating a person with depression was included • Salient points of Mental Health Care Act, 2017, and Mental health insurance policy relevant to MHSUs in the Indian context were incorporated • Adapted to include four common myths around mental illness, e.g., mental illness is caused by black magic or by evil spirits and were used during the trainings	• These adaptations are found to be culturally appropriate to training participants which they can relate to in their present context and discuss these more meaningfully • Adaptations of mental health policies are appropriate to the Indian context and is critical in discussions around MHSUs rights and policies • Positive stories would inspire other participants as they can relate with a real-life example of a MHSU being treated	• Situational analysis in north Indian site • Cultural adaptation work of Indigo study • Literature review	Kaur et al., 2023 (44) and internal documents of Indigo study; Daniel et al., 2023 (45)

(Continued)

TABLE 3 Continued

Adaptation Dimension	Original Content	Pages/Location	Contextualization Strategy	Rationale	Evidence	Source
Methods	• Duration and no. of sessions for study participants' training program	• Sections in original training materials • Adapted training manual • Adapted PPT training slides	• Training timings were reduced, and the no. of sessions were also truncated to accommodate schedule of participants • For e.g., all 5 modules were covered for the MHPs' training, but it was reduced from 6:30 to 3:15 hours • Used a short video of a young man with alcohol use and depressive disorders narrating his recovery story from an earlier study in a similar geographical location	• CHWs had additional responsibilities of implementing national programs on mother and child health • MHSUs were women with childcare and household responsibilities • PCPs have a busy schedule with responsibilities of implementing the national health programs • In addition to having MHSU with anxiety and depression who was a married woman with children, having a young single man with substance use disorder and depression will add to the diversity of testimonies and methods used in training program	• Situational analysis in north Indian site • Cultural adaptation work of Indigo study • Literature review	• Kaur et al., 2023 (44) • Internal documents of Indigo study • Daniel et al., 2021 (40) • Daniel et al., 2023 (45)
Context	• Recruitment of study participants	• Original training manual • Adapted training manual	• Recruited ASHAs being mindful of their job responsibilities • Recruited MHSUs keeping in mind their cultural context • Considering busy schedule of MHPs, duration of training was limited to one half of a day when they were free from their clinical duties	• ASHAs and MHSUs who consented to devote time for trainings and subsequent intervention activities were included • MHSU men who had initially joined training had to drop out because of employment commitments • Training timings had to be adjusted to accommodate schedule of participants	• Situational analysis in north Indian site • Cultural adaptation work of Indigo study • Literature review	• Kaur et al., 2023 (44) • Internal documents of Indigo study • Daniel et al., 2021 (40) • Daniel et al., 2023 (45).

3.5 Content

The intervention and training content used several case studies to substantiate and prompt discussions on aspects related to mental health and mental health stigma. The case examples were adapted with changes in names, places, and health system context to assist study participants relate to these in a more meaningful way. For instance, a real-life example of successfully treating a person with a mental health condition was narrated by a primary care provider. Based on a situational analyses study and earlier formative research, common myths of mental illness prevalent in the study area were adapted (44, 45) and included in the intervention trainings. Policies relevant to MHSUs in the Indian context were included and discussed in the trainings, which is critical in any discussion around MHSUs representation and rights.

3.6 Methods

There was no major change in the methods of imparting trainings for study participants as per the intervention protocol templates, which included didactic lectures, group exercises, case studies, and individual presentations. However, the duration of the trainings was reduced with the number of sessions shortened. The timings of the trainings were also scheduled in a way that accommodated the caring and household responsibilities of MHSUs, community outreach work of ASHAs, and clinical commitments of PCPs and MHPs. Trainings with participants who were extremely busy with their day-to-day work were conducted at the end of the program. In addition to using lived experience testimonies of MHSUs, we included a short video of a lived experience testimony to add to the diversity of the methods used in the intervention trainings.

3.7 Context

The research team conducting the interventions with different groups of study participants were mindful of their background, which included both their personal and professional context. Only those participants who gave their consent and agreed to take part and continue in the trainings were recruited. MHSUs who were men, for instance, could not continue in the trainings and intervention as they had to take care of their job commitments. The context of the study participants across all categories, i.e., mental health service users, primary care providers, community health workers, and mental health professionals, to a large extent had a bearing on the training methods employed in the intervention (Table 3).

3.8 Concepts and goals

While six dimensions of the intervention were adapted to the local context, the dimensions of 'concepts' and 'goals' were not changed and retained as they were. It was not necessary to change the different concepts that went into the Indigo interventions. The idea to engage with key community stakeholders prior to intervention activities to gain buy-in has been integral to the work that we do. During the stakeholders meetings we took feedback from community members on the strategies for the Indigo-Local media campaign. The social contact element was incorporated into all the interventions (33). The social-contact based concept of engagement in Indigo-Primary where PCPs interacted with SUs and aspirational figures in reducing potential survival, social and professional threats (37) also applied in our setting. Additionally, the concept of reflective practice, intergroup contact theory, and mechanisms that sustain social distance remained the same in the Indigo-READ intervention that involved mental health professionals (48, 49). There was no change in the goals of stigma reduction across all study groups, especially in terms of integrating a social contact element in the interventions.

4 Discussion

This study used a cultural framework to contextually adapt mental health stigma reduction interventions among community members and community health workers, PCPs, and mental health professionals in a north Indian site as part of the larger Indigo Partnership study. Guided by the EVM framework, six dimensions (language, persons, metaphors, content, methods, context) were adapted either before, during or after the interventions were implemented. However, two dimensions, (concepts and goals) were retained and used as they were in the original training materials. The team members involved in the adaptation process had experience working in mental health and could read, write, and speak the local language of study participants.

4.1 Elements of cultural adaptation

The purpose of using a validated cultural adaptation framework – that is, the EVM framework (42) - in this study was twofold. Firstly, to document the entire intervention adaptation processes; and secondly, to increase the cultural acceptability and effectiveness of the intervention strategies used among different target groups. We did this by making certain changes in different dimensions of the interventions that align with the culture of the study participants and the context of the health system, while retaining the core elements of the intervention that are backed by evidence informed practices (32, 42, 50, 51). While encouraging adaptations that are receptive to the requirements of study participants, it is also necessary to implement the intervention as intended. The methods dimension was adapted whereby the duration of the interventions were truncated while not making any changes to the concepts and goals. This reflects what researchers have termed the balance between fidelity and fit elements of an intervention that promotes cultural relevance of the intervention while also adhering to evidence-based practices to increase effectiveness (52, 53).

The eight dimensions that were used in the EVM framework are based on cultural adaptation facets proposed by Bernal and Rodriguez (54) in documenting the adaptation process while conceptually adhering to the intervention's primary mechanisms of actions. Like other researchers who have pointed out that the dimensions of content and context overlap with each other (42), we also found this to be similar in the Indian setting. We found considerable commonalities across these dimension groups: language, metaphor, and content; and persons and context. While using the language dimension in the adaptation process of this study, stigmatizing labels associated to mental health conditions that emerged were quite similar to those reported from the same north Indian region (29). Under the two latter dimensions, we considered the role of gender, age, caste, and class that go into the relationships among study participants and with researchers, where social constructs such as these largely influence cultural practices (45). In one of our mixed methods formative research in the adjoining rural areas of where this present study was conducted, we found caste-based marginalization among community members and gender and age related cultural practices (45). The metaphor dimension was adapted by using a pre-existing adapted print material from an ongoing study with simple culturally relevant illustrations that were informed by formative research (45, 47). Researchers involved in cultural adaptation of psychological interventions have observed that using ethnically relevant pictorial materials identical to the study participants context improved their retention, which is referred to as surface level adaptations (55). This highlights the importance of simple, yet crucial, cultural adaptation processes (56). Engagement with participants at various stages of the study to understand their experiences and overall acceptability of these stigma reductions interventions were possible because of the cultural adaptations. However, it is critical to keep in mind that while contextually adapting complex community and health system-based interventions, some of these cultural adaptations processes are not as straightforward as they may initially appear. An important aspect of any cultural adaptation of stigma and discrimination reduction strategies should consider that the processes of contextualizing different cultural elements do not in turn reinforce or increase perceptions of stigma among study participants and service users in particular.

4.2 Need for cultural adaptation

The nature and extent of stigma and discrimination expressed by different groups and experienced by people with mental health conditions is greatly influenced by their cultural beliefs and practices (22–25). Despite these cultural influences, research on stigma and discrimination reduction interventions have noted that almost all interventions that are implemented in LMICs have predominantly been developed in high-income countries (HICs) based on western principles, values, and frameworks (57). This ignores how existing diverse local health systems and practices might influence the ways in which stigma and discrimination around mental health conditions are socially constructed, perceived and expressed, across culturally heterogeneous global settings (26, 27, 58). Programs in reducing stigma and discrimination of mental health conditions have made phenomenal global progress over the past few decades (1). However, unfortunately most programs are carried out in HICs (59). Most of these interventions are resource intensive and complex, and not suitable to the sociocultural contexts and health systems in LMICs making it a challenge to introduce these programs in low resource settings (32). Although it is encouraging that several interventions to address stigma and discrimination among people with mental health conditions are being implemented in LMICs (1, 60), little is known on the extent to which of these interventions have been effective, and whether these have used culturally appropriate approaches (32).

A scoping review conducted to examine the role of culture in programs to reduce stigma towards people with mental health conditions in LMICs found that only a handful of studies considered cultural elements of mental health stigma in the design and implementation of such programs (32). More importantly, the studies also lacked a systematic way of comparing cultural dimensions across and within countries. The larger Indigo Partnership study in seven sites across five LMICs (33), within which the work reported on in this study is conducted, has a dedicated work stream of culturally contextualizing interventions to reduce stigma and discrimination among people with mental health conditions. As such it will be able to provide insights into many of these research gaps. Moreover, using the EVM framework for the three interventions in the larger Indigo Partnership study provides a method to evaluate and compare cultural adaptation strategies across the seven contextually and culturally varied sites. Overall, it would be important to assess how these adaptations might possibly have an impact on the intervention outcomes, so as to identify which modifications appear to enhance intervention acceptability and effectiveness.

5 Conclusion

In this study stigma reduction interventions were implemented as a small-scale proof of principle interventions across different target groups in one of the North Indian sites of the Indigo collaborative research. We documented the process of culturally adapting these strategies across different dimensions and domains. Unlike previous work, we used the well validated Ecological Validity Model framework to capture these modifications and to inform the cultural adaptation and implementation science research. Stigma reduction strategies encompassing varied target groups, based on culturally appropriate adaptations and evidence, will be more applicable to stakeholders involved in the intervention in the future to achieve program acceptability and effectiveness, and possibly in taking these anti-stigma interventions to scale.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material. Further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by The George Institute Ethics Committee, The George Institute for Global Health (18/2020 dated 04.09.2020). Approval from the Health Ministry Screening Committee, Department of Health Research/ICMR was also sought (HMSC- 2020-10098). The studies were approved by by the KCL PNM Research Ethics Subcommittee (HR-19/20-17252). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

MD: Writing – original draft. SK: Writing – review & editing. PCG: Writing – review & editing. SW: Writing – review & editing. BK: Writing – review & editing. GT: Writing – review & editing. PKM: Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

The George Institute has a part-owned social enterprise, George Health Enterprises, which has commercial relationships involving digital health innovations.

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The effect of an e-intervention on intellectual disability stigma among Nigerian and Kenyan internet users: a comparative randomised controlled trial

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Introduction: The negative consequences of stigma for the wellbeing of people with disabilities have raised public and global health concerns. This study assessed the impact of an e-intervention to reduce intellectual disability (ID) stigma among Nigerian and Kenyan internet-users.

Method: Participants aged 18+ and citizens of Nigeria and Kenya were recruited through online advertising. Qualtrics, a web survey platform, randomly assigned (1:1) participants to watch either a short experimental or control film, while masked to their assignment. The experimental film featured education about ID and indirect contact. The control film was on an unrelated topic. Their attitudes were measured on three dimensions (affect, cognitions and behaviour) at three time points (baseline, post intervention and one-month follow-up). Between October 2016 and April 2017, 933 participants were randomised, 469 to the experimental condition and 464 to the control condition. Of these, 827 (89%) provided pre-and post-intervention data but only 287 (31%) were retained at follow-up.

Results: An intent-to-treat analysis revealed that participants in the experimental but not the control condition showed a positive shift in their attitudes towards people with ID over time. Their willingness to interact with people with ID increased post-intervention.

Discussion: A brief intervention that integrates education and indirect contact can make an effective contribution to efforts to reduce stigma faced by people with ID in Africa. Trial registered with the ISRCTN trial registry (number ISRCTN92574712).

KEYWORDS

intellectual disability, stigma, attitudes, intervention, Africa, Kenya, Nigeria

1 Introduction

People with intellectual disabilities (ID) are heavily stigmatised and marginalised globally (1–4). They are more likely to have their fundamental rights and freedoms denied. They are also more likely to experience higher levels of health, social and financial inequalities than their non-disabled counterparts (1, 3). Africa has been identified as one of the world regions where pejorative terminology, stigmatising beliefs and discriminatory practices towards people with ID continue to exist (3, 4). Misconceptions around the causes and abilities of people with ID have been identified as key drivers of stigma in African regions (1, 5, 6). Embedded cultural beliefs that disability is caused by spiritual forces or misdeeds from others, and a perception of people with ID as a burden to family/community resources have been identified in multiple studies (1, 5, 6). Such beliefs have resulted in people with ID becoming victims of ostracism, harmful traditional practices, violence and in some cases, death (5, 6). Accordingly, public health concerns regarding ID stigma have been voiced, resulting in a call for more global initiatives to challenge ID stigma particularly in low-income and middle-income countries (2, 5).

Documented efforts to reduce ID stigma in African countries have occurred at multiple levels, such as parent support and training groups, education campaigns, community-based rehabilitation programmes and mass media initiatives, with evidence of positive results in changing cultural beliefs and tackling discrimination (6–8). A community-based programme in Kenya promoted social inclusion and access to education for children with developmental disabilities by demonstrating their ability to learn through an 8-week motor skills programme (7). Another initiative in Egypt demonstrated changes in teachers' attitudes by increasing knowledge and challenging misconceptions about ID as well as creating opportunities to work with people with ID in a sheltered workshop (8). While these initiatives appear promising, conceptual and methodological concerns regarding the case for their support have been noted (9). Furthermore, many persons with ID are yet to benefit from anti-stigma efforts due to huge disparities between world regions where high levels of stigma are prevalent and those where efforts to reduce ID stigma are mostly undertaken (2, 4). Accordingly, there is a need to do more to tackle societal barriers that impede the quality of life of people with ID in Africa and elsewhere (2, 4).

Contact and education have been identified as key routes to challenging stigma in other fields (10). In the case of ID, educational approaches challenge misconceptions and stereotypic myths about ID, and their benefits include their potential low cost and broad reach. However, for brief interventions, the effects of educational strategies vary in magnitude and duration and need to be combined with contact approaches to achieve longer-term change (10, 11). Contact approaches stem from Allport's contact hypothesis (12) and propose that interactions between in-group members (i.e., those doing the stigmatising) and out-group members (i.e., those being stigmatised) can reduce prejudice, when certain conditions are met. These conditions, usually as part of direct contact, include one-to-one interactions with an out-group member of equal status, with intergroup cooperation, a pursuit of a common goal and support from authorities (12). A recent study in Kenya successfully used a contact-based approach to promote awareness of the capabilities of people with disabilities (ID included) and challenge dehumanisation. This was done by positioning people with disabilities as agents of change and supporting them in voicing their own narratives as 'experts by experience' (13).

However, securing direct contact on a large scale can prove difficult and costly and can limit control over quality. Furthermore, in light of growing evidence it is now known that while Allport's key conditions enhance the positive effects of contact approaches, they are not required to produce positive outcomes (12). Research has shown that the level of positive outcomes achieved in any contact situation is based on the extent to which the exposure reduces threat and anxiety about future intergroup contact, while also inducing positive affect such as empathy (12, 14).

Indirect contact with people with ID, via film footage as a standalone intervention or as a component of a multi-faceted anti-stigma programme, is scalable and a viable way to control for some of the potential drawbacks of direct contact (14). Indirect contact through film seeks to achieve change in three major ways: 1) by creating an experiential learning situation, 2) eliciting empathy, and 3) encouraging inferential processes in the viewer (14). Several studies have tested the impact of brief digital interventions and found that indirect contact is an effective way to change attitudes towards people with ID among the general public (14–16).

However, it has been reported that intermittent connectivity problems in Africa may serve as a barrier in the deployment and uptake of digital initiatives that deliver film-based contact (17). Despite these concerns, there is growing evidence that Nigeria and Kenya are increasingly recognising the need to establish strong information and communication technologies (ICTs) for health initiatives. In the Kenyan National e-Health Strategy, providing equitable and affordable healthcare at the highest achievable standard to Kenyan citizens was listed as a main goal. E-learning was identified as a key strategic area of implementation (18). Also, according to the United Nations Foundation, the Nigerian government has formally recognised the importance of ICTs to improve access to health services and interventions (16). As such, looking at the effectiveness and appropriateness of digital integrated approaches to reduce stigma warrants more attention in African countries. Digital approaches may not only provide a viable medium to carry out anti-stigma initiatives but also align with the ICT agenda put forth by the Nigerian and Kenya governments respectively. The present study aimed to test the effectiveness of an e-intervention integrating education and indirect film-based contact in raising awareness about ID and reducing public stigma in Nigeria and Kenya.

2 Methods

2.1 Study setting, design, and participants

In this randomised controlled trial (RCT), a film-based intervention was delivered to Nigerian and Kenyan internet users and its efficacy tested using repeated measures. The intervention was produced in collaboration with non-governmental organisations in Nigeria and Kenya. Qualtrics, a web survey platform, was used to randomly assign participants to the experimental or control condition and to collect data. Data were collected at three time points: baseline, immediately post film, and one-month follow-up to allow estimation of the size of any effects and assessment of any lasting positive effects. The trial was registered with the ISRCTN trial registry (ISRCTN92574712).Eligible participants were at least 18 years of age, English speaking, and Nigerian/Kenyan internet users. Participants who did not meet the above criteria were excluded. All participants were recruited through social media advertising (Instagram, Facebook and email promotions), containing brief details of the study, and a link to the data collection site. They were informed about their right to withdraw from the study at any time, and that starting the survey would be taken as informed consent. No adverse effects were reported by participants.

2.2 Randomisation and masking

Participants were randomly assigned on a 1:1 ratio to the experimental group or the control group using a block randomisation code embedded within Qualtrics. Enrolment, generation of sequences and assignment of participants were all pre-programmed. Participants were informed that the aim of the study was to gather public opinions regarding personal difficulties some people face. They were not aware that the study's primary objective was to measure potential attitude change. Both groups were presented with the same information and outcome measures. The only difference between groups was the content of the video shown after participants had completed the baseline survey. Before the baseline measures, participants were provided with a brief description of ID to ensure that they had an adequate understanding of the condition as basis for completing measures on their attitudes to ID. The description was as follows:

For the purpose of this study, intellectual disability is a term used when a person has certain delays in their cognitive development. These delays must be present before the person reaches adulthood and can lead to difficulties understanding, learning and remembering new things. It may also affect the person's communication, social and self-care skills. A person with an intellectual disability may therefore develop and learn more slowly or differently than others. In the past, the term 'mental retardation' was used to describe intellectual disability. Some specific syndromes and conditions like Fragile X and autism may in some cases be associated with having an intellectual disability. Intellectual disabilities are different from specific learning difficulties such as dyslexia, which are NOT the focus of this study.

To reduce ascertainment bias and ensure blinding, the control group watched a documentary film of a similar length and structure to the experimental group. Dropout rates between groups after watching the film-intervention were compared to assess the success of masking. Investigators were not blinded to the intervention.

2.3 Procedure

Once participants had completed the baseline measures, they were randomised to one of two film conditions in each study. Participants in the experimental group watched a 6-minute film providing information about ID and its causes and consequences, countering stigmatising beliefs known to be common in Africa, and indirect contact. Stigmatising beliefs targeted in the film were based on a global review conducted on ID stigma (4). Also, all stages in the development of the film were reviewed by experts, researchers and representatives of organizations/advocacy networks in the ID field in Nigeria and Kenya. Some of them also held dual roles as parents of people with ID. The length of the film was determined by reviewing what similar studies had found to be effective (14, 19). The educational segment of the film was structured based on Leventhal's Common Sense Model of how illness is conceptualised within the general population (20). This model proposes that five main components make up our representation of illnesses and influence our perceptions, attitudes and actions towards different illnesses. These include identity, cause, timeline, consequence and curability/controllability. As such, the selection of factual knowledge delivered was guided by identity (What is ID and what isn't)?, causes (What causes ID and what doesn't), timeline/curability (Is there a 'cure')?, and consequence (How might having an ID impact on someone's abilities)? (20). This model has been used successfully in past anti-stigma initiatives as a framework for how factual information regarding ID is shared (19). This section of the film was delivered by local experts, to ensure its credibility. Experts were chosen based on their level of experience and involvement with families and individuals with ID locally. Two experts (a community paediatrician and the president of the Down Syndrome Foundation Nigeria) ran ID learning centres in their local community that focused on education and social care; another was a religious leader and one a psychiatrist, all with frequent contact with people with ID.

The indirect contact section featured people with moderate ID who varied in life roles and the challenges they faced, talking about their experiences, demonstrating their capabilities and talking about their hopes and aspirations. It also highlighted the magnitude of stigma they face in their respective countries. Separate but similar films were produced for the Nigerian and Kenyan studies to ensure credibility of both the experts and people with ID. The authors met and heard first-hand experiences from local people with ID and collaborated with them on how to create a film that would help change public misconceptions.

Written informed consent was obtained from all people featured and their parents for the recording and sharing of the film. An easy read version of the consent form, which included shorter sentences and images, was available for people with ID. The films are publicly viewable on YouTube: https://www.youtube.com/watch?v=2MpipkGk9Zs (Nigeria) and https://www.youtube.com/watch?v=ZSi_DJxGPrs&t=99s (Kenya).

The control group watched a film that was unrelated to ID, which focused on the challenges children in Kenya/Nigeria face in receiving an education. It had a similar length and format to the experimental video. It showed an expert talking about the education crisis in the respective country and demonstrated its impact on children. This film was chosen to control for the following variables that might influence observed change: reactivity to the outcome measures, study participation, length of film, and the social and demographic characteristics of people featured in the film. A feature on Qualtrics, known as force response, was embedded after both films to ensure that all participants watched the films before progressing to the next part of the study. Following the film, participants completed post-intervention measures and, if consenting, were contacted by email asking them to complete the follow-up survey a month later. Given the novelty of conducting an online longitudinal study within an African population, retention strategies were used to try to minimise participants' attrition rates. This included the use of non-monetary incentives (i.e., gift vouchers) and reminder emails with patients' consents. Local experts in the field were consulted regarding what incentives would be most attractive in the local context. Steps were also taken to prevent multiple submissions by embedding an "end of survey" function in Qualtrics. This function ensured that any attempts to retake the questionnaire on a browser or device that had previously been used was flagged and stopped.

2.4 Measures

The Attitudes towards Intellectual Disabilities (ATTID) scale, which draws on a multi-dimensional understanding of attitudes was used as the primary outcome measure in both countries (21, 22). The ATTID assesses the cognitive, affective, and behavioural components of attitudes across five-factors: two factors (*Discomfort* and *Sensitivity/Tenderness*) in the affective dimension; two factors (*Knowledge of Causes* and *Knowledge of Capacity and Rights*) in the cognitive dimension*;* and one factor (*Interaction*) in the behavioural dimension. The affective and behavioural dimensions of the scale are measured using two vignettes that present two men with ID, one with a higher and the other with a lower level of functioning. This study used the ATTID short form which consists of 36 items, using a 5-point Likert scale (1 = agree completely to 5 = disagree completely; plus an option of 9 to indicate "I don't know"/"not applicable"). Its psychometric properties were examined for both the Nigerian and Kenyan data sets, yielding a six-factor structure for both, with three factors loading on the cognitive dimension instead of two as in the original Canadian sample (*Knowledge of Causes*, *Knowledge of Capacity*, and *Knowledge of Rights*) but an otherwise identical factor structure. The short version showed acceptable to good internal reliability with Cronbach's alphas ranging from 0·68 to 0·88 for the six factors.

The causal beliefs listed in the ATTID were supplemented with three items from the supernatural causes subscale of the Intellectual Disabilities Literacy Scale (IDLS) to tap into superstitious causal attributions common in African countries and implicated in ID stigma (23). These items addressed ID potentially being seen as due to a test from God/Allah, possession by spirits, and punishment for past wrongdoings. This IDLS subscale has previously been tested in a range of cultural contexts, showing high internal (α= 0·76) and acceptable test-retest reliability (>0·7) (23).

Socio-demographic data (age, gender, ethnicity, religious affiliation, educational attainment, and prior contact with someone with ID) were also recorded at the end of the post-intervention survey.

2.5 Statistical analysis

An *a priori* power analysis completed using G*Power 3·1·8 (24), indicated a sample of 398 participants for each of the two studies (199 per group) to ensure an 80% chance (alpha set at 0·05) of detecting a 'small' effect of d= 0·25 as observed in a similar previous study (14) when comparing two independent means. Separate intention-to-treat analyses including all randomised participants were computed for the Nigerian and Kenyan samples using SPSS version 22. Assumptions of normality, linearity, multicollinearity and homoscedasticity were checked to ensure no violation. To assess the pattern of missing data due to participant drop-out, Little's MCAR test was carried out, which showed that data were missing at random: χ^2 (273, N=571)= 291·80, p= 0·207 (Nigerian study); x^2 (39, N=457) = 40·45, p =·406 (Kenyan study). As such, intervention effects were analysed using a linear mixed model. This model is a superior way to handling missing data in RCTs, outperforming other traditional methods; it uses all data presented at each time point and does not rely on complete cases to run analyses (25). For all analyses, p values of <0·01 were considered significant to manage the risk of type 1 error. Effect sizes were calculated following Morris' guidelines for repeated measures control group designs (26).

2.6 Ethical considerations

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation. All procedures involving human patients were approved by the authors' institutional research ethics committee (ID: 8807/001). Written informed consent was provided by all persons who participated in the study.

3 Results

Participants were recruited between October 26, 2016 and April 28, 2017. In the Nigerian study, a total of 917 participants visited the survey site. Three did not meet the study's inclusion criteria and were excluded. Of the remaining 914 participants, 215 (23·5%) dropped out after reading the information sheet and before beginning the study. Of the 699 that started, 571 (81·6%) completed the survey assessing baseline attitudes and were subsequently randomised (291 to the experimental group and 280 to the control group). A further 64 (9·2%) participants from both groups dropped out during the post-intervention survey. Another 311 (44·5%) dropped out between post-intervention and follow-up; of these participants, 51(7·3%) declined being contacted for the follow-up survey.

In the Kenyan study, a total of 720 participants visited the survey site. Ten did not meet the inclusion criteria and 253 (35·6%) dropped out before beginning the study. Of the 457 that started the study, 362 (79·2%) completed the survey assessing baseline attitudes and were subsequently randomised (178 to the experimental group and 184 to the control group). During the post-intervention survey, 42 (9·2%) dropped out. A further 229 (50·1%) dropped-out between post-intervention and follow-up, including three participants who declined being contacted for the follow-up survey. The intention-to-treat analysis contained all 571 Nigerian and 418 Kenyan randomised participants (Figure 1).

In both studies, participants who completed the study were predominantly female, aged 25 to 34, and Christian, with a university/postgraduate degree (Table 1).

Descriptive data for both groups are presented in Table 2. A series of linear mixed models were computed to test for intervention effects across all six ATTID subscales and the IDLS supernatural causal beliefs subscale. In the Nigerian study, significant time x group interactions were found for the affective attitude dimensions *Discomfort* and *Sensitivity*; for the behavioural dimension *Interaction*; and for two of the three cognitive dimensions, *Knowledge of Rights* and Knowledge of *Capacity*, but not for *Knowledge of Causes*. Significant interactions were also found for *Supernatural Beliefs* (Table 3). In the Kenyan study, significant time x group interactions were observed for all ATTID subscales, except for *Knowledge of Rights.* No significant interactions were found for the *Supernatural Beliefs* subscale (Table 3). The significant interactions indicated that there were substantial differences in attitude scores between groups over time.

Post hoc analyses of least significant difference (LSD) comparisons were then carried out for subscales that showed significant interactions in order to determine the exact nature of attitude change. In the Nigerian experimental group, LSD comparisons showed a significant reduction in negative attitudes from pre-to post-intervention for the following factors: *Discomfort*, *Sensitivity*, *Interaction*, *Knowledge of Rights*, *Knowledge of Capacity*, and *Supernatural Beliefs*. These favourable changes were all maintained at follow-up when compared to baseline with the exception of *Sensitivity* and *Knowledge of Rights* (Table 4). The positive shifts from baseline to follow-up were medium to large for *Knowledge of Capacity* (d = -0·624), small for *Interaction* (d = -0·234), *Supernatural Beliefs* (d = -0·206) and *Discomfort* (d = -0·163).

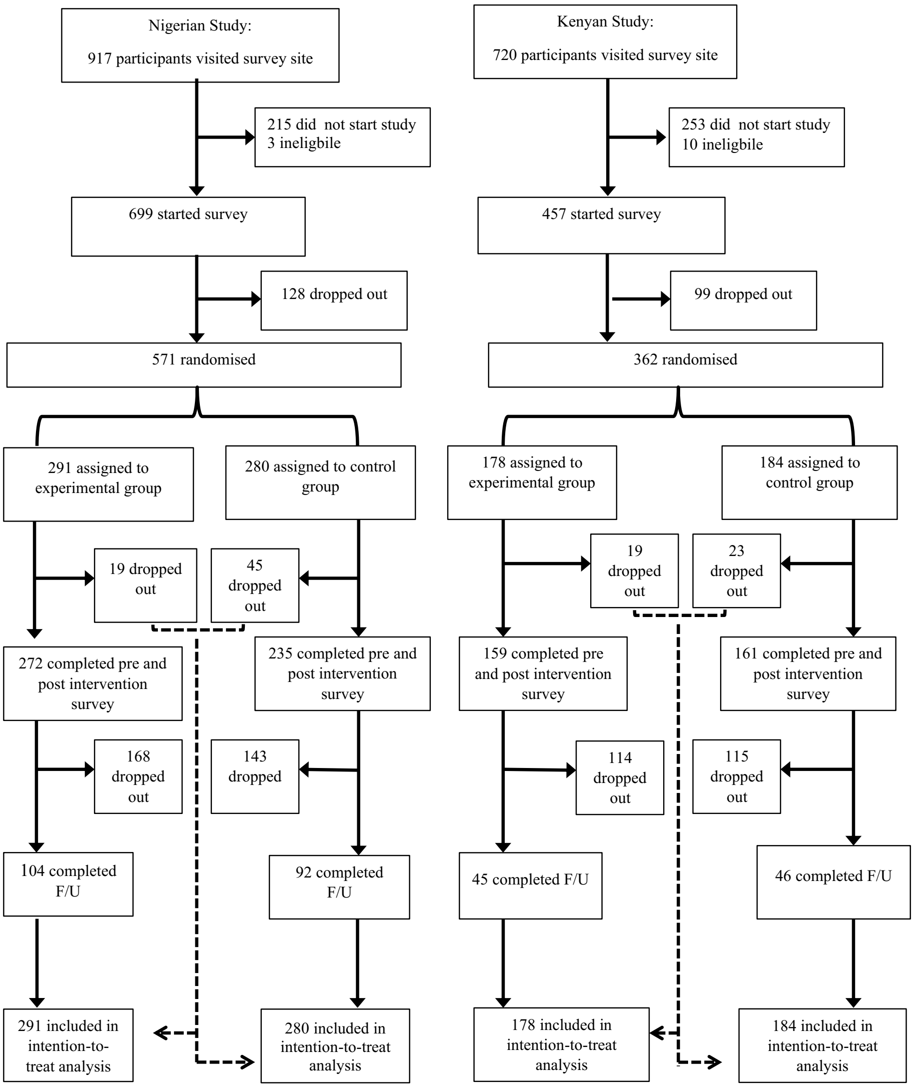

FIGURE 1
Trial profile. All dropouts occurred during transition points in the study. This included starting a vignette in the ATTID at time point 1, 2 and 3, during the film and the time period between post-intervention and follow-up.

TABLE 1 Participant Characteristics.

	Nigerian Study		Kenyan Study	
	Intervention group (n=272) n (%)	Control group (n=229) n (%)	Intervention group (n=158) n (%)	Control group (n=161) n (%)
Sex*				
Male	62 (22%)	55 (24%)	48 (31%)	47 (29%)
Female	210 (77%)	173 (76%)	110 (70%)	114 (71%)
Missing	0	1 (0%)	0	0
Age (years) *				
18-24	49 (18%)	41 (18%)	14 (9%)	20 (12%)
25-34	153 (56%)	130 (57%)	109 (69%)	103 (64%)
35-44	52 (19%)	39 (17%)	15 (9%)	18 (11%)
45+	18 (7%)	18 (8%)	20 (13%)	20 (13%)
Education*				
Primary/Secondary	10 (4%)	12 (5%)	3 (2%)	10 (6%)
University	153 (56%)	122 (53%)	83 (53%)	90 (56%)
Post-graduate	109 (40%)	95 (42%)	61 (39%)	53 (32%)
Vocational qualification (Kenya Only)			11 (7%)	8 (5%)
Religion*				
Christian	270 (99%)	217 (95%)	143 (90%)	128 (80%)
Muslim	1 (0%)	9 (4%)	2 (1%)	8 (5%)
Hindu/Buddhist	0	0	2 (1%)	3 (2%)
Traditional religion	0	1 (0%)	1 (1%)	3 (2%)
Non-religious	1 (0%)	2(1%)	10 (6%)	19 (12%)
Prior Contact*				
Yes	191 (71%)	151 (66%)	128 (81%)	127 (79%)
No	80 (30%)	77 (34%)	30 (19%)	34 (21%)
Missing	1 (0%)	1 (0%)	0	0
Nature of Contact*				
Family member	44 (16%)	37 (16%)	48 (30%)	45 (28%)
Friend/Neighbour	57 (21%)	30 (13%)	36 (23%)	35 (22%)
Professional/Educational	35 (13%)	35 (15%)	17 (11%)	29 (18%)
Acquaintance/ secondary relationships	42 (15%)	33 (14%)	21 (13%)	12 (7%)
Multiple Relationships	8 (3%)	6 (3%)	3 (2%)	2 (1%)
Stranger	3 (1%)	9 (4%)	3 (2%)	2 (1%)
Missing	3 (1%)	2 (1%)	0	2 (1%)
Not applicable	80 (29%)	77 (34%)	30 (19%)	34 (21%)
Frequency of contact*				
Weekly	50 (18%)	31 (14%)	19 (12%)	22 (14%)

(Continued)

TABLE 1 Continued

	Nigerian Study		Kenyan Study	
	Intervention group (n=272) n (%)	Control group (n=229) n (%)	Intervention group (n=158) n (%)	Control group (n=161) n (%)
Frequency of contact*				
Several times a month but < weekly	26 (10%)	16 (7%)	14 (9%)	16 (10%)
Occasionally during the year	58 (21%)	47 (21%)	56 (35%)	45 (28%)
Less than 1x a year	21 (8%)	22 (10%)	38 (24%)	43 (27%)
A one-off encounter	32 (12%)	33 (14%)	0	0
Missing	5 (2%)	3 (1%)	1 (1%)	1 (1%)
Not applicable	80 (29%)	77 (34%)	30 (19%)	34 (21%)

* Due to attrition, demographic information collected at the end of the survey does not include all participants included in the intention-to-treat analysis.

TABLE 2 Attitude subscale scores by time point and study: Means (standard deviations).

	Nigerian Study						Kenyan Study					
	Treatment group			Control group			Treatment group			Control group		
	Pre	T1	FU	Pre	T1	FU	Pre	T1	FU	Pre	T1	FU
ATTID Subscales												
Discomfort	2.58 (0.80)	2.16 (0.76)	2.40 (0.86)	2.54 (0.82)	2.49 (0.83)	2.39 (0.79)	2.39 (0.79)	1.95 (0.79)	2.08 (1.01)	2.39 (0.82)	2.29 (0.78)	2.14 (0.65)
Sensitivity	3.68 (0.75)	3.36 (0.85)	3.50 (0.77)	3.68 (0.73)	3.60 (0.83)	3.51 (0.84)	3.57 (0.74)	3.05 (0.90)	3.05 (1.02)	3.54 (0.81)	3.35 (0.85)	3.32 (0.77)
Interaction	2.56 (0.64)	2.21 (0.63)	2.39 (0.67)	2.50 (0.64)	2.46 (0.67)	2.48 (0.66)	2.62 (0.75)	1.88 (0.78)	2.33 (1.34)	2.48 (0.52)	2.40 (0.49)	2.51 (0.61)
Knowledge of Rights	1.91 (0.72)	1.83 (0.69)	1.93 (0.67)	1.85 (0.78)	2.03 (0.76)	2.10 (0.86)	1.75 (0.74)	1.69 (0.68)	1.95 (0.69)	1.81 (0.71)	1.91 (0.76)	1.91 (1.12)
Knowledge of Capacity	2.81 (0.75)	2.13 (0.68)	2.47 (0.79)	2.91 (0.79)	2.71 (0.78)	2.75 (0.66)	2.54 (0.48)	2.29 (0.50)	2.43 (0.77)	2.61 (0.79)	2.33 (0.84)	2.71 (0.79)
Knowledge of Causes	2.38 (0.63)	2.37 (0.71)	2.36 (0.72)	2.39 (0.65)	2.41 (0.74)	2.47 (0.71)	2.24 (0.59)	2.16 (0.76)	2.33 (0.82)	2.24 (0.68)	2.32 (0.79)	2.23 (0.62)
IDLS: Supernatural Causal Beliefs	2.22 (0.89)	1.78 (0.78)	1.85 (0.85)	2.14 (0.85)	1.97 (0.87)	1.95 (0.86)	1.82 (0.06)	1.45 (0.06)	1.54 (0.11)	1.82 (0.06)	1.78 (0.06)	1.93 (0.10)

In the Nigerian control group, LSD comparisons revealed no significant change in *Discomfort, Sensitivity*, and *Interaction* over time. However, there was a significant positive shift in attitudes observed from pre-to post-intervention for *Knowledge of Capacity*, and *Supernatural Beliefs* (Table 4). These changes were not maintained at follow-up. In addition, a significant negative shift in *Knowledge of Rights* was observed in the control group post-intervention and maintained at follow-up.

The observed pre-post reductions in negative attitudes were consistently larger in the Nigerian experimental group when compared to the control group (Table 2). An interaction analysis comparing the Nigerian experimental and control groups from pre-to post-intervention showed significant effects for *Discomfort*, *Sensitivity*, and *Interaction* (Table 5).

In the Kenyan study, *post hoc* LSD comparisons in the experimental group showed significant reductions in negative attitudes from pre-to post-intervention for the following factors: *Discomfort*, *Sensitivity*, *Interaction*, and *Knowledge of Capacity*. *Knowledge of Rights* and *Knowledge of Causes* showed no significant change post-intervention. Looking specifically at the significant positive changes observed, these were maintained at follow-up when compared to baseline for *Discomfort*, *Sensitivity*, and *Interaction* but not for *Knowledge of Capacity* (Table 6). The positive shifts from baseline to follow-up were medium sized for *Interaction* (-0.489), small to medium for *Sensitivity* (-0.388), and negligible for *Discomfort* (-0.075).

In the Kenyan control group, *Discomfort* and *Supernatural Beliefs* showed no significant pre-to post intervention change but a reduction in negative attitudes was observed for *Sensitivity*, *Interaction*, and *Knowledge of Capacity*. However, these changes were not maintained at follow-up. Similar to the Nigerian study, a significant baseline to post-intervention increase in negative attitudes was found in the Kenyan control group for *Knowledge of Rights*, but also *Knowledge of Causes*, although none of these changes were maintained at follow-up.

TABLE 3 Results of linear mixed models testing for time x group interactions.

	Nigerian Study		Kenyan Study	
	F	p	F	p
ATTID Subscales				
Discomfort	*F* (2,750) = 21.23	<0.001**	*F*(2, 443) = 12.67	<0.001**
Sensitivity	*F* (2,750) = 11.13	<0.001**	*F*(2, 445) = 11.57	<0.001**
Interaction	(*F* (2,751) = 23.14	<0.001**	*F*(2, 488) = 13.95	<0.001**
Knowledge of Rights	*F* (2,791) = 10.74	<0.001**	*F*(2, 473) = 3.42	0.033
Knowledge of Capacity	*F* (2, 841) = 23.84	<0.001**	*F*(2,444) = 6.45	0.002*
Knowledge of Causes	*F* (2, 796) = 0.69	0.503	*F* (2, 466) = 4.97	0.007*
IDLS: Supernatural Causal Beliefs	*F* (2,784) = 11.13	0.001*	*F*(2, 463) = 2.49	0.084

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

TABLE 4 Results of *post hoc* analyses for subscales showing significant interactions (Nigerian Study).

	Intervention								Control							
	Pre - Post				Pre - FU				Pre - Post				Pre - FU			
	b (CI)	*t*	*df*	*p*	*b (CI)*	*t*	*df*	*p*	*b (CI)*	*t*	*df*	*p*	*b (CI)*	*t*	*df*	*p*
ATTID Subscales																
Discomfort	0.40 (0.32 - 0.48)	10.42	279	<0.001**	0.20 (0.08–0.33)	3.14	148	0.002**	0.05 (-0.02–0.11)	1.39	243	0.166	0.05 (-0.07 – 0.17)	0.83	112	0.408
Sensitivity	0.31 (0.24 - 0.39)	8.49	279	<0.001**	0.19 (0.07-0.32)	2.99	152	0.030	0.63 (0.00-0.13)	1.20	245	0.047	0.15 (0.02-0.27)	2.36	127	0.020
Interaction	0.34 (0.28 - 0.40)	11.52	279	<0.001**	0.22 (0.12-0.32)	4.45	145	<0.001**	0.05 (-0.01-0.10)	1.69	245	0.093	0.03 (-0.08-0.14)	0.60	132	0.550
Knowledge of Capacity	0.68 (0.59-0.78)	13.63	289	<0.001**	0.39 (0.25-0.53)	5.29	194	<0.001**	0.19 (0.09-0.29)	3.63	265	<0.001**	0.12 (-0.03-0.27)	1.62	158	0.107
Knowledge of Rights	0.85 (0.02 - 0.15)	2.42	285	<0.016*	0.37 (-0.09-0.16)	0.58	167	0.560	-0.16 (-0.23–0.84)	4.24	259	<0.001**	-0.20 (-0.34–0.58)	2.79	154	0.006*
IDLS: Supernatural Causal Beliefs	0.44 (0.36 - 0.53)	10.0	286	<0.001**	0.36 (0.22 - 0.50)	5.37	151	<0.001*	0.17 (0.08 -0.26)	3.98	258	<0.001**	0.08 (-0.06-0.23)	1.15	123	0.253

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

The baseline to post-intervention reductions in negative attitudes observed in the Kenyan study were consistently larger in the experimental group when compared to the control group (Table 2). Similar to the Nigerian study, an interaction analysis comparing the two groups showed significant effects for *Discomfort*, *Sensitivity*, and *Interaction* (Table 5).

4 Discussion

The present study set out to investigate the effectiveness of an e-intervention that integrated education and indirect contact to challenge public stigma associated with ID in Nigeria and Kenya. It distinguished and measured all three components of attitudes (cognition, affect and behavioural intention) in order to adequately assess attitude change. Our key findings were: (1) the experimental group in both Nigeria and Kenya on average showed a small to medium positive shift in participants' affect and behavioural intentions, which were maintained at 1-month follow-up expect for the *Sensitivity* subscale in the Nigerian study; (2) both studies also showed a change in participants' beliefs regarding capacity, however, this shift was only maintained in the Nigerian study at follow-up; (3) only the Nigerian study showed a shift in supernatural causal beliefs, which was maintained over time (4)

TABLE 5 Interaction analysis comparing attitudes by group: baseline to post-intervention.

	Nigeria Pre to Post x group				Kenya Pre to Post x group			
	b (CI)	*t*	*df*	*p*	*b (CI)*	*t*	*df*	*p*
ATTID Subscales								
Discomfort	0.31 (0.18-0.45)	3.53	515	<0.001**	0.30 (0.14-0.47)	3,53	515	<0.001**
Sensitivity	0.25 (0.12-0.38)	3.10	517	0.002*	0.27 (0.10-0.45)	3.10	517	0.002*
Interaction	0.23 (0.12-0.34)	5.57	612	<0.001**	0.46 (0.30-0.62)	5.57	612	<0.001**
Knowledge of Capacity	0.25 (0.12-0.38)	2.10	513	0.036	0.11 (0.01-0.23)	2.10	513	0.036
Knowledge of Rights	0.19 (0.06-0.31)	2.46	554	0.014	0.20 (0.05-0.36)	2.54	528	0.011
Knowledge of causes	0.03 (-0.08- 0.15)	0.65	515	0.515	0.14 (-0.01-0.29)	1.79	519	0.075
IDLS: Supernatural Causal Beliefs	0.18 (0.04-0.32)	2.53	833	<0.012	-0.25 (-0.44 - -0.06)	-2.63	512	0.009*

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

TABLE 6 Results of *post hoc* analyses for subscales showing significant interactions (Kenyan Study).

	Intervention								Control							
	Pre - Post				Pre - FU				Pre - Post				Pre - FU			
	b (CI)	*t*	*df*	*p*	*b (CI)*	*t*	*df*	*p*	*b (CI)*	*t*	*df*	*p*	*b (CI)*	*t*	*df*	*p*
ATTID Subscales																
Discomfort	0.44 (0.33-0.56)	7.72	166	<0.001**	0.34 (0.12-0.56)	3.08	83	0.003*	0.07 (-0.01-0.16)	1.79	166	0.075	0.22 (0.05-0.39)	2.64	51	0.011
Sensitivity	0.52 (0.41-0.64)	8.75	166	<0.001**	0.55 (0.32-0.77)	4.81	111	<0.001**	0.17 (0.09-0.26)	4.23	166	<0.001**	0.14 (-0.02-0.30)	1.79	59	0.079
Interaction	0.71 (0.60-0.84)	12.11	170	<0.001**	-0.31 (0.12-0.51)	3.17	73	<0.002*	0.27 (0.15-0.40)	4.25	179	<0.001**	-0.12 (-0.33-0.10)	1.10	99	0.276
Knowledge of Capacity	0.24 (0.17-0.31)	7.05	165	<0.001**	0.10 (-0.02-0.22)	1.62	73	0.109	0.08 (0.03-0.14)	3.08	167	0.002*	-0.12 (-0.12-0.08)	0.38	65	0.706
Knowledge of Rights	0.04 (-0.06-0.15)	0.83	170	0.410	-0.19 (-0.38 - -0.01)	-2.09	67	0.040	-0.11 (-0.21-0.02)	2.35	177	0.020	-0.10 (-0.29-0.09)	1.06	86	0.292
Knowledge of Causes	0.87 (-0.01-0.19)	1.69	170	0.090	-0.99 (-0.27 - -0.09)	-0.09	91	0.322	-0.09 (-0.17-0.12)	2.29	176	0.023	-0.00 (-0.13-0.13)	0.01	62	0.990

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

the Nigerian study also showed a shift in participants' knowledge of rights but this change was not maintained over time; (5) neither study showed changes in participants' knowledge of causes; and (6) all observed changes were statistically superior in the intervention group in comparison to the control group.

The use of an online platform to disseminate anti-stigma interventions raises questions around two competing agendas: population penetration versus level of impact (11). Film-based (indirect) contact allows for dissemination through multiple media channels leading to larger audiences for anti-stigma interventions. On the other hand, direct contact yields better intervention effects due to its ability to promote more personalised, targeted efforts (11). As opposed to the medium to large effects often reported in response to direct contact, the magnitude of change observed in this study was mostly within the small to medium range which is consistent with other indirect contact studies (11, 14). However, the number of people reached through the present study was exponentially larger when compared to other non-government led anti-stigma efforts in Africa (4, 7, 8). To date, most interventions coming out of African regions are grassroot efforts that are mostly limited in duration, size and impact due to very limited resources (1, 2). This is not for a minute to diminish the value of local grassroots efforts but to highlight a parallel need for cost-effective anti-stigma initiatives that have the potential for population penetration. This is particularly important given that public awareness and acceptance play an important role in encouraging community participation for stigmatised individuals (1). Having said that, the use of an integrated approach of education and indirect contact may offer an avenue for larger impact within public stigma efforts. The Nigerian study showed a medium to large effect on *Knowledge of Capacity* which was maintained over time, a magnitude of change that is more commonly seen for standalone direct contact efforts (11). However, this effect was not replicated within the Kenyan study and this difference between both countries may offer insight to important mechanisms of change.

Some noticeable differences in attitude change post-intervention were observed between the two countries. While in the Nigerian study endorsement of stigmatising supernatural causal beliefs decreased in response to the intervention, the experimental film had no effect on *Supernatural Beliefs* in the Kenyan study. This may have been due to the Kenyan sample's much greater endorsement of supernatural beliefs at baseline compared to the Nigerian sample. Also, a slightly higher number of participants were affiliated to a religion in the Nigerian study compared to the Kenyan study which had more participants that identified as non-religious. While the difference was small, religious affiliations may have had an impact on participants' willingness to confront their preconceived ideas.

In the Nigerian study, recognition of the capabilities of people with ID increased over time following the intervention. In the Kenyan study while there was a positive change observed in *Knowledge of Capacity* post-intervention, this change was not maintained at follow-up. An explanation for this difference might be due to the capabilities of people with ID being showcased differently in both videos, despite attempts to make the film contents the same in both countries. The Kenyan film implicitly showed the capabilities of people with ID by featuring them engaged in a range of activities. In contrast, the Nigerian film presented this information explicitly by having the individuals with ID featured state what they could do in addition to demonstrating it. This approach in the Nigerian study of combining education and indirect contact/firsthand observation of members of the stigmatised group to challenge common stereotypes of people with ID as incapable, seemed to have had a greater positive impact on participants' attitudes than relying on indirect contact/observation alone. Furthermore, unlike *Knowledge of Capacity*, all other cognitive constructs (i.e. *Knowledge of Rights, Knowledge of Causes and Superstitious Beliefs*) were addressed by experts in both studies while images of people with ID were shown. Taking a more educational approach in this section of the films, with little input from people with ID sharing their views, appears to have resulted in the opposite effect when compared to *Knowledge of Capacity*, as little to no change was observed for these constructs, with the exception of *Supernatural Beliefs*.

These findings are in line with other studies that have shown that people with disabilities advocating for attitude change can help to promote parity over pity and be more impactful in changing attitudes in disability contexts than non-disabled others leading the charge (13). It also suggests that when trying to change beliefs within an African context, mere exposure (e.g. through images) of people with ID may not be sufficient and a level of interaction is required in order to produce positive contact outcomes. Thus, an integrated approach that positions people with ID as agents of change in public initiatives within African regions warrants further research.

Looking specifically at *Knowledge of Rights*, the difference in effects observed between both studies and at different time points may be explained with reference to Allport's contact hypothesis. One of the images shown in the Nigerian study implicitly suggested institutional endorsement of the rights of people with ID. The image showed people with ID who were also featured in the film holding their voter's card for the presidential election that had recently taken place in the country. This could not be replicated in the Kenyan study. Indeed, institutional support, one of Allport's conditions, is believed to be important in producing positive contact outcomes (12). However, the magnitude of its effects has been reported to diminish when isolated from other facilitating contact conditions, conditions that were not fully met in the educational section of the intervention (12). This may explain why even though participants' endorsement of the rights of people with ID increased, this effect was not lasting.

Irrespective of the cognitive components of attitudes and the differences identified between both films, the behavioural factors saw positive shifts that were maintained over time. In light of these findings, one might argue that while Allport's conditions may not be necessary to reduce behavioural intent, their ability to enhance the likelihood of positive change is of importance when targeting cognitive constructs. This is because cognitive aspects of stigma within this study seemed to be more sensitive to varied contact conditions. This warrants further research.

However, the extent of noted effects in the present study comes into question when considering how attitude change based on self-report translates into actual behaviour. A meta-analysis of the intention-behaviour relationship concluded that a medium to large change in behavioural intention (d = 0·66) leads to a small to medium change in actual behaviour (d = 0·36) (27). As noted, a medium to large effect size (d = -0·624) was observed in Nigerian participants' increased understanding of the capabilities of people with ID. Medium effect sizes were also observed for Kenyan participants' increased willingness to interact with people with ID at follow-up. This suggests that brief film-based interventions have the potential to make a positive contribution to efforts to reduce hostile attitudes and treatment of people with ID in countries such as Nigeria and Kenya.

Given that the effect sizes for different subscales varied between the Nigerian and Kenyan samples, most likely reflecting the subtle differences between the two experimental films, future research should assess how to maximise the potential for change through similar interventions.

Some of the attitudinal changes observed in this study may be due to measurement effects, which can create small but transient positive shifts in attitudes that could be erroneously attributed to the intervention (28, 29). This may explain why the control groups experienced some gradual increases in positive attitudes post-intervention. However, these positive changes were not significant over time. The experimental group showed more lasting and larger attitude changes in a desirable direction than the control group.

While delivery of such interventions via the internet risks only reaching internet users, through liaison with local community groups and stakeholders, film-based interventions can readily be disseminated through events at local community level, and in schools, churches or village centres. This method of dissemination is in keeping with reports from African experts in the ID field who state that small scale face-to-face campaigns in group settings across different towns and villages in Nigeria and Kenya have a wider reach and have proven vital in tackling ID stigma (4). However, mostly education-based approaches have been used. A film-based intervention similar to the one produced in this study, which combines both education and indirect contact can be used in such efforts to: (1) increase the effectiveness of anti-stigma initiatives used; (2) standardise the interventions delivered; and (3) reduce the amount of manpower needed to carry out anti-stigma initiatives, thus opening up opportunities for low-cost, accessible approaches. This study also reinforces the usefulness of global partnerships, highlighting the different ways academics and practitioners can work together to improve the well-being of people with ID around the world. Future research should assess how to ensure impact of such interventions to enable greater reach.

4.1 Limitations

Despite evidence of poor internet connectivity, this barrier did not significantly affect the delivery of the intervention or data collection, as the study had a wide reach. However, the diversity of the sample was, as expected, affected by the chosen delivery method. Both samples were unrepresentative and the findings should not be generalised to the general population. In accordance with other longitudinal studies, retention rates at follow up were low in both studies, further threatening the generalisability of the findings. However, the impact of the attrition rate on the studies' internal validity was controlled through statistical analysis. It should also be noted that the participants' characteristics (typically educated, young, and reporting prior contact with people with ID), which were influenced by the chosen method of delivery, have all been associated with more positive attitudes in previous studies (3), and as such may have contributed to the success of the present intervention.

While statistical analysis may allow for the intention-behaviour relationship to be estimated, this relationship is limited to medium to large intervention effects (27). Effects of this magnitude were only observed for two of the six subscales across both studies. As such, the likely effects of self-reported attitude change on actual behaviour within this study remain unclear. Furthermore, measuring attitudes through self-report always poses the risk of socially desirable responding. The following steps were taken to try to control for this bias: informing participants of their anonymity, blinding them to the purpose of the study, and using a scale that includes a neutral point thus reducing a forced response. Nonetheless this is a limitation.

Using an online platform for data collection did pose the risk of encountering trolls, bots and multiple responses. While some measures were put in place to try to control for this, such as installing timestamps and having open-ended questions at the end of the survey, more could have been done to prevent for this. Future research should explore the use of more stringent procedures to uphold the quality of the responses received in online research. This may include using a completely automated public Turing test to tell computers and humans apart (CAPTCHA) and adding some quality check questions.

5 Conclusions

This study found that a brief, film-based e-intervention was successful in reducing stigmatising attitudes towards people with ID among Internet users in both Nigeria and Kenya. E-interventions like the integrative approach used in this study present a viable contribution to stigma reduction efforts by promoting awareness in in a manner that is cost-effective, sustainable and can reach mass audiences, while still maintaining the quality of the evaluation methods used. How to maximise the potential for attitudinal change and stigma reduction, and whether similar brief interventions can have positive effects when delivered through mediums other than the internet and thus accessible to more representative audiences are questions for future research. Furthermore, given the risk that short-term interventions may only have short lived effects, future research should assess intervention effects over a longer term.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by University College London Research Ethics Committee. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

DO: Conceptualization, Formal analysis, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing. WC: Conceptualization, Formal analysis, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing. KS: Conceptualization, Formal analysis, Methodology, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2024.1331107/full#supplementary-material

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Social perceptions and the stigmatization towards fifteen mental illnesses in France: a preliminary study on the role of vital force and burden

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Introduction: This study examined social perceptions and rejection towards fifteen mental illnesses, as well as a preliminary test of the SUBAR model, that hypothesized perceptions of both vital forces and burden would be negatively and positively related to social rejection, respectively.

Methods: Using an online survey with participants from France (n = 952), social rejection was assessed using a feeling thermometer and a social distance scale, while social perceptions were measured using visual analog scales.

Results: A stigma map for these different disorders is drawn up, revealing the social perceptions and levels of stigmatization specific to certain mental illnesses. Controlling for relevant social perceptions (i.e., danger, warmth, competence), we found that perception of burden was positively and significantly associated to social distance and negative feeling for 73% and 67% of mental illnesses, respectively. The perception of vital force was negatively and significantly related to social distance and negative feeling for 87% and 20% of mental illnesses, respectively. The change in $R2$ between model 1 (i.e. perception of danger, warmth, competence) and model 2 (i.e. model 1 + perceptions of vital force and burden) significantly improved in 100% of cases for social distance and 67% of cases for negative feeling.

Conclusion: These preliminary data provide support for the SUBAR model and call for further investigations to better understand the social rejection of people with mental illnesses.

KEYWORDS

mental illnesses stigma, social rejection, vital force, burden, SUBAR, danger, communal/agentic traits

Introduction

People living with mental illnesses are subject to stigmatization, social rejection, and even dehumanization (1–6). However, not all mental illnesses are rejected to the same degree. For example, Marie et al. (Study 2) (3) revealed that the general population (in New Zealand) is significantly more likely to engage in an interpersonal relationship with a person labeled as having depression than with a person labeled as having schizophrenia. It appears that this difference in social distance is explained, at least in part, by an increased perception of dangerousness towards schizophrenia, which is consistent with theories indicating that threat leads to stigmatization and prejudice (7).

Duckitt's dual-process cognitive-motivational model of ideology and prejudice proposed that two main pathways would lead to the stigmatization of certain social groups: on the one hand, perceptions of threat and danger and, on the other, dominance/subordination stakes (8). There is some support for this model in the context of schizophrenia (2); the more individuals perceive danger and favor social dominance, the more they stigmatize people with schizophrenia. A second theoretical model that appears relevant explaining the stigmatization of mental illnesses is the stereotype content model (9). This model is based on the premise that individuals are predisposed to (i) first assess a stranger's intention to harm or help them (warmth dimension) and then (ii) judge the stranger's ability to act on this perceived intention (competence dimension). The different combinations between these two dimensions reliably predict affective reactions towards a variety of social groups (10). Sadler et al. (11) found that the stereotype content (i.e. warmth and competence) underlying the stigmatization of mental illnesses is not the same for all disorders. For example, individuals with disorders associated with psychotic symptoms (e.g., schizophrenia) are perceived as hostile and incompetent, whereas those with disorders associated with neurocognitive deficits (e.g., Alzheimer) are only perceived as incompetent.

In addition to these models, the Social Utility-Based Acceptance/Rejection (SUBAR) Model (12) has recently been proposed to explain the emergence of stigmatization towards different social categories, including mental illnesses. This model offers a complementary explanation to previous models, which could help improve our understanding of stigmatization. In addition to the perception of dangerousness and the ability to carry out a negative intention (9), the SUBAR model proposes that stigmatization can also stem from the target's perceived social utility. As this model has not yet been empirically tested, the current study was a preliminary test of the SUBAR model. This model proposes that human social cognition evaluates and reacts to agents/groups in a given social system on the basis of a social utility calculation aimed at determining whether individuals/groups contribute as much to the system as they benefit from it. To perform this calculation, individuals essentially dichotomize two perceived antagonistic forces: upward and downward forces. Upward forces are perceived *vital forces* (e.g., skills, resources, willpower), as they add value to a system and make a system more efficient in creating resources with positive social value. On the other hand, there are the downward forces, which are made up of perceived weaknesses that are likely to harm the system and weigh it down. This is the dimension of perceived *burden* (e.g., demotivation, use of benefits, dependence on others), which can fall on society or, in an interpersonal or family context, on the caregiver, for example. The model proposes that the result of the calculation predicts attitudes and behaviors towards the targets concerned. Overall, the perception of vital forces would promote the acceptance of the target agents/groups (i.e., positive attitudes and behaviors), as those ranked high in this dimension are perceived as contributing positively to the given social system. Conversely, the perception of a burden on others and/or society would promote the rejection of the target (i.e. negative attitudes and behaviors towards it), and therefore its stigmatization.

This new model leads to the prediction that mental illnesses would be associated with varying degrees of vital force and burden, which may explain why some disorders are more stigmatized than others. Firstly, we predicted that certain disorders, such as alcohol addiction and schizophrenia (highly stigmatized mental disorders (13);), would be associated with low vital force and high perceived burden. This would be less the case for other disorders that are stigmatized to a lower degree, such as eating disorders, obsessive compulsive-disorder (OCD) or anxiety, for example (11). Secondly, we predicted that the perceptions of vital force and burden will predict stigmatization. Specifically, we hypothesized that perceptions of vital force will be negatively and significantly related to stigmatization. Conversely, the perception of burden should correlate positively and significantly with social rejection.

To test our predictions, we assessed negative feeling (i.e. emotional response) and social distance (i.e. a proxy measure of behavioral rejection/discrimination) towards 15 different mental illnesses. To test the added statistical contribution of the SUBAR model to the explanation of stigma, we compared model 1 (i.e. perceptions of danger, warmth, and competence) to model 2 (i.e. model 1 + perceptions of vital force and burden) by computing the change in R^2 in a two-step multiple linear regression procedure.

Method

Participants

One thousand and sixty French citizens opened the online questionnaire, with 952 completing at least 60% of the questionnaire. The inclusion criterion was simply having answered all the questions for a single disorder. Thus, the statistical analyses included 952 participants. Of these 952 participants, 487 completed the entire questionnaire, including the demographic questions at the end. Among these 487 participants, 70.2% were women (*N* = 342), 25.9% were men (*N* = 126), and 3.9% were another gender (*N* = 19). The average age of the sample was 21.0 years (*SD* = 6.0; minimum = 18; maximum = 59). Most of the participants were University students from various fields (92%), with 10% of the sample being psychology students (*N* = 50). The study was approved by local Ethics Committee (IRB00013412, "CHU de Clermont Ferrand IRB #1", IRB number 2022-CF061) with compliance to the French policy of individual data protection. All participants have given informed consent to participate in the research.

Materials

Social distance

We used the social distance scale from Mather, Jones, and Moats (14) as a proxy measure of behavioral rejection/discrimination (15). Of the eight original items, we selected the four items that were most relevant for the context of mental illnesses, as well as to increase brevity. The four selected items were: (1) "I would be willing to accept a person with [a X disorder] as a close relative by marriage"; (2) "I would be willing to accept a person with [a X disorder] as a close friend"; (3) "I would be willing to accept a person with [a X disorder] as a neighbor on the same street"; and (4) "I would be willing to accept a person with [a X disorder] as a coworker". For each item, participants indicated their level of agreement with each statement using a Visual Analog Scale (VAS) ranging from (0) strongly disagree to 100 (strongly agree). We followed the recommendations of Mather et al. (14) and computed an intensity score (iScore) by multiplying Item 1 by 1, Item 2 by 2, Item 3 by 3 and Item 4 by 4. We divided this score by 10 to obtain a mean score with a minimum of 0 and a maximum of 100. This score was then subtracted from 100, so that a higher score indicates greater social distance (global Cronbach α = 0.89; global McDonald ω = 0.89).

Feeling thermometer

Negative feeling (i.e. prejudice) was assessed using a VAS ranging from 0 (very negative) to 100 (very positive). Participants had to indicate their general attitude towards adults' people with a X disorder. The score on this scale was reversed coded. Thus, a higher score indicated a greater negative feeling.

Social perceptions: vital forces/burden, warmth/competence and dangerousness

For each item, participants had to answer with a VAS ranging from 0 (strongly disagree) to 100 (strongly agree) the extent to which they personally perceived that adults with a X disorder are: (1) "able to occupy a position of high status and responsibility in society" (perception of vital force); (2) "a drag on society" (perception of burden); (3) "dangerous" (perception of dangerousness); (4) "friendly, sociable, warm" (perception of sociability); (5) "moral, honest, sincere" (perception of morality); (6) "competent, intelligent, efficient" (perception of ability); (7) "ambitious, self-confident, persevering" (assertive dimension). The last four items grouped together three traits each, to keep the questionnaire as short as possible. A score of "warmth/communal-traits" was computed by averaging sociability and morality (global Cronbach α = 0.85; global McDonald ω = 0.85). A score of "competence/agentic-traits" was computed by averaging the ability and assertive dimensions (global Cronbach α = 0.79; global McDonald ω = 0.79). For a similar methodology, see Aubé, Rohmer, and Yzerbyt (16).

Procedure

The Qualtrics online platform was used to deploy this online questionnaire. Participants were contacted by email via the university's mailing list to participate in the study. Once providing consent, participants completed the social perceptions, negative feelings, and social distance questions towards five randomly assigned mental illnesses out of a total of 15 (i.e., Attention deficit hyperactivity disorder – ADHD, Alcohol addiction, Anorexia, Autism spectrum disorder – ASD, Bipolar disorder, Bulimia, Burnout, Depressive disorder, Digital addiction, Gender dysphoria, Generalized anxiety disorder - GAD, Obsessive-compulsive disorder – OCD, Post-traumatic stress disorder – PTSD, Schizophrenia, Suicidal thoughts and behaviors) that appear in the Diagnostic and Statistical Manual of Mental Disorders (5th Ed, DSM-5; American Psychiatric Association, 2013). Participants only completed the assessments for five of the mental illnesses, as opposed to 15, to keep the questionnaire brief. The order of the measures (i.e., social perceptions, negative feeling, and social distance) and the order of items for each measure were also randomized. The number of participants that responded to each mental disorder is presented as Supplementary Material in Table S1. Based on *a priori* power analysis using G*Power 3.1 (alpha = 0.05, Power = 95%, expected r = 0.30), we had planned for a minimum of 138 participants per mental disorder. This was achieved, with a minimum of 176 and a maximum of 203 participants per disorder.

Statistical analysis

First, for the descriptives, we calculated the means for each measure and for each mental disorder. In order to compare mental illnesses with one another, we also calculated the grand mean for all illnesses. To enhance comprehension of the main results, these descriptives are presented graphically. As participants were randomly assigned to only 5 mental illnesses out of a total of 15, it was not possible to conduct cluster analyses. Thus, groupings were based on the grand means. Next, we tested our main hypothesis concerning the relationships between different social perceptions, negative feeling, and social distance. We thus conducted a series of correlational analyses. As most social perceptions did not follow a normal distribution, we performed Spearman correlations. Next, we performed a series of multiple regression analyses to identify the robust relationships between social perceptions and both negative feeling and social distance. Using a two-step multiple linear regression procedure, we computed the change in R^2 between model 1 (perceptions of danger, warmth and competence) and model 2 (i.e. model 1 + perceptions of vital force and burden). There was no multicollinearity (i.e., all *VIFs* < 3). We calculated the cook distance for each analysis and found that no extreme values were present. The normality test rejected the normality hypothesis most of the time (i.e., failed to achieve statistical normality). For this reason, we conducted bootstraps (i.e. bootstrapping based on 5000 replicates).

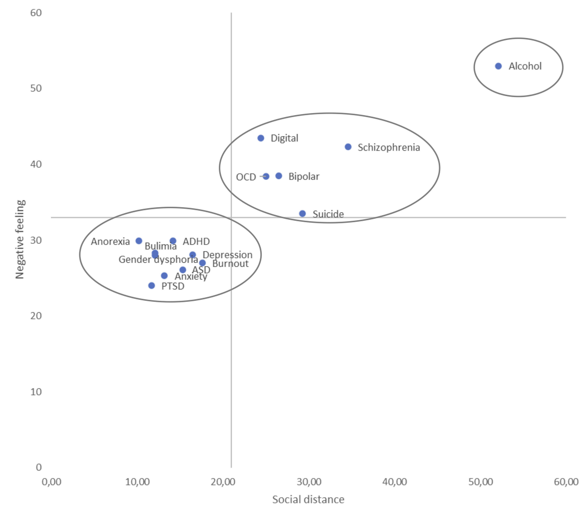

FIGURE 1
Social distance and negative feeling for fifteen mental illnesses in France.

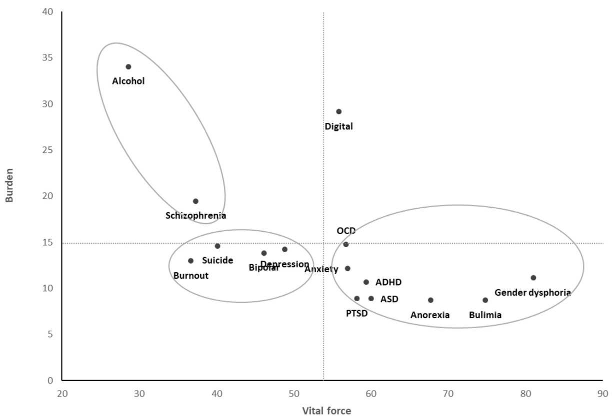

FIGURE 2
Perceptions of vital force and burden for fifteen mental illnesses in France.

Results

Descriptives

Social distance and negative feeling

The grand mean of social distance for the 15 mental illnesses was 21.0 (see X-axis on Figure 1) and the grand mean of negative feeling was 33.05 (see Y-axis on Figure 1). The mean scores of social distance and negative feeling for each mental disorder are displayed on Figure 1. Alcohol addiction was the most rejected mental disorder follow by a group of five mental illnesses (i.e., schizophrenia, digital addiction, bipolar disorder, OCD, and suicidal thoughts and behaviors). The other mental illnesses were rated more favorably.

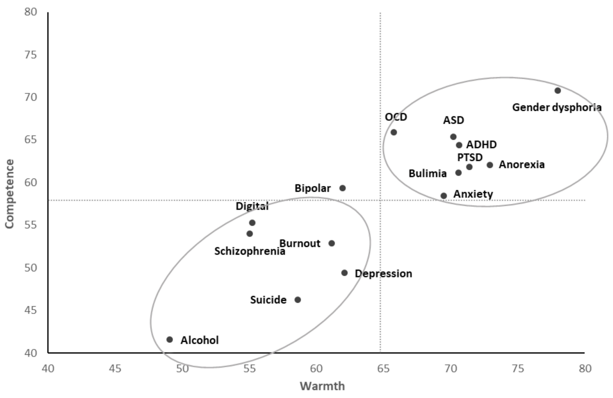

FIGURE 3
Perceptions of warmth/communal and competence/agentic for fifteen mental illnesses in France.

Vital force and burden

The grand mean of vital force for the fifteen mental illnesses was 53.9 (see X-axis on Figure 2) and the grand mean of burden was 14.8 (see Y-axis on Figure 2). The vital force/burden means for each mental disorder are presented in Figure 2. There were three groups: the low vital force/high burden group (i.e., alcohol addiction and schizophrenia), the high vital force/low burden group (i.e., gender dysphoria, bulimia, anorexia, ASD, ADHD, PTSD, generalized anxiety disorder and OCD). An intermediate group characterized by low vital force/intermediate burden was constituted of four mental illnesses (i.e., burnout, suicidal thoughts and behaviors, bipolar disorder, and depressive disorder). Digital addiction did not align with other conditions, with a high level of burden and an intermediate level of vital force.

Warmth and competence

The grand mean of warmth for the fifteen mental illnesses was 64.8 (see X-axis on Figure 3) and the grand mean of competence was 57.9 (see Y-axis on Figure 3). The warmth/competence means for each mental disorder are shown in Figure 3. There are two main groups. First, there is a low warmth/low competence group in which there are six mental illnesses (i.e. alcohol addiction, suicide thoughts and behaviors, schizophrenia, digital addiction, depression and burnout). The second group included the nine other mental illnesses (i.e. generalized anxiety - GAD, bulimia, PTSD, anorexia, ADHD, OCD, ASD, and gender dysphoria) and corresponds to the high warmth/high competence combination. The most stigmatized groups on the warmth and competence dimensions were alcohol addiction and suicidal thoughts and behaviors. Gender dysphoria was the one rated most favorably on these dimensions.

Dangerousness

The grand mean of dangerousness for the fifteen mental illnesses was 22.7, with five groups above this score: alcohol addiction (62.7), schizophrenia (41.2), bipolar disorder (35.5), suicide thoughts and behaviors (33.4) and OCD (26.4). All the means are presented in Supplementary Materials (see Table S2).

Relationships between social perceptions and rejection

Zero-order Spearman correlations between social perceptions and the rejection measures (i.e., social distance and negative feeling) are presented in Supplementary Materials (see Tables S3, S4). While vital force (*Rho* ranged from -0.18 to -0.60), warmth/communal (*Rho* ranged from -0.29 to -0.57) and competence/agentic (*Rho* ranged from -0.29 to -0.53) were negatively and significantly related to both social distance and negative feelings, burden (*Rho* ranged from 0.20 to 0.48) and dangerousness (*Rho* ranged from 0.10 to 0.52) were positively related to these outcomes positively.

We conducted a series of multiple regression analyses. The bootstrapped unstandardized beta coefficients of the relationships between the various social perceptions, social distance and negative feeling are presented in Table 1. To summarize the results, we computed to percentage of significant relations for each social perception across the fifteen mental illnesses. Concerning social distance, the most frequently related social perceptions were vital force (87%), burden (73%), danger (60%) and warmth traits (53%). Competence traits were not frequently related to social distance (7%). Adding vital force and burden (model 2) significantly improved the percentage of explained variance in 100% of cases (see R^2 change in Table 1). The average R^2 change was 0.075 (average total adjusted $R^2 = 0.37$). Concerning negative feeling, the most frequently related social perceptions were warmth traits (80%) and burden (67%). Danger (27%), vital force (20%) and competence traits (7%) were less frequently related to negative feeling. Change in R^2 between model 1 and 2 was significant for 10 out of the 15 mental illnesses (67%). The average R^2 change was 0.037 (average total adjusted $R^2 = 0.26$).

Conclusion

This study revealed some important results concerning stigmatization towards different mental illnesses in France and the SUBAR model. Firstly, the results reveal that of the 15 mental illnesses investigated, alcohol addiction was by far the most stigmatized in terms of social distance and negative feeling. When we examined communal/agentic and vital force/burden perceptions, once again the disorder that was perceived least favorably was alcohol dependence. This is consistent with the literature review by Schomerus et al. (13), who concluded, based on several surveys carried out in different parts of the world, that alcohol addiction "is a particularly severely stigmatized mental disorder" (p. 105).

On the dimensions of warmth and competence, Sadler et al. (11) found that the mental disorders rated most favorably were eating disorders, OCD, anxiety, bipolar disorder, and depression. Some similarities were found for the first three, but depression and bipolar disorder seem to be rated less favorably on these dimensions in France. Concerning the most stigmatized, in addition to alcohol addiction, we also found schizophrenia and other mental illnesses that were not investigated in Sadler's study, such as suicide, burnout, and digital addiction. So, there seems to be some cultural variation.

This study provides an initial mapping of perceptions of mental illnesses in relation to the SUBAR model dimensions of vital force and burden. As expected, the two most stigmatized mental disorders (alcohol addiction and schizophrenia) were in the area associating a low level of vital force and a high level of burden. In other words, they are depreciated on both dimensions. Conversely, low-stigma groups such as eating disorders, gender dysphoria, PTSD, and autism were positively evaluated on both dimensions (i.e., low burden/high life force). Lastly, some groups were depreciated only on the dimension of vital force, but not on the dimension of burden. These were moderately stigmatized mental illnesses, such as burnout, suicide, depression, and bipolar disorder. Those in society may not perceive those with these specific mental illnesses as having the ability to obtain high status or responsibilities, but are not necessarily perceiving them as a burden to society (e.g., on the healthcare system). Only one disorder, digital addiction, was depreciated solely on the burden

TABLE 1 Multiple linear regression bootstrapped unstandardized beta coefficients of the relationships between various social perceptions and social distance (A), and negative feeling (B) and R^2 change between model 1 and model 2^+.

	Multiple independent variables						
	Vital force	Burden	Danger	Warmth/ Communal	Competence/ Agentic	R^2 change model1/ model2^+	Total adjusted R^2
A. Social distance towards							
1. Attention deficit hyperactivity disorder-ADHD	-0.11**	0.32***	0.16*	-0.15*	-0.06	0.10***	0.43
2. Alcohol addiction	-0.28***	0.15*	0.24**	-0.14	-0.18	0.06***	0.38
3. Anorexia	-0.08**	0.18*	-0.06	-0.10*	-0.02	0.09***	0.21
4. Autism spectrum disorder - ASD	-0.26***	0.15	0.24***	-0.05	-0.05	0.14***	0.43
5. Bipolar disorder	-0.29***	0.13	0.16**	-0.22*	-0.10	0.09***	0.43
6. Bulimia	-0.10*	0.13*	0.20**	-0.28***	0.06	0.04**	0.36
7. Burnout	-0.05	0.14	-0.04	-0.10	-0.16*	0.03*	0.18
8. Depressive disorder	-0.10*	0.20*	0.20***	-0.15*	0.00	0.06***	0.43
9. Digital addiction	-0.25***	0.15**	0.08	-0.24**	0.00	0.09***	0.40
10. Gender dysphoria	-0.15***	0.16*	0.16	-0.09	-0.05	0.09***	0.51
11. Generalized anxiety disorder	-0.14**	0.15*	0.10	-0.08	-0.07	0.07***	0.22
12. Obsessive-compulsive disorder - OCD	-0.10	0.12	0.27***	-0.33**	-0.03	0.02*	0.46
13. Post-traumatic stress disorder - PTSD	-0.12**	0.26***	0.18***	0.01	-0.09	0.07***	0.33
14. Schizophrenia	-0.22**	0.24***	0.27***	-0.19*	-0.14	0.08***	0.50
15. Suicidal thoughts and behaviors	-0.17*	0.24*	0.07	-0.08	-0.19	0.10***	0.26
% of significant relations	**87%**	**73%**	**60%**	**53%**	**7%**		
B. Negative feeling towards							
1. Attention deficit hyperactivity disorder-ADHD	0.08	0.25***	0.05	-0.40***	0.09	0.05**	0.24
2. Alcohol addiction	0.01	0.13**	0.14**	-0.20*	-0.15	0.03*	0.32
3. Anorexia	0.03	0.05	0.10	-0.29**	-0.08	0.00	0.19
4. Autism spectrum disorder - ASD	-0.02	0.25**	0.05	-0.25**	-0.19*	0.03*	0.27
5. Bipolar disorder	0.05	0.13	0.07	-0.30***	-0.10	0.02	0.25
6. Bulimia	-0.15*	0.18**	0.10	-0.24*	-0.03	0.05***	0.30
7. Burnout	-0.04	0.19**	-0.0	-0.19*	-0.08	0.04**	0.19
8. Depressive disorder	-0.07	0.18*	0.04	-0.18*	-0.08	0.04*	0.22
9. Digital addiction	-0.19***	0.12**	0.06	-0.20*	-0.07	0.07***	0.36
10. Gender dysphoria	-0.22**	0.17*	0.14	-0.23*	0.02	0.07***	0.36
11. Generalized anxiety disorder	-0.09	0.07	0.21*	-0.24**	0.00	0.02	0.19
12. Obsessive-compulsive disorder – OCD	-0.08	0.04	0.07	-0.34***	-0.04	0.01	0.37
13. Post-traumatic stress disorder – PTSD	-0.02	0.12	0.15*	-0.22	-0.15	0.01	0.23
14. Schizophrenia	-0.05	0.22***	0.15**	-0.11	0.05	0.08***	0.27
15. Suicidal thoughts and behaviors	0.04	0.19*	0.00	-0.20	-0.17	0.03*	0.17
% of significant relations	**20%**	**67%**	**27%**	**80%**	**7%**		

*** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$; $^+$ R^2 change between model 1 (danger, warmth, competence) and model 2 (danger, warmth, competence, vital force and burden).
The bold values corresponds to the % of significant relations among the 15 disorders for each variables.

dimension (but not on the life-force dimension), making this a unique situation requiring further investigation to understand this outcome. The study population consisted overwhelmingly of students who are regularly exposed to excessive screen use (17). Perhaps familiarity with this disorder would partly explain its stigmatization on the dimension of burden alone. In a broad perspective, this would be consistent with the perspective developed by Corrigan and Nieweglowski (18), who proposed that familiarity with a disorder can sometimes increase its stigmatization, particularly when this is underpinned by a perception of burden for caregivers. Here, we are not talking about caregivers, but about people exposed to the interpersonal constraints exerted by excessive screen use. This seems to suggest that the burden dimension can be relevant to different contexts (13).

The analysis of the relationships between social perceptions and the stigmatization of mental illnesses provides preliminary support for the SUBAR model (12). Indeed, not only do bivariate correlations reveal significant relations of moderate size in most cases, but more importantly, when statistically controlling for perceptions of dangerousness and warmth/competence traits (factors known to predict the stigmatization of mental illnesses), perceptions of burden and vital force remained significantly predictive of stigmatization for a significant number of mental illnesses. As expected, while perception of burden was positively related to stigmatization, assessed by social distance and negative feeling, perception of vital force was most negatively related to social distance. The results also confirm that perceptions of danger and warmth/communal (but not competence/agentic) are robust predictors of stigmatization, but sometimes less so than perceptions of vital force and burden, particularly in the case of social distance. While social distance is considered a behavioral proxy for rejection/discrimination, negative feeling is a measure of prejudice (emotional response). Research suggests that emotional response to mental illness predates rejection/discrimination (15). In the present research, while the perception of warmth seems closely related to the "like-dislike" emotional response, the intention to reject and discriminate (a variable with potentially important social consequences) is more closely related to perceptions derived from the SUBAR model. Further investigation is required for these findings, specifically exploring if the SUBAR model yields distinct predictions for stereotypes, prejudice, and behavioral intentions (variables which typically exhibit weak correlations) (19).

In addition, comparisons between model 1 (i.e., perception of danger, "communal-traits", "agentic-traits") and model 2 (i.e. model 1 + perceptions of vital force and burden) revealed significant improvement in 100% of cases for social distance and 67% of cases for negative feeling. This suggests that SUBAR model could make an additional contribution to explaining the stigmatization of mental illnesses. Apart from the sense of threat (7) elicited by a target (perception of danger) and the perception of a target's capability to enact a negative intention toward us (stereotype content model (9)), stigmatization—particularly in the context of mental illness—may also stem from a perception of low social utility. A wealth of research reveals that two main dimensions are involved in the perception of other people and social groups: *agentic content*, which refers to goal achievement and task functioning (competence, assertiveness, decisiveness), and *communal content*, which has a social function of maintaining relationships and facilitating positive social interactions (e.g. helpfulness, benevolence, trustworthiness). These two dimensions have been described as "fundamental" or the "Big Two" (20–24). Although there are links, the SUBAR model also posits that individuals within a specific social system engage in a calculation to assess the contributions of others to the system. This model proposes that this utility calculus is the result of two dimensions: the perception of vital force and the perception of burden, which do not seem to be reducible to the agentic and communal dimensions. According to a recent literature review (12), the emphasis on perceived social utility is primarily linked to perceptions of a target's efficacy, dynamism, and confidence. On the other hand, perceived burden is primarily attributed to perceptions of fragility/vulnerability, a tendency to demotivate, and a propensity to depend on others. Of course, future research may test these hypotheses.

This preliminary study has several limitations. The first limitation concerns the study sample, which consisted mainly of female French students. Replication with a more heterogeneous and culturally diverse sample would be welcome, especially considering age and gender can play a role in mental illness stigma (25). Secondly, although it has been shown that a single item can have similar psychometric qualities to a scale made up of several items (26–28), we think that it would be important to develop, in a future study, a scale assessing vital force and burden made up of items assessing different aspects of these perceptions. It is unlikely, for example, that the item used in the present study to assess the perception of vital force would cover all aspects of this construct. Thirdly, warmth and competence (mean $r = 0.73$) on one hand, and vital force and burden on the other hand (mean $r = -0.34$), are not independent constructs. They shared a common variance (see Table S5 in Supplementary Materials). Thus, caution should be exercised when interpreting our figures with two right-angles. In sum, while these results are encouraging for the SUBAR model, further research is needed.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary Materials, further inquiries can be directed to the corresponding author/s.

Ethics statement

The studies involving humans were approved by IRB00013412, "CHU de Clermont Ferrand IRB #1", IRB number 2022-CF061. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

MD: Conceptualization, Data curation, Formal Analysis, Investigation, Methodology, Project administration, Software, Supervision, Validation, Writing – original draft, Writing – review & editing. GM: Data curation, Formal Analysis, Investigation, Methodology, Software, Writing – original draft, Writing – review & editing, Validation. LMn: Conceptualization, Investigation, Methodology, Writing – review & editing, Resources, Validation. MCl: Investigation, Methodology, Project administration, Writing – review & editing. FD: Conceptualization, Investigation, Methodology, Project administration, Writing – review & editing. NC: Conceptualization, Methodology, Writing – review & editing. FT: Conceptualization, Methodology, Writing – original draft, Writing – review & editing. LMt: Conceptualization, Methodology, Writing – original draft, Writing – review & editing. MCo: Conceptualization, Methodology, Resources, Writing – review & editing. IC: Conceptualization, Methodology, Resources, Writing – review & editing. JF: Formal Analysis, Investigation, Software, Writing – review & editing. MI: Resources, Writing – review & editing. JD: Resources, Writing – original draft, Writing – review & editing. RdlS: Resources, Writing – original draft, Writing – review & editing. BL: Resources, Writing – original draft, Writing – review & editing. AS: Resources, Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyt.2024.1336690/full#supplementary-material

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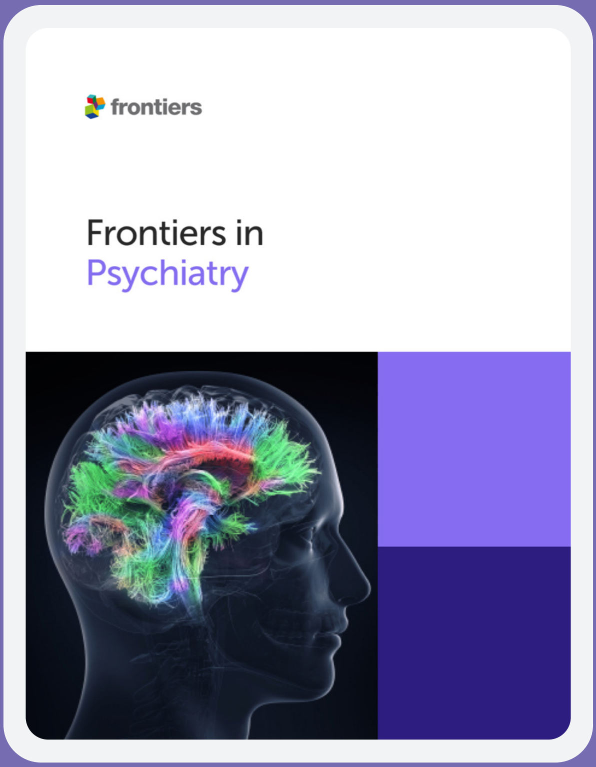

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