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Unraveling the stigma: a qualitative descriptive exploration of the relationship between culture, religion, and mental disorders in Saudi Arabia

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Abstract

Background A lack of understanding about the needs of people in Middle Eastern and Islamic contexts living with mental health disorders, and their experiences of diagnosis-related social and personal stigma inhibits high-quality care.

Methods This qualitative descriptive study, based in Saudi Arabia, used the Stigma Mitigating Conceptual Model to explore mental disorder-related stigma from the perspective of challenges and strategies connected to knowledge, attitudes and behaviours. Thirteen adults with mental health disorders completed semi-structured interviews, analysed using reflexive thematic analysis.

Results Four major themes and nine subthemes pertaining to the impact of stigma on public and self/personal knowledge, attitudes, and behaviors were identified: (1) *effects of the mental disorder on everyday life*, (2) *challenges*, (3) *overcoming the challenges*, and (4) *types of stigma experienced*. Greater knowledge of mental health disorders promoted Islamic principles of compassion and support, while the absence of knowledge exacerbated public stigma and fears the individual is under the influence of the 'Evil Eye', or lacks prayers and devotion. Participant strategies to mitigate stigma include education, and more opportunities for those living with mental health disorders to share their stories.

Conclusions Study findings provide nuance into the role of stigma in the context of cultural and religious factors in Saudi. These insights can be used to help tailor care and interventions to people from Middle Eastern contexts, as Western perspectives have predominantly driven mental health care.

Keywords Social stigma, Self-stigma, Mental disorders, Saudi Arabia, Qualitative research

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Background

People living with mental health disorders often experience personal and public enforced stigmatising attitudes and behaviours based on prevailing social misconceptions [1]. This is a wide-spread phenomenon, also found in Saudi Arabia [2, 3]. However, there is limited qualitative exploration of the experiences of those living with mental health disorders from a Saudi context. Specifically, exploration of how people perceive and navigate the barriers, challenges and associated stigma [4] that can accompany mental illness, with such knowledge needed to help inform health interventions with incorporation of cultural context [5–8].

Stigma is a socially discrediting attribute, behavior, or reputation causing an individual to be classified by others as an undesirable, rejected stereotype, rather than an accepted individual [9, 10]. Stigma has been classified within two types: public and self-stigma [1]. Within the context of mental illness, this means that people are responding to overlapping and compounding public and personal challenges both of the condition itself, and then of the reactions and responses to the condition. Impacts of self-stigma occur when individuals internalise public attitudes and beliefs, and suffer negative consequences as a result [1]. Public stigmatisation of mental disorders can directly lead to harm in various areas of everyday life, for example, building and maintaining relationships, gaining and maintaining employment and housing, and accessing healthcare including for treatment and recovery [11, 12]. The impact of stigma can be so significant that the impact has been described as a ‘second illness’ [4]. With a Saudi context, this ‘second illness’ can be understood within concerns of social isolation, a reluctance to seek help, and concerns around shame and potential reactions that may subsequently further exacerbate existing mental disorders [2, 3].

Stigmatization of people with mental health disorders is a global phenomenon, with multiple studies showing that stigma-related fears and experiences serve as a major barrier to treatment and a reluctance to adhere to treatment [13–18]. Global reports also show that the lived experiences of stigma are varied, making it an unpredictable phenomenon. For example, public and self-stigma can inhibit relationships due to misconceptions and preconceptions among people with mental health disorders as well as those around them [13, 19–21]. Conversely, there can also be positive experiences in contexts where social, relational and health needs are openly addressed. For example, a Swedish study discussing life domains, healthcare facilities and services provided to people with mental disorders other than psychiatric services found that many services were adequate and suitable such as dental care and social services [22]. Friends and family could also play a powerful role, as found in one

Australian study, in which positive treatment provided by family and friends exceeded the amount of discrimination by 74.1%, with positive treatment defined as the provision of emotional support, maintaining contact, following-up on a client’s mental disorder and being good listeners [23]. An important observation in a UK-based study was the disclosure by participants that having a diagnosis of a mental disorder did not stop them from achieving what they wanted on social and personal levels with the highest satisfaction was reported with regards to living accommodation, personal security, and family relationships [24]. In some instances, people with mental health disorders have shared that negative stigma encounters can result in greater psychological resilience [25, 26], while the humanity and personhood of those living with mental health disorders was compassionately discussed in a South African study, stressing the desire of people with mental disorders to be treated with love and respect [14].

Notably, a survey of 4000 individuals in Saudi found that approximately 34% meet the criteria for a mental health condition but only 5% seek treatment [27]. Exploration of stigma towards people with mental disorders in Middle East communities shows a prevalence to discriminate more toward culturally incongruent mental disorders such as alcohol abuse, compared to disorders such as depression [28, 29]. Stigma was also experienced at the hands of healthcare professionals [7], while this is not an uncommon finding in other countries [30], in Saudi Arabia it may in part be connected to religious beliefs and other cultural norms such as the Evil Eye and role of spiritual causes [2]. Conversely, religious and other cultural norms have also been a greater cause for compassion and support, such as beliefs in helping others [9]. Efforts to identify effective methods to alleviate stigma are also underway in the Middle East. One Saudi Arabian-focused study discussed the negative effects of seeking inappropriate community care, such as unlicensed Muslim clergymen [16]. In response, study participants in focus groups shared useful recommendations such as providing mental health services by primary healthcare centers, participation of licensed clergymen in health education campaigns, providing mental health consultation by psychologists at schools and developing a hotline for confidential psychiatric consultation services [16].

As shown above, regardless of the commonalities found in experiences of the negative impacts of stigma across the global literature cited, it is not always possible or appropriate to generalize practice recommendations and responses between different countries [5]. While global work can reveal patterns and relationships, it is necessary and important to listen to people from within their own unique settings. Thus, while there is vast exploration of experiences of people with mental disorders in

many countries, this is an area of sparse research in Saudi Arabia.

The lack of understanding and inclusion of the perspectives of people with mental health disorders is addressed in the 2030 vision of Saudi Arabia [31] recommending a need for improvements to mental health services and care from the standpoint of those receiving the care. As such, this present work is part of a wider effort in Saudi Arabia to further understand and mitigate stigma towards people with mental disorders [16]. The interpretation of our work was guided by the Stigma Mitigation Model, a conceptual framework [8] to guide categorization and interpretation of data and identify attitudes, behaviours and knowledge about the role of stigma. Specially, this study aimed to explore and understand the experiences, challenges and coping strategies of mental health disorders and stigma among people living in Saudi Arabia, with the intention of generating context-specific insights to inform stigma-reducing interventions and influence policy adaptations.

Conceptual framework

This study examines stigmatising experiences in mental health, adapting the Stigma Mitigation Model (SMM) (Fig. 1) [8]. The original SMM provided a structure for intervention research aiming to reduce stigmatising attitudes, knowledge and behaviour [8]. It was first developed and tested in a quasi-experimental trial of an educational intervention to reduce stigmatizing attitudes among nursing students in Saudi Arabia by author (L.S.)

[8]. The SMM was developed by drawing together the overlapping relationship between the work of Thornicroft [12] and Steckler et al. [32], and embedding experiential data from people with mental health disorders.

Thornicroft theorises that stigma is a threefold problem of attitudes, behaviour and knowledge, wherein stigmatising attitudes lead to prejudice, behaviours lead to discrimination, and knowledge leads to ignorance [12]. Steckler et al. [32] developed an operational model illustrating connections between healthcare education interventions and outcomes in healthcare status. According to Steckler et al. [32], an overall aim of health education interventions is to influence health status positively, which is best reflected via changes in intermediate outcomes such as knowledge, behaviour or attitudes that in turn bring about 'identifiable and measurable' changes in health status [32]. Where Thornicroft's theory explores the negative outcomes and processes of stigma formation, the SMM reverses these negative perceptions, using Steckler's operational model to actively work against stigmatising attitudes, behaviour and knowledge. Thus, the threefold problem of attitude, behaviour and knowledge is reversed by implementation of health interventions, so that 'ignorance' (knowledge) becomes 'awareness'; 'prejudice' (attitudes) becomes 'justice'; and 'discrimination' (behaviour) becomes 'affirmative action'.

The present study offers an important opportunity to strengthen the original SMM framework with a wider scope of experiences that addresses cultural nuance, and thus, supports intervention development and application

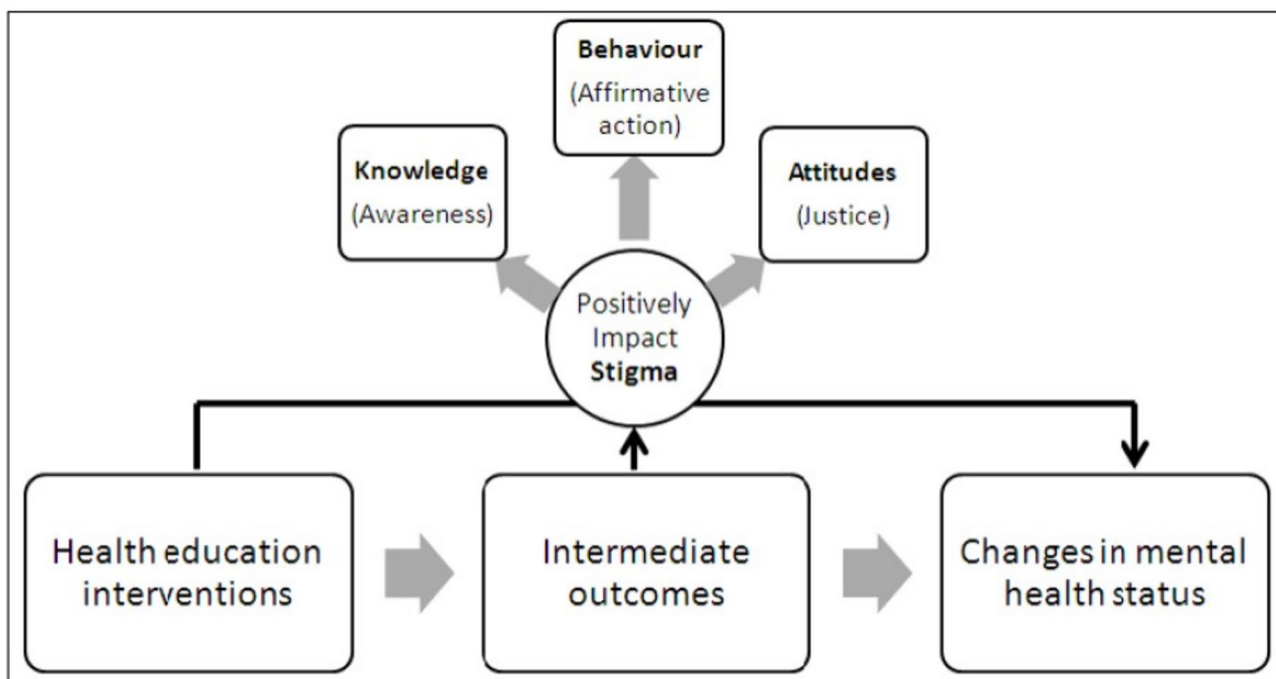


Fig. 1 Sharif's stigma mitigation conceptual model

of the SMM to Middle Eastern contexts. First, the original application of the framework to inform intervention development was limited by a lack of culturally-nuanced experiential data specific to those living in Middle Eastern cultures and contexts [8]. While the original SMM successfully used data from Western perspectives, demonstrating modest reductions in stigmatizing knowledge, attitudes and behaviours among nursing students towards mental disorders, it is still vitally important to integrate core cultural perspectives [2, 3, 9]. Thus, the present study builds on this gap in the literature, offering both the opportunity to learn important insights about the experiences of mental health disorders and related stigma, along with strategic responses of people living with mental health disorders in Saudi Arabia, and further, a mechanism for which these data can be rapidly applied to stigma reduction interventions. Per Fig. 2, the present application of the SMM now embeds culturally congruent qualitative data focused on the domains of knowledge, attitudes and behavior into the process mapping for intervention development, implementation and outcome evaluation of stigma reduction.

Methods

Design

This study used a qualitative descriptive research design as it enables the extraction, summarization and presentation of events experienced by a group of individuals as themes that are described in simple relatable terms [33].

Further, a value of qualitative research in mental health service research is in capturing the lived experiences and personal perspectives of those being studied [34].

Ethical considerations

The necessary ethical approval to conduct this study was obtained from the Nursing Research Ethics Committee (NREC) at the Faculty of Nursing (FON), King Abdulaziz University (KAU) (approval number: (NREC serial: Ref No IF.23). Participants signed a consent to participate declaration form prior to the interview which outlined the study ethical approval, purpose, data management and confidentiality, and intended use of the data to improve mental health services in Saudi Arabia. Interviews were recorded using a hand-held Dictaphone and uploaded to a University-owned encrypted drive.

Setting

The study was led from a governmental university in Saudi Arabia. Interviews were conducted in a public library private study room rather than on university grounds to limit distractions, and provide a comfortable and anonymous setting.

Sample and sample size

Recruitment comprised purposeful, convenience sampling via three popular social media platforms in Saudi Arabia: WhatsApp, Facebook and 'X' (formerly Twitter) [35]. Adults aged 18 years and above, who were English

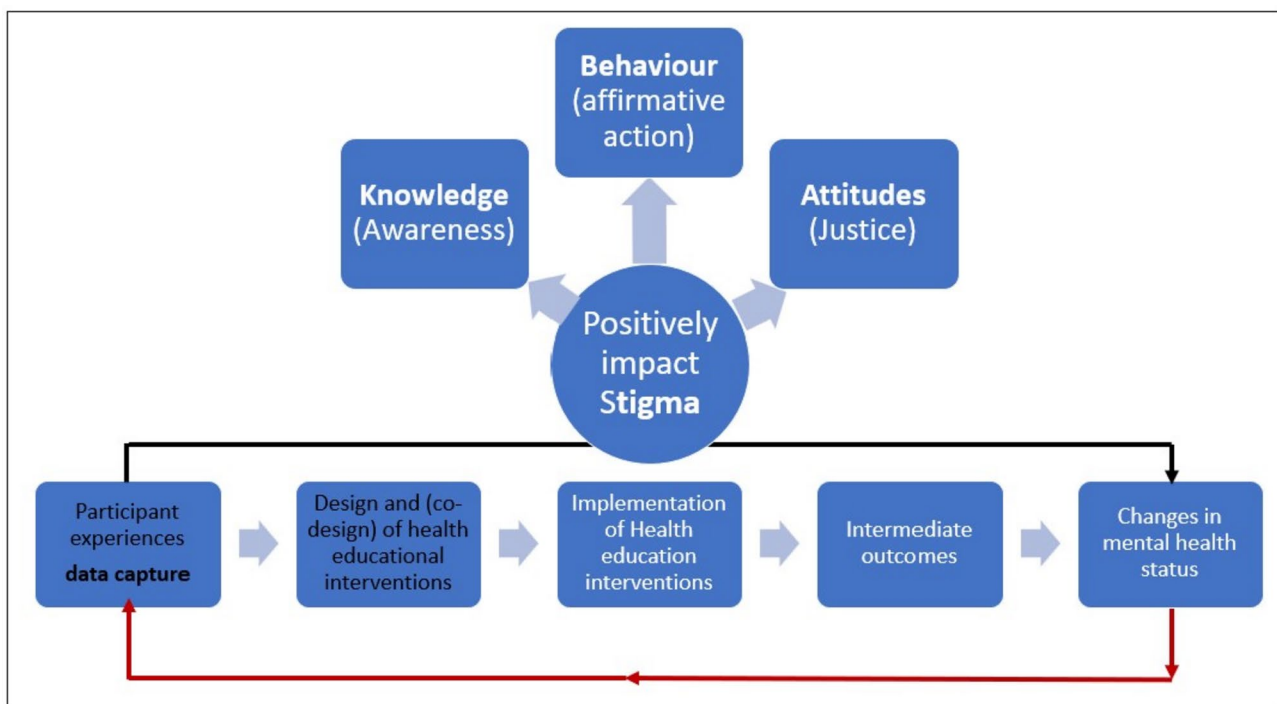


Fig. 2 Revised Sharif's stigma mitigation conceptual model

or Arabic speakers living in Saudi Arabia, with mental health disorder diagnosis were invited to complete a short survey indicating their interest in participating. Those meeting the inclusion criteria were contacted to arrange the interview.

Rather than using data saturation to determine sample size, we considered information power and data sufficiency [36–38] as this provides a qualitative framework *pre-data collection* [36, 37]. Within information power's five concepts this work had: (1) a narrow study aim, (2) anticipated dense specificity of experience and expertise of the participants, (3) use of an applied conceptual framework, (4) potentially weaker dialogue due to the novice status of student interviewers (under the supervision of an experienced researcher), and (5) cross-case analysis. We subsequently anticipated data sufficiency through a modest sample size of approximately ten to sixteen participants.

Data collection process

Semi-structured, audio-recorded interviews lasting 30–45 min supported by a topic guide were conducted by undergraduate student researchers, trained in qualitative research methods under the supervision of PhD trained nurse faculty who was the principal investigator for the study and an expert in mental health research. The study team were all female. The topic guide (refer to [supplementary file](#)) was developed around the concepts of the SMM [8], and gaps in knowledge identified in the literature [3, 9, 39]. The guide explored three core aspects of living with mental illness: (1) Individual history and daily challenges; (2) Reactions of people when mental illness was disclosed; and (3) Public awareness and attitudes towards mental illness, including messages participants would like to share with the public. Fieldnotes were made during the interview to provide supplementary context for analysis.

Data analysis

Data were analysed inductively using reflexive thematic analysis (RTA) [40] within the three concepts of the SMM [8]. RTA was selected as its deliberate and contemplative nature encourages rigorous and rich discourse among the research team in the processes of understanding the meaning of qualitative data [41].

Translation and transcription processes aided in the first stage of reflexive thematic analysis (see below), including data familiarization and generation of initial codes. Codes were arranged in a table and considered for patterns and relationships which could be understood as categories. Categories were reviewed for meaning within the context of the concepts in the SMM (knowledge, attitudes and behaviours), and drawn out into broader themes and sub-themes. Throughout this process, senior

researchers (L.S., A.M., R.A.), all doctoral trained nurse researchers with expertise in mental health and nursing research, provided support with analysis and identification and structuring of themes. As part of the analytical process, a coding tree was developed (Table 1), mapping themes, subthemes and quotations to the underpinning SMM.

Rigor

Guided by Braun and Clarke's methodology for reflexive thematic analysis and Lincon and Guba's criteria for trustworthiness (credibility, transferability, dependability and confirmability) we embedded a number of strategies to ensure all data collection and analysis processes were trustworthy, rigorous, and grounded in reflexivity [40–44]. As per Braun and Clarke's recommendations for reflexivity in thematic analysis [40], the supervisors established routine briefings and debriefings pre and post-data collection in which students discussed their expectations, assumptions and feelings, and the areas of possible bias that could influence data collection.

As with data collection discussions, the study team attended regular meetings throughout the data analysis process, wherein the supervising researchers facilitated discussions to aid reflexivity [40]. This included reflection on where and how personal biases may influence data interpretation. They also supported resolution to help navigate conflicting opinions on interpretation of meaning within participant experiences, and to agree final interpretation. Interview data were transcribed verbatim into English by the student researchers, as healthcare is predominantly conducted in English in Saudi [45]. Each participant was assigned a unique code, and six student researchers (R.B., D.A., A.A., A.K., R.A., and L.A.) individually reviewed transcripts to ensure accuracy in translation and transcription. To ensure accuracy and validity of the translation, the supervising researchers who are fluent in English (L.S., A.M., R.A., and K.S.) reviewed and co-checked the transcriptions. Finally, to build further credibility and dependability, (R.W.), a doctoral trained nurse with expertise in qualitative research and a native English speaker, worked with the team to review the analysis for credibility and context in the interpretation of the translated data, which included back-translation into Arabic by (L.S.) [44].

Two other steps were taken to ensure credibility and trustworthiness in our processes. First, as part of the analytical process, the student researchers returned to participants to verify their understanding and interpretation of the data. Participants were also invited to provide additional information about their data where there was a lack of clarity or understanding on the part of the research team. Though not all participants agreed to validate (see Limitations), this additional step provided

Table 1 Coding tree

THEMES (T) & SUBTHEMES (ST)	CODED, SUPPORTING QUOTATIONS	Relationship to Stigma Mitigation Conceptual Model Components		
		K*	A**	***B
T1: EFFECTS OF MENTAL DISORDER ON EVERYDAY LIFE				X
ST: Effects on family and social life	<i>I didn't leave the house much, malls bothered me, and crowds and noises had me feel disassociation – (P2).</i> <i>“...not in the mood all the time...became careless” (P3)</i> <i>“I used to isolate myself from people so no one will notice the symptoms that I have... when I had to, I would lie and fake laughs but inside of me I feel like there is a baby crying” – (P1)</i>			x
ST: Effects on work/studies	<i>“had to temporarily suspend my studies” – (P11)</i> <i>“completely withdrew from college - (P10)</i>			x
ST: Effects on physical health and wellbeing	<i>“Sleeping was difficult... I was distracted...” - (P10)</i> <i>“...my sister noticed the cuts on my arms...” – (P2)</i>			x
T2: CHALLENGES		X	X	X
ST Public	<i>“...didn't actually believe [me]...” (P7)</i>		x	x
•Family and friends rejecting the idea of illness	<i>“...thought I was just being spoiled and not actually suffering...” (P8).</i> <i>“...they don't understand and think it's a false subject” (P1).</i>	x		
•People's lack of knowledge about mental illnesses	<i>“people aren't accepting it [because] they don't have enough knowledge in this field to consider it just like any other disease”. – (P10)</i>			
•Religious beliefs standing in a way of accepting the illness	<i>“...less sensible, unable to make decisions and that they have done that to themselves in one way or another, not being religious enough and not being close to god is one of the reasons for their suffering. Society could never believe in patients with mental disorders and their abilities to take care of themselves...” - (P11).</i> <i>“people blame you for feeling like this and assume it's from how distant you are from God, and ask you to pray and read Quran [Muslim holy scripture]” (P8).</i>		x	
ST Personal				
Being afraid of telling people/ concealing the illness:	<i>“[my] view [of the illness] was so negative... [I] didn't take it as a normal illness”. (P3)</i>		x	x
> Worrying about public stigma and people's reaction			x	x
> Perceiving the illness as something personal, shameful and embarrassing				
Isolation and not having anyone to talk to about the illness	<i>“to isolate myself from people so no one would know” (P1)</i>			x
Trivializing or rejecting the illness	<i>“[this is] something normal for a human being... [something that] would pass” (P1)</i>		x	x
Lack of knowledge about the illness	<i>P3 did not seek treatment because she was convinced that only introverts may suffer from depression, and she was “the opposite of this”.</i>	x		
T3: OVERCOMING THE CHALLENGES		X	X	X
ST Public factors	<i>“Their acceptance made me accept myself peacefully” (P6)</i>		x	x
•Family and friends' positive reaction	<i>“...extremely positive and my family still is... ‘so what if they diagnosed you? Let them diagnose you with whatever because, in the end, this is meant to happen, and it will happen, and it was written before you were even in this world and I'm sure it is for the best” (P12)</i>			
•Family and friends' ongoing support and understanding	<i>The brother tried supporting her by telling her “this disorder happens to intelligent people” (P12).</i>		x	x
•Other people being aware and educated about the illness	<i>“...it's the kindness of those around me...” (P8)</i> <i>“they've got a background about mental health treatment”. (P2)</i>			x

Table 1 (continued)

THEMES (T) & SUBTHEMES (ST)	CODED, SUPPORTING QUOTATIONS	Relationship to Stigma Mitigation Conceptual Model Components		
		K*	A**	***B
ST Personal factors & strategies	"did a lot of search[ing] on the internet" (P1),	x		x
•Doing their own research on the illness	"searching and digging deeper" (P4)			
•Having knowledge about your illness	"I now understand my disorder and I really understand how it makes me think" (P8)	x		
•Talking about it openly and reaching out to other patients	"I was happy because there were a lot of unclear things to me...I thought it was normal to hear voices...it could be my imagination it could be anything, I didn't have the insight but afterward I knew that's not it, there was something wrong and it should stop and it should get treated." (P5)			
•Finding positive distractions and facing the triggers	"I answer freely about it if I'm asked" (P2)		x	x
•Reverting to religion	"was at peace with it and didn't really mind the topic." (P10)			
•Working on self-perceptions and self-positioning	"...would distract myself by exercising and spending time with my children" (P11)			x
	"I tried to avoid the things that possibly will make me angry, I started to do the things that I love, I did join volunteer teams, so I don't stay alone and overthink - (P3).			
	"I reverted back to religion for peace and comfort" (P3)			x
	"I started considering myself as a champion for getting over it, and indeed they have been better and I come out of them sooner instead of living two weeks of self-hate and blame...(P8)		x	x
	"felt like I should have done that a long time ago." (P9)			
T4: TYPES OF STIGMA		X	X	X
ST: Public stigma	"people aren't accepting of [mental health disorders]...people look at people with mental diseases in an inferior way or stay away from them...if you go to a Psychiatric clinic then you're crazy" (P10).	x	x	x
	"People's beliefs about you doesn't reflect who you truly are, it's not a shame to ask for therapeutic help from a specialist or anyone in case of psychological distress. And we should be proud of ourselves because at some point even sleeping was a great achievement. You will get through it just like you got through a lot of stuff and still made it. Your health is above all." (P2).			
ST: Self-stigma	"...felt weak and stupid...used to really hate myself back then". (P8)	x	x	x
	"to explain and apologize" (P11)			

*K=Knowledge, **A=Attitudes, ***B=Behaviour

greater confidence in the analytical conclusions for the study team. Second, (K.S.) a senior consultant psychiatrist and (R.W.) provided a peer review of the rigor in methodological conduct and subsequent credibility of the findings, through review of the documented processes and in discussion with the study team.

Results

Thirteen individuals were interviewed (Table 2), aged between 20 and 42 years with a diagnosis of a mental health disorder according to Diagnostic and Statistical Manual of Mental Disorders (DSM-5) [46]. Twelve were female, and all but one Saudi who was from Jordan. Four were married and the rest were single. Nine participants were students (69%), with two unemployed, one employed, and one who declined to share their work status. Seven participants had a single diagnosis, and six had between two to four diagnoses. Diagnosis period ranged from one week to six years, and included depression, anxiety, panic disorders, bipolar disorder and social phobia.

The analytical process identified four main themes and nine subthemes reflecting presence or mitigating effect on stigma through either knowledge, attitudes or behaviour (Table 1). The main themes were: (1) Effects of

the mental disorder on everyday life (*subthemes: effects on family and social life, effects on work/studies, effects on physical health and wellbeing*), (2) Challenges (*subthemes: public challenges, personal challenges*), (3) Overcoming the challenges (*subthemes: public factors and personal factors and strategies*), and (4) Types of stigma (*subthemes: public stigma and self-stigma*).

Theme 1: effects of mental disorder on everyday life

Participants were asked about the impact of living with a mental health disorder and how it impacted the various facets of their life. Participants shared that both their own behaviours and the behaviours of others, experienced through relationships could have a profound impact on everyday life. Relationships could be volatile or unpredictable, with repercussions for the participant's abilities to focus on, and manage studies and work. The influence was captured within three subthemes: *Effects on family and social life, Effects on work/studies, and Effects on physical health and wellbeing*.

Participants described relationships with friends and families affected by "mood shifts" (P11) often resulting in tense situations, fights, "a lot of screaming and noise" (P1). P2 reported "regularly feeling tired or not in the mood", resulting in "clashes with people". In one instance,

Table 2 Participants characteristics

Part. code	Gender	Age	Nationality	Marital status	Edu. level /Employment	From whom they sought treatment	No. of dx.	Dx.	Dx. period	Hx. Of treatment
P1	Female	42	Saudi	Married	Employed	Psychiatrist	Two	Depression/ Anxiety	Two years	Psycho/pharmacotherapy
P2	Female	20	Saudi	single	Student	psychiatrist	One	Moderate depression	One year	Psycho/Pharmacotherapy
P3	Female	20	Saudi	Single	Student	Psychiatrist	Two	Depression/ anxiety	Six years	Psycho/Pharmacotherapy
P4	Female	28	Saudi	Married	Unemployed	Psychiatrist	Two	Depression/ anxiety	Six years	Psycho/Pharmacotherapy
P5	Female	21	Saudi	Single	Student	Psychiatrist	Two	Depression/ Panic disorder	One year	Psycho/Pharmacotherapy
P6	Female	23	Saudi	Single	Student	Psychologist	One	Depression	One year	Psychotherapy
P7	Female	23	Saudi	Married	Student	Psychiatrist	Four	Depression/ Panic disorder/ Anxiety / social phobia	Five years	Psycho/Pharmacotherapy
P8	Female	22	Saudi	Single	Student	Psychiatrist	Three	Depression\ general anxiety\ panic disorder	One year	Pharmacotherapy
P9	Female	21	Saudi	Single	Student	Psychiatrist	One	Depression	Four years	Psycho/Pharmacotherapy
P10	Male	25	Saudi	Single	Student	Doctor	One	Bipolar disorder	Two years	Pharmacotherapy
P11	Female	32	Saudi	Married	Unemployed	Psychiatrist	One	Bipolar disorder	Four years	Psycho/Pharmacotherapy
P12	female	21	Jordanian	Single	Student	Psychiatrist	One	Bipolar disorder	Three years	Psycho/Pharmacotherapy
P13	female	20	Saudi	Single	-----	Psychiatrist	One	Depression	One week	Psycho/Pharmacotherapy

Part = participant; Dx = Diagnosis; Hx = History; (-----) = participant did not provide information

a participant described a jarring sense when her husband tried to encourage her to socialise more: “*like he’s bothering me, he’s cutting my thoughts, cutting the mood I was having*” (P1). Common to all of these experiences was a resulting lack of socialization and increasing isolation (Table 1).

When reflecting on the effects on work/studies, participants described behavioural challenges to maintaining regular patterns. P3 described how she was constantly not in the mood to go to school, and lost interest in her studies due to her depression and insomnia. P12’s disorder affected her attendance at school, as she “*started questioning whether I should go or not*”. P6 “*asked to change my duty hours without any clarification or reasoning*”, and “*lost my passion*” for work. Some participants asked their bosses to change the location of their desk to a more isolated place.

Behaviours were experienced within *effects on physical health and wellbeing*. This could manifest as nausea, lack of sleep, lack of appetite and neglecting self-care. More severe symptoms experienced by participants included visual and auditory hallucinations, and self-harm: “*I had command hallucinations that made me almost kill both*

my sister and my father” (P5). Across relationships, work and health, the key point for many participants was a profound impact on everyday life from behavioural changes due to mental disorders.

Theme 2: challenges

The major theme ‘Challenges’ was intentionally broadly named due to the vastness of obstacles participants encountered (Table 1). Challenges were influenced by personal and societal knowledge, attitudes and behaviours, and additionally exacerbated by severity of illness. To break down this theme, we used the framing of public and personal experiences of stigma, and noted several subthemes. Within public challenges, subthemes included a sense of rejection or lack of knowledge from family and friends, and the role of religious beliefs impacting acceptance of mental illness. Within personal challenges, subthemes were observed connecting to the complex interplay of how the individual felt about the mental disorder, e.g., that it was shameful, embarrassing or too personal to share, which then influenced expectations of how others might respond which led to internalized fear and concealing the illness. As explored below,

within these personal reflections, participants shared about how this could lead to a sense of isolation or trivializing or rejecting their own situation. A personal lack of knowledge was also a factor underpinning this subtheme.

Public challenges

Public challenges related to negative behaviours or unsupportive responses from those external to the participant such as friends, family, or work or school colleagues. The most discussed public challenges were closely aligned and identified as subthemes '*Family and friends rejecting the idea of illness*' and '*People's lack of knowledge about mental illness*.' These were particularly important as participants shared their hope that support would come from those closest to them. Rejection was understood through family members saying participants were "overreacting" (P4), or "didn't actually believe [me]" (P7). P1 reported that her family and friends told her "nothing is wrong with you... you're imagining". This dismissal was painful, "as if I weren't depressed at all" (P6), or "reacted in a way that minimized the problem and that I'm exaggerating" (P11). Rather than offering help, people tried convincing the participant that "I was just fine" (P12). There was a perception a mental health disorder lessened the personhood of the individual. P5 explained that her family was well informed about the illness, but could not accept the thought of her suffering from it: "My family think...other people can have it...but when it comes to me...I don't want my daughter to have it', and then she would change the subject." P3 discussed the personal impact from this lack of knowledge:

...people need to be educated...because we do not have this culture...if I tell anyone from my family about the matter it's possible that they will laugh, mock me...their impression about psychological illness is...you will end up going to the mental hospital...It does not have a treatment and that a depressed person is not a human being that wants to be understood....

Reflections on the role of religion as a public challenge were particularly poignant given the central role of faith within this culture, leading to the subtheme '*Religious beliefs standing in the way of accepting the illness*.' People would often turn away from the affected person, believing that he or she "doesn't pray, doesn't worship Allah [God] like other people do, this is why she is not good" (P5). Therefore, rather than offering appropriate support or exploring the nature of the disorder, people could be "very afraid and worried and uncertain of what has happened to me" (P10), assuming that "it's magic or evil eye" (P11). Subsequently, instead of recommending seeking professional help, prayer and faith as a source of support,

recommendations were perceived as coming from a place of judgement and stigma.

Personal challenges

Personal challenges meanwhile, refer to impact of participants' own decisions, beliefs and actions. The most commonly mentioned was the subtheme '*Being afraid of telling people/concealing the mental disorder*'. Participants who discussed this issue pointed to two main reasons for doing so: *Worrying about public stigma and people's reaction*, and *perceiving the illness as something personal, shameful and embarrassing*. Participants mostly worried about being perceived as simply "wanting attention" (P2) or being mocked. Another reason for concealing the illness was (subtheme) '*Perceiving the illness as something personal, shameful and embarrassing*'. About half of the participants shared P10's view that "this is a personal issue to me, and I didn't like to share it with anyone", 'hating' the idea that someone may know.

Personal challenges exacerbated personal isolation, emotionally and physically: "a dark mood, a will to stay isolated" (P4); "[I] moved to a separate room at home not to face anyone" (P6). In some instances, personal challenge included finding ways to accept living with a mental health disorder, for example, belief that symptoms were "personality" (P5), or things "any other teenager would feel" (P9). Both P1 and P7 explained their symptoms of depression as a result of stressful circumstances. The internally experienced isolation could also exacerbate gaps in knowledge. P10 explained he initially neither sought help nor told anyone about the illness because he "considered it like a flu which attacks a person and gets cured [quickly]...it's not something permanent". Similarly, P3 did not seek treatment because she was convinced that only introverts may suffer from depression, and she was "the opposite of this". Most participants reported although they felt something was wrong, a previous lack of knowledge of mental health disorders meant it had not occurred to them that they might have this diagnosis.

Theme 3: overcoming the challenges

Theme 2 captures the resilience and response participants demonstrated to the challenges previously explored. We use the same public and personal lens to present them, which contain three and six subthemes respectively (Table 1), highlighting unique nuances. Within public factors, positive reactions, ongoing support and understanding from family and friends reflected 'overcoming challenges' in different ways, such as influencing the participants to seek out additional treatment or care. Likewise, the strategic subthemes housed within personal factors show that participants reflect upon their challenges and devise different mechanisms and coping strategies. While there was overlap in types

of approaches, these were tailored and bespoke by each participant to address the unique circumstances of their situation. Subthemes explaining the experiences of ‘overcoming personal challenges’ include addressing a lack of knowledge by conducting one’s own research, overcoming personal fears and talking to others, finding positive distractions including peace and comfort in religion, and working on internalised self-perceptions. As described below, it is notable that despite the many challenges, participants showed they were active players in their own lives, and that ongoing small but significant actions could be a powerful way of gaining back ownership of the negative impact of mental health disorder related stigma.

Public factors

Public responses reflected the opposite of the challenges described in theme 2. Just as negative attitudes and behaviours and lack of knowledge from friends and families could present significant challenges, the two subthemes of ‘positive reactions’ and ‘support and understanding’ show how the converse could be a major source of support. P2 explained, positive attitudes and behaviours “played a big role” in the subsequent experiences of the disorder, with family reacting well when they learned about how she felt, and later supporting her to seek professional help. However, a key point found in family and friend support and acceptance was presence of pre-existing knowledge about mental disorders.

The subtheme of ‘Others being aware and educated’ reflected where pre-existing knowledge could also be an additional source of practical help. P7 was “relieved” when her brother, a doctor, confirmed the psychiatrist’s diagnosis and reassured her that the prescribed medicine was safe. P2 and P9 felt previous cases of mental health disorders in their families was “a big contributing factor” to their families’ positive reactions. P3, in turn, had a friend who had suffered from depression and provided both a positive reaction and motivated her to seek professional help. Ongoing positive encounters beyond the first response were rewarding and helpful. P10 described how their family and friends “didn’t pressure me at home with responsibilities, they let me be as free as I wished, and I used to sleep a lot... [his friends]...didn’t keep asking me what was wrong with me and what has changed”. P12 recollected ongoing support, commenting that “the fact that my surroundings understand my case is comforting to me.”

Participants discussed a variety of coping strategies. Positive strategies included talking with a therapist and/or someone close to them, distraction techniques such as exercising, faith, prayer, reading and listening to Qur’an, and by volunteering. However, some participants spoke of negative coping techniques, including isolation and self-harm:

I always tried to isolate myself from people so no one would know the symptoms that I had or I’d lose someone - (P1).

Coping strategies were often connected to handling the reactions of others, rather than the mental disorder itself: “Their acceptance made me accept myself peacefully” (P6), or conversely “I once revealed it to one of my friend and I almost regretted it so I decided to close the subject completely” (P4).

Personal factors and strategies

Personal factors and strategies were those related to the participants’ behaviours or attitudes. The most discussed strategy that helped several participants was (subtheme) ‘Doing own research on the illness.’ About half the participants described that they were “asking people about it, reading and researching” (P12) to understand their conditions. P2 explained that her research prepared her mentally to hear the doctor’s diagnosis: “I was somewhat expecting what I heard”. ‘Having knowledge about one’s illness’ was a core subtheme in helping participants face their mental health disorders. Regardless of where the knowledge came from, several participants shared they were “happy that I got an answer” (P9). P8 explained that this knowledge helped transform her self-perception and self-esteem, as well as helping her control her panic attacks: “I could return back from that state of mind”.

In several instances, knowledge influenced behaviours, for example participants with knowledge to understand their own situation felt more comfortable to ‘Talk openly.’ This subtheme was identified by accounts of participants going on to reach out to other patients for support or to offer support. This, in itself, was a positive coping strategy, linking a personal strategy to external relationships and challenges. P4 describes this connection, sharing the moment she decided to tell a nurse about her symptoms as “a big change”. She was advised to see a doctor who helped her understand her illness, described it as “the best thing”. Subsequently, she started reaching out to other people in similar situations, explaining “they made me understand my feelings more and accept my treatment”.

Another strategic subtheme was ‘Finding positive distractions and facing triggers.’ The participants focused on positive things to divert themselves from negative feelings and emotions. P11 “would distract myself by exercising and spending time with my children”. P8 writes positive affirmations and future plans on a board after every panic attack. P9 works out and exercises. Other participants discussed ‘Turning to religion’ and praying as a strategy that helps them cope with mental illness. P8 additionally shared that working on ‘Self-perceptions and self-positioning’ was particularly helpful:

I started considering myself as a champion for getting over it...I come out of them sooner instead of living two weeks of self-hate and blame...like when I felt choked around people...Our society is miserably screwed up when it comes to this! I now consider my disorder as a crown....

Theme 4: types of stigma

The fourth and final theme captures broader participant reflections on the role of stigma in mental health disorder in Saudi. The participant's experiences spoke to *public* and a *self-stigma*, which were central to negative experiences, and seemed to both *be influenced by* and *influence* the challenges they discussed. This ultimately resulted in negative effects on their *family and social life, work/studies and physical health and wellbeing*.

Public stigma was not a fixed state and as previously discussed was often tied to lack of knowledge. Some families and friends were reported as having initial reactions of shock, dismay, denial and sometimes even anger, and then, upon processing the diagnosis, often becoming supportive and helpful:

"They left me...it was so hard for me but I wasn't surprised...I thought that they were bad friends but they came back. It was like they were preparing themselves...they were positive and very supportive and I love them." (P5).

Participants differed in their reflection of whether society was changing and becoming more accepting of people with mental health disorders:

"I believe it will still take long till this topic is considered semi-normal in the society and people don't feel ashamed when talking about it and having appointments to check up their mental health or taking med [medications]..." (P12).

"I feel that it is getting so much better...The new generation is aware, cultured and bold and will take the ways of science and treatment faster than the previous generation, I feel like this subject is spreading and its spread helped people accepted faster" (P5).

All the participants agreed that in order for society's perception to change, it is up to people with mental health disorders to be more open about their illness, to show a willingness to talk about it publicly, regardless of others' reactions:

"It made me sad that us people with mental disorders aren't open and talking about it and we're always expecting negative reactions." (P9).

The instances of *self-stigma* were present in several accounts related to other themes, as well as in the very language the participants used to talk about their experiences. Several participants reported feeling embarrassed their mental disorder, not sharing information because they believed it was a private issue. Additionally, the language the participants used when talking about their disorder included expressions such as *"not being normal"*, having *"something unnatural in me"* (P1). Per several participants, public stigma results from people not having *"enough knowledge in this field"* (P10). Another factor is the previously discussed religious beliefs, where a common perception could be that mentally ill people were *"not being religious enough and not being close to God"* (P11). Participants also had many positive messages to share with other people with mental health disorders. They revolved around the notion that mental health disorders are similar to physical disorders.

"Mental disorders are no different to any other organic illness. Without exception, we are all susceptible to a psychological setback in one point in our life. This is life, there is no society that is 100% healthy, but there is a society that can adjust to the illnesses and reduce the human losses as much as it can." (P4).

These reflections highlight the strength of the participants, and their messages of ignoring negative reactions from others, avoiding letting reactions affect them, and having self-pride. They also emphasize the importance of seeking help as soon as possible, and never losing hope.

Discussion

The purpose of this study was to examine how individuals with mental health disorders in Saudi Arabia experience stigma. The results highlighted widespread negative effects across multiple life domains, including everyday activities, family and social interactions, work and education, physical health, and general wellbeing. The study findings showed that public and self-stigma were experienced by participants which impacted daily life, mainly within interpersonal relationships, as found in other research [47, 48], including research with people from Arab cultures [49–52]. We found that societal perceptions about mental health disorders were overall negative, but participants developed coping skills and psychological resilience leading to positive views about themselves.

Cultural and societal norms around mental disorders in Saudi Arabia were reflected in the attitudes of responses that suggested participants were 'spoiled', exaggerating their symptoms, or in some way diminished in their spirituality and relationship to God [3, 50]. Public stigma also impacted those connected to participants, wherein

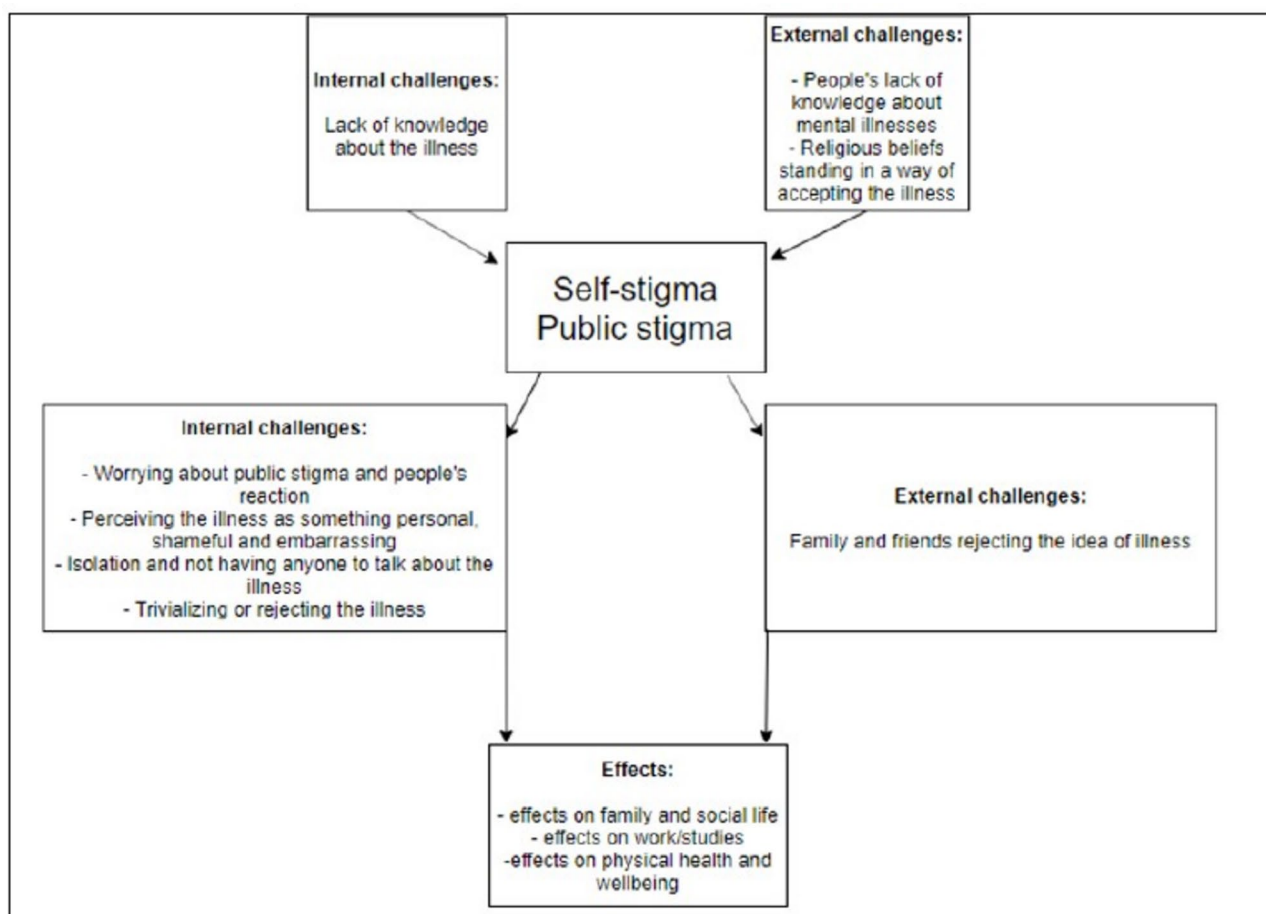


Fig. 3 The relationship between self- and public stigma and challenges faced by the participants

families rejected the notion that someone related to them could be diagnosed with a mental health disorder. These findings are reflected in a recent systematic review of stigma, beliefs, actions, and attitudes in Arab culture which found an overarching negative perception towards mental health disorders [49]. The article highlights a preference to seek faith-based care over medical treatments, but additionally states that reasons for not seeking medical care are tied to stigma on the personal and family level, such as shame associated with having a family member live with a mental health disorder [49]. Figure 3 provides a visual representation of the challenges experienced by many of the participants through the more negative or mixed reactions of family members and/or friends, showing how attitudes, behaviours, and lack of knowledge can foster development of both public and self-stigma.

We found that mental health disorders had a negative impact on people's work performance, reflected in other research, including exploration of mental health illness related stigma in Arab contexts, in which people with mental health disorders were worried about keeping their

jobs and not being treated differently than others [21, 49]. The impact of these types of stigma-related challenges cannot be understated. As the participants outlined, the accompany worry, fear, and subsequent changes in behaviour and relationships often aggravated the underlying condition and reflect that 'second-illness' impact that stigma brings. Our results found participants had different coping strategies, negative (isolation and self-harm), and positive (exercising, relaxation techniques, return to religion) to help them resume control over life. These strategies were particularly important as people with mental disorders can often be infantilized, paternalized or treated as though they are unable to care for themselves [9]. The rich descriptions of seeking out information, help, treatment, and crafting personal routines and rhythms to regain a sense of normalcy has implications for health policy in terms of treatment, but also in terms of adding important knowledge that can be used to address negative and stigmatizing attitudes and behaviours. According to the literature, an additional way for participants to regain control over their lives, is to share experiences with others who have similar disorders.

This further helped participants develop psychological resilience [26], a factor born out in the reports of our participants.

Many participants reported distorted familial relationships. This differs from other research which found highest satisfaction was achieved in family relationships [23]. These differences may be due to cultural differences regarding the acceptance of mental health disorders, and the nature of family relationships across countries. For example, AlAteeq et al. [53] compared family relationships with individuals with mental health disorders in Canada and Saudi Arabia. Cultural differences around family engagement were found with higher levels of family engagement with people with mental health disorders in Canada compared to Saudi Arabia. A contributing factor for lack of relationship satisfaction may be lack of knowledge about mental health disorders in Saudi Arabia, reported by all participants in the present study. Additionally, our participants noted that society's perception about mental health disorders was overall negative, due to numerous misconceptions regarding mental health disorders.

Participants stated the need for disclosure of their mental health disorders and family support to achieve better recovery outcomes. However, as Alegiry et al., found people with mental health disorders in Saudi Arabia may link the cause of their disorder to the loss of a family member or beloved person [54]. However, it is unclear if the cause of the mental disorder is due to grief from loss, or due to the loss of a supportive relationship. These differences between our work and Alegiry et al. [54] in findings warrant further investigation. Nonetheless, similar results to the present study were found in previous research where incidents of positive treatment increased when clients chose to disclose their mental health disorder to family and friends [25]. However, disclosure was a risk. In some instances, individuals received increased support and help from family and friends, therefore enabling them to carry on with their lives. In others, disclosure led to negative behaviours, such as avoidance and discrimination [25]. This is consistent with our findings, but an additional negative connection was associating mental illness with a personal lack of faith and religion. This misconception often led to blaming of the client, subsequently triggering guilt and feelings of shame [2, 55].

Theoretical framework

The Stigma Mitigation Model provided an effective framework in which to interpret the experiences provided by participants within their cultural setting, within knowledge, attitudes and behaviours. The data generated by this study provided cultural context and specific examples which can be integrated into future intervention development research as per the updated SMM

(Fig. 2). While there can be many interpretations of qualitative data depending on the scope and focus of investigation, we found that the 'knowledge, attitudes, behaviour' framework was practical, and supported a clinical and educational lens geared towards taking action. This is of particular importance in qualitative research where the investigating team is encouraged to disclose their interest and reasons for investigating a given topic to enhance transparency and rigor [56].

Implications for practice

Clinical and educational

Suggestions on how to reduce stigma were shared by participants that can be integrated into the SMM to guide practice and educational interventions. The first recommendation was that Saudi society needs greater awareness regarding mental health disorders, and greater patience when dealing with clients with mental health disorders. Various studies have discussed different strategies to reduce stigma which may prove helpful in a Saudi context. Mahsoon et al. [38] recommended the use of educational programs in the media and in schools to change the attitudes of the students in Saudi Arabia regarding mental health problems by reading students to interact with people with mental illnesses. Egbe [57] presented mental health disorders in a poetic way, encouraging greater understanding of patients' feelings, thus increasing awareness in a non-traditional way [57].

Research

Our findings demonstrate that people living with mental disorders and experiencing stigma are designing and implementing their own strategies to cope and often thrive despite the challenges they experience. This raises implications for future research using co-design or co-production research designs to partner those living with mental disorders with healthcare practitioners, educationalists, and policy makers to ensure that practices and clinical recommendations align with the nuanced contexts people experience [58]. This could include informing and collaborating with the SMM, identifying specific areas for research focus, strategy development, and application. Additionally, future studies could further explore the effectiveness of stigma-reduction interventions within the Saudi context, such as longitudinal studies assessing the impact of educational programs or campaigns over time.

Policy

Our study also speaks to governmental and institutional policies that integrate mental health education into school curricula or public health initiatives [31]. One such example is using the study findings to enhance nurse education curriculum requirements for nursing students

who must participate in community engagement activities [59]. Further support for such engagement is found in the literature, for example, provision of mental health services in schools and primary healthcare centers, and mental health campaigns with the participation of Muslim clergyman [16].

Limitations

Whilst the present study contributes new and important insights and information from people living with mental health disorders in Saudi Arabia, it is not without limitations. The research team had received permission to follow up with participants after the initial interview if there were additional questions about their responses. However, some participants did not respond after their first interview leaving the interpretation to the research team. Lack of response may be due to the nature of the challenges the participants live with, and it highlights an important consideration for future research and support of participant well-being. A further limitation was that the use of convenience sampling. This means participant experiences address only the mental disorders they have personal knowledge of, and may not be reflective of stigmatising knowledge, attitudes and behaviours that people with other mental disorders experience. For example, none of our participants had a diagnosis of schizophrenia, which is often associated with 'the evil eye' [2]. In addition, convenience sampling and use of social media platforms may also explain why the majority of our sample were students. While the insights provided offer insightful explanations and strategies, further research is required to understand if the experiences and strategies are reflective of other populations living with mental disorders in Saudi.

Conclusions

This study explored experiences of mental health disorders from people within Saudi Arabia, identifying mixed experiences. Not all participants reported experiencing stigma regarding their mental health disorder, though societal perceptions were generally negative, due to lack of knowledge. Despite overlap between the experiences and presence of stigma towards mental health disorders across different countries, efforts to mitigate stigma require cultural tailoring and for which the Stigma Mitigating Model provides a practical framework.

Abbreviations

FON	Faculty of Nursing
KAU	King Abdulaziz University
NREC	Nursing Research Ethics Committee

Supplementary Information

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Supplementary Material 1

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Author contributions

L.S., R.B., D. A., A. A., A. K., R. Alzahrani, L. A.: Conceptualization, Methodology, Software, Validation, Formal analysis, Investigation, Resources, Data curation, Writing - original draft, Writing - review & editing. L.S., R.B., D. A., A. A., A. K., R. Alzahrani, L. A.: Supervision, Project administration. A. M., K. S., R. Alharazi, R. W.: Conceptualization, Formal analysis, Writing - review & editing, Visualization. All authors have agreed to the final version of the submitted manuscript.

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Data availability

The datasets used and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

All methods employed in this study strictly adhered to the applicable rules and regulations set forth in the Declaration of Helsinki (DoH-Oct2008). Ethical approval was obtained from the Nursing Research Ethics Committee (NREC) at the Faculty of Nursing (FON), King Abdulaziz University (KAU) (approval number: (NREC serial: Ref No IF.23). Written informed consent was obtained from the study participants at the start of the interviews.

Consent for publication

The participants provided written informed consents for their personal and clinical details to be published in this study. No identifying images were used in this study.

Competing interests

The authors declare no competing interests.

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