

Parental Perceptions of Child Mental Health Stigma

Mixed-Method Study

by

Julia Ilkova Ivanova

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Graduate Supervisory Committee:

Jonathan Maupin, Chair
Megan Jehn
Devina Wadhera

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ABSTRACT

This study considered three main aims of (1) developing and validating a tool to measure parental perceived child mental health (MH) stigma, (2) determining whether perceived stigma levels corresponded in any way to parental identities, and (3) producing a decision-making process flow identifying where barriers such as perceived child MH stigma may affect families dealing with child MH issues. Recruitment of parents/guardians (18 years or older) with children (under the age of 18 years) was done through convenience and respondent-driven sampling in Phoenix, Arizona. A 44-prompt MH stigma tool was developed and validated (N=65, Cronbach's alpha 0.89) prior to utilizing (N=623) it to measure levels of perceived child MH stigma in the community. Analysis of variance showed potential significant ($p < .005$) interactions among education, income, and race/ethnicity (white, non-Hispanic/Latinx and Hispanic/Latinx) and levels of stigma. Specifically, higher education and lower income among the Hispanic/Latinx population in Phoenix showed a greater likelihood for higher levels of perceived child MH stigma. Factor analysis yielded three underlying factors of this stigma: interaction with MH, discrimination, and positive aspects. Content and thematic analysis of free response questions in the survey conveyed parents talk about MH diagnoses differently between general MH and child MH (e.g., child MH included ADD/ADHD while general MH included anxiety and schizophrenia). Fifteen, one hour-long, semi-structured interviews were completed, transcribed, and analyzed using narrative analysis to develop a parental decision-making process flow. The resulting flow showed parents went through informal methods of accessing MH care (e.g., research, awareness of MH issue)

prior to formal methods such as seeking medical experts or school support. While the study was able to address these three aims, a significant shift in the landscape of MH occurred with the COVID-19 pandemic, increasing child MH risk and decreasing care access. This study developed a tool and set of methods that may be applied to identify changes in perceived child MH stigma and in how parents make decisions to access child MH care.

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Introduction

Research has demonstrated that diagnosis of mental health (MH) issues (e.g. attention deficit disorder, autism spectrum disorder) during early childhood is crucial for effective treatment . Yet those closest to the children—their parents—are frequently not open to accepting and reporting symptoms due to fear of stigma . In the Phoenix metropolis area, prior to enrollment in formal education options, free programs exist to evaluate young children and assist parents in helping their children through special education and access to treatment. Parents who do not know about these services may be at a disadvantage as many of the programs have limited space after the age of 3 years such as the Arizona Early Intervention Program and the federally funded Head Start programs . Health providers also may be limited in their access to evaluating and diagnosing children. Parents become proponents of child MH upon accepting their children’s need for evaluation or diagnosis, but, often, they need help in understanding the warning signs of MH issues and what to do upon observing these warning signs (Johnston & Burke, 2020).

Medical anthropologists, sociologists, and psychologists have shown that MH stigma has a negative effect on family outcomes, including child performance relative to his/her peers, family socioeconomic status (SES), and family and child quality of life (*Rural Parents’ Perceived Stigma of Seeking Mental Health Services for Their Children*, n.d.). Parents who perceive types of MH stigma, such as fears of disclosure or economic burdens, make decisions whether to access or navigate child MH care: care that is not always accessed in the simplified, linear schema of problem recognition (red flag),

evaluation, diagnosis of issue(s), treatment(s) psychology (Dishion & Stormshak, 2007). The differences in how parents respond to MH issues have been alluded to by Phoenix psychologists, behavioral health providers, parents, and teachers consulted for this study.

Ascertaining the state of a child's MH is crucial, but immensely challenging. Not only are many of the illnesses, disabilities, and developmental problems not visible (Hess et al., 2004), but their diagnosis is rendered difficult because many child diagnostic criteria cannot be definitively judged (*DSM-5*, n.d.). There is little insight into how families may be integrated into the evaluative process for child MH that is the beginning of MH care and prevention. This research explores perceptions of MH stigma and its effects on decision-making by parents/guardians on behalf of their children (ages up to 18 years). Understanding types of MH stigma is crucial in providing insight as to how and why parents perceive the stigma and how these types of stigma affect their decision-making on behalf of their children during the process. The following three papers will focus on three main aims: (1) developing and validating a parental perceived child MH stigma survey to measure levels of stigma, (2) utilizing the tool in the Phoenix metropolis, and (3) understanding parental decision-making through semi-structured interviews.

Stigma and Theoretical Frameworks

Identifying stigma as a "situation of the individual who is disqualified from full social acceptance," Goffman inherently also links an individual's social identity, roles, and interactions to one's ability to be socially accepted (Goffman, 1963). Therefore, stigma

may end in an individual being branded as abnormal within society. Illness stigma, as explained by Parsons, provides links for social acceptance, social identity and roles, and individual responsibility (Parsons, 1975). Specifically, Parsons applies stigma to illness in his consideration of the sick role, whereby a sick individual is in a socially accepted but marginalized position, expected to make attempts toward recovery and back to his/her normal societal roles (Parsons, 1975). Thus, a person experiencing the traditional sick role is exempt from stigma as they recover their prior social identities and roles; however, the sick role fails to consider how those with invisible or chronic illnesses can make such a recovery or access the sick role (Lonardi, 2007; Varul, 2010). These types of illnesses cannot be enacted within the typical sick role: individuals cannot fully take back their previously held social identities or be accepted within the sick role, meaning that there is a high probability of being ostracized (Murphy et al., 1988). Considering that much of the theoretical framework of MH stigma relies on social perception of non-normative behavior, the issue of concealability, when someone chooses to suppress a certain aspect of his identity, and coping arises.

Of course, many MH illnesses are not easily observed, and poor outcomes due to MH issues tend to be attributed fully to the individual (Joachim & Acorn, 2000). Individuals may find it appealing to prevent the observation of their symptoms and often use concealability as a coping mechanism, but by doing so, they potentially exacerbate their condition (McCoy et al., 2015). Consequently, people with MH issues find that the sick role may not fully apply to them socially and, at the same time, that concealment can separate them from access to help via a strong social network (Kelner & Wellman, 2014). Since suppression of symptoms as a coping mechanism has been linked to lower quality

of life and higher stress levels, navigating social norms, expectations, and medical recommendations may be especially difficult (Danckaerts et al., 2010). Ultimately, the issue of concealability of MH symptoms makes MH stigma and especially child MH stigma—where parents may try to conceal MH issues—of great importance in providing and improving MH care access (Quinn & Chaudoir, 2009). This study includes concealability as an issue within the adapted stigma scale, which may help to understand parental feelings toward concealment and disclosure topics.

There are three forms of stigma that are particularly useful in a discussion of MH: enacted, anticipated, and internalized stigmas. Enacted stigma refers to actions carried out against someone with a MH issue or someone associated with the afflicted individual, while anticipated or perceived stigma is never expressed in direct actions against an individual but guides said individual via his or her social interactions (Jacoby et al., 1987). Internalized stigma reduces feelings of competence and satisfaction with oneself due to “negative beliefs and feelings” pertaining to the health issue (Corrigan & Watson, 2002; Earnshaw & Quinn, 2012). In terms of parental perceptions of child MH, internalized and anticipated stigmas affect decision-making and outcomes for families and are difficult to separate from one another especially as they tie into feelings of parental responsibility and guilt (Corrigan, 2005; Corrigan & Miller, 2004; Dinos et al., 2004; Landsman, 2009; Watson et al., 2007).

Ultimate responsibility lies with the decision makers and issues of guilt, shame, and embarrassment often feed internalized and anticipated stigma, manifesting in different forms (Landsman, 2009; McKeever & Miller, 2004): fear of discrimination and disclosure of MH diagnosis, for example (King et al., 2008). Further, parents tend to

perceive situations more negatively due to internalized and anticipated stigma leading to reinforcement of the fear and misunderstandings (Green et al., 2005). As MH stigma instigates and breeds misunderstandings, uncertainty, and fears, finding the underlying causes of stigma can inform how stigma affects parental decision-making (Ablon & Part, 1981; Carr & Steele, 2010; Corrigan, 2000). Parents experience anticipated stigma from the public toward themselves and from the public toward their children (Landsman, 2009). Parents will also potentially stigmatize their own children (enacted) and themselves (Landsman, 2009). The ability to discern among the root causes of stigma is critical to understanding where an intervention to lessen experienced and perceived stigma could be most effective.

To better understand perceptions of MH, researchers document how lay people's cognition can affect stigma perceptions (*Causal Theories of Mental Disorder Concepts*, n.d.). Schreiber et al. found that introduction of biological causal explanations, among others, for depression (e.g. genetics) may help to reduce perceived stigma levels (Schreiber & Hartrick, 2002). Measuring causal explanations may be helpful in understanding pathways for decision-making and how parents perceive MH issues in general . Parents are the legal decision-makers for children and therefore have the responsibility to attempt to increase their children's quality of life. Their decisions are based on their knowledge of MH, child development, and their notions of what a normal childhood should be (a social construct reinforced by their communities and society) (Hess et al., 2004). Deviation from the normal, socially-accepted experience can introduce fears and stigma of MH issues for parents (Landsman, 2009). Unfortunately, parents who are not well-prepared with knowledge of MH and health care networks

cannot navigate decision-making effectively and often make decisions while undergoing self-doubt due to fear and uncertainty (Gray, 2002; McKeever & Miller, 2004).

Knowledge (and beliefs) and accessibility to health care, screening, and community awareness all have an impact on how parents make their decisions. Understanding how parental perceptions of MH affect decision-making will help to clarify the impact stigma has on family outcomes, and this concept needs further elucidation within medical anthropology and psychology to form effective interventions.

Intersectionality theory provides a framework on how different, intersecting, initial social identities of parents and families can lead to different pathways of navigating the diagnosis and treatment process (Crenshaw, 1990). Intersectionality theory brings together multiple social identities that may/may not be affected and that do not exist all at the same time for each parent (Viruell-Fuentes et al., 2012). The theory directly relates inequality and discrimination to social identities used by researchers to better conceptualize how complex identities affect outcomes (*Intersectionality and Research in Psychology*. - *PsycNET*, n.d.). Applying this theory in the space of perceived child MH will provide further insight into whether there is indeed an effect on parental perceptions of MH stigma levels (Collins, 2015). Ultimately, intersectionality will help to understand perceived MH stigma results in a diverse community and then also individualize intervention approaches. This study considers whether intersectionality should become a bigger part of the MH stigma discussion within literature.

Intersectionality as a research framework is especially difficult to operationalize quantitatively due to the complexity of identities and the need for a large sample size of

in-depth data to understand interactions: both issues make intersectionality an ideal that may be considered in exploratory analyses but difficult to achieve in research.

Broader Impacts

This study will create a measurement of perceived child MH stigma for parents that also provides a way of understanding the roots of stigma (e.g. fear of communication or disclosure) and types of stigma (e.g. anticipated, felt) are experienced by parents by using factor analysis on survey data (King et al., 2008; Siu et al., 2012). The previously validated scales chosen for adaptation for parental perceptions include these concepts within their format (King et al., 2008; Siu et al., 2012). Knowing such information will help to create effective, efficient interventions to prevent or decrease stigma levels in communities. Applying efforts to educate a community about MH in general is significantly different from efforts to create better social networks for parents. The developed perceived stigma scale is a compilation of psychometrics from psychology and sociology used in tandem with an anthropological method of ethnography. By using mixed methods in this interdisciplinary research, the study informs current literature in psychology, sociology, sociocultural anthropology, and medical anthropology on child MH stigma and stigma in general. Bolstering the academic infrastructure of stigma research and intervention, this research will be useful in applications around the United States as it is an examination of child MH stigma within the Phoenix metro—an ethnically and culturally diverse area (Lukinbeal et al., 2012; Singer, 1 C.E.).

Further, this project brings voice to a vulnerable and stigmatized group within communities and empowers them through discourse and future applied anthropology in the form of effective intervention and education. Parents and families suffering from stigma are not alone. This project will foster parental agency in applying their increasing knowledge of MH, the MH care system, and stigma (Siu et al., 2012).

Parental Perception of Child Mental Health Stigma Scale:

Development and Validation

Background: Parents are a key stakeholder and agent in accessing mental health treatment for their children. Their perceptions of child mental health and mental health stigma impacts their understandings, knowledge, and decision regarding child mental health. Currently, no tool exists to measure parental levels of general child mental health stigma—a first step in understanding how stigma affects parent recognition and decision-making of child mental health services.

Aims: This study intends to (1) adapt existing scales to measure general and parental perceived child mental health stigma, (2) validate the adapted scale, and (3) assess resulting factors and levels of stigma affecting parental understandings of child mental health.

Method: Developing and adapting from two previously validated scales, the study includes general and parental-perceived child mental health stigma scales (44 items total). Using validation techniques based on one of the studies, this new scale was assessed for descriptive statistics, distribution of responses, common factor analysis, and internal reliability after being disseminated to parents and guardians.

Results: Sixty-five responses were collected. Descriptive statistics supported a normal distribution with overall mean stigma levels leaning toward higher levels of stigma (3.17

on scale of 1-5). Meanwhile, the distribution of responses showed 65.9% of statements from the scale predominantly were found with higher levels of stigma. Factor analysis yielded three components: (1) interactions with mental health, (2) discrimination, and (3) positive aspects. Internal reliability of the scale was 0.89 (Cronbach's alpha).

Conclusion: At each step of analysis, the study showed results consistent with expectations for validation purposes. This validated scale is a first step to standardizing how parental perceptions of child mental health stigma can be measured and assessed in research and intervention.

Introduction

With COVID-19's impact on social interactions and mental health (*Children and the COVID-19 Pandemic.*, n.d.), child development and mental health are at the forefront for parents and health professionals. Statistics for children often focus on attention deficit/hyperactivity disorder (ADHD), behavior problems, anxiety, and depression (Danielson et al., 2018; Ghandour et al., 2019). Child mental health (MH) issues, including developmental disorders, begin in early childhood with one in six children ages two to eight years diagnosed . Indeed, according to data from National Survey of Children's Health from 2019-2020, 22.6% of children between ages of three and 17 years has one or more reported mental, emotional, developmental, or behavioral problems (*Data Resource Center for Child and Adolescent Health*, n.d.). Child MH statistics can be difficult to locate: these statistics rely on diagnoses and provide little context on overall

child MH or the processes leading up to diagnoses (CDC, 2020a). Importantly, children under the age of 18 years, with few exceptions (McNary, 2014), are reliant on parents or guardians for the processes of evaluation and treatment of child MH issues (O. G. Johnston & Burke, 2020). Thus, significant problems to consider regarding child MH are how parents make the decision to enter the typical process of evaluation and treatment and what factors, especially MH stigma, affect the decisions (Corrigan, 2004; Corrigan & Watson, 2002; Schnyder et al., 2017; Thurston et al., 2015; Villatoro et al., 2018).

Stigma, an attribute that leads an individual to be perceived as less than normal or whole (Goffman, 1963), comes in many forms such as enacted stigma (actions carried out against a stigmatized individual) and felt/anticipated stigma (though never strictly expressed, this stigma is present in how stigmatized individuals expect stigmatization towards themselves from others) (Jacoby et al., 1987). Self-stigma, or internalized stigma, is a form of felt stigma whereby the afflicted people have a reduced self-regard and satisfaction with themselves as individuals due to the perception of the issue (Corrigan & Watson, 2002; Earnshaw & Quinn, 2012). Within this space of different types of stigmas, MH stigma is unique as many MH issues are not physically visible, and individuals may find themselves able to conceal diagnoses and symptoms to avoid potential enacted stigma (Joachim & Acorn, 2000; Jones et al., 1984). While adult MH stigma has been considered in literature (Fox et al., 2018; Link et al., 2004; Sampogna et al., 2017; Sickel et al., 2019; Wu et al., 2017), child MH stigma has garnered less attention. Child MH issues are viewed as a deviation from the normal, childhood and parental experiences that can introduce stigmas for both child and parents (Landsman,

2009). It is this view of societal abnormality that is so heavily linked to MH stigma, sometimes resulting in negative pressures on parents to make decisions (Gray, 2002; Landsman, 2009; McKeever & Miller, 2004).

In a 2004 systematic literature review by Link et al., of the 123 articles measuring mental illness stigma, only four pertained to children and child MH (Link et al., 2004). All four studies' scales measured how children perceived and stigmatized adult MH issues: these scales allowed understanding of children's perceptions of MH issues (Link et al., 2004). In a 2018 systematic literature review looking at conceptualization and measurement of mental illness stigma, of the 400 measures of mental illness stigma found, only 140 studies were identified to have a validated or evaluated scale (Fox et al., 2018). This review by Fox et al. also highlighted studies with potential subscales of stigma along with main scales, thus finding factors of interest related to MH stigma such as discrimination (Fox et al., 2018). Although more studies were found related to child MH than in prior literature reviews, Fox et al. only identified 11 interested in MH of children under the age of 18 years (Fox et al., 2018). These studies tended to focus on the relationship between stigma levels and access to appropriate services and on service delivery providers (Heflinger et al., 2014). Ideas of childhood and normal behaviors were not discussed as measurable within the surveys; however, these concepts could be broached with the use of qualitative methods in juxtaposition with the stigma scales developed in these studies. Specifically looking at studies where children and parents were being assessed regarding stigma levels, ten studies were found that had children (under the age of 18 years) taking a stigma measure (Fox et al., 2018). While only one study considered

parental perceptions of child MH, no study considered general, non-specific child MH (Austin et al., 2004). Measuring non-specific child MH stigma is of grave importance as parents do not know a specific diagnosis for their child as they (1) have to recognize a potential symptom even before they (2) attempt to have their child evaluated. While specific MH condition stigma scales are important, child MH poses the unique issue of difficult diagnoses (especially for younger children who are unable to articulate their experiences) that may translate to parents' understanding of general child MH. Though MH stigma studies for adults have shown variance in stigma levels based on the type(s) of diagnoses—even among MH professionals (Sansone & Sansone, 2013; Sowislo et al., 2017), having a generalized MH stigma measurement for children is especially important for understanding parental perceptions as recognition of MH problems and decision to act on the recognition may be impacted by vague stigma of a MH issue.

The Fox et al. literature review found one study focused on both child and parental perceptions of stigmatization of epilepsy (Austin et al., 2004)—a disorder characterized by recurrent, unpredictable seizure activity relating to both mental and physical health (Beletsky & Mirsattari, 2012; Dekker, 2002). The epilepsy study identified parental perceptions of epilepsy as a key component in understanding stigmatization of the disorder (Austin et al., 2004). The epilepsy study also provided a review of relevant literature and found only one study considered stigma regarding children with epilepsy, which resulted in a paradox, where children did not feel stigmatized but also avoided disclosure (59%) or discussion (70%) of their disorder (Austin et al., 2004; Westbrook et al., 1992). Indeed, their own review showed further work regarding child stigma scales

not only needed to be done but also that as “the family environment is an important influence on children’s perceptions, it is also important to obtain perceptions of stigma from others in the family” (Austin et al., 2004). They developed separate scales for parents and children; a total of 397 parents took the scale (173 of those with children with epilepsy, and 224 children with new-onset seizures) (Austin et al., 2004). Content validity, internal consistency reliability, and construct validity were used to test the scale and assess stigma. While this study was able to include parental perceptions of epilepsy, there is a need for a measurement geared toward parental perceptions of overall child MH and not a specific disorder. Considering research geared toward the general and specific labelling of MH issues, there is evidence that laypeople accept and understand the two—specific disorders versus general terms such as mental illness—in a different way (Kermode et al., 2009; *A Handbook for the Study of Mental Health*, 2017). There is evidence showing general labelling yields differing levels of stigma (Kermode et al., 2009; “Labeling of Mental Disorders and Stigma in Young People,” 2011), and thus needs to be considered when trying to understand how MH perceptions may impact not only treatment seeking behaviors but also evaluation-seeking behaviors for parents.

The Fox et al. review identified one study by King et al. that focused on a general MH stigma scale and used qualitative results to develop a scale based on the themes and subthemes identified from 46 interviews of MH service users (Dinos et al., 2004; King et al., 2007). The 42-item scale was piloted with a self-esteem scale (N= 193 people with MH diagnoses) and retested (N= 60 of the earlier pilot sample); items’ reliability kappa coefficients (≥ 0.4) showed 28 items should be kept, which were then subjected to factor

analysis and internal reliability testing (King et al., 2007). While the majority (76.5%) of participants were white, the study included participants who identified as black (5.5%), southeast Asian (3.5%), and other race/ethnicities (9.0%) (King et al., 2008). The mixed-methodology used for the King et al. study provides a level of depth to the scale, which also showed the significance of discrimination, disclosure, and positive aspects of mental illness in enacted and anticipated MH stigma (Austin et al., 2004; King et al., 2007).

Adapting such a scale would be especially useful in understanding perceived child MH stigma by parents as the questions were developed to measure a participant's experience. The systematic approach of King et al. to validating the tool lends itself to development of focused iterations of the tool.

One of the Fox et al. resulting studies that included children and their perceptions on MH disseminated a scale to a wide range of demographics within the diverse Hong Kong community, from young children (secondary school) to the elderly (Siu et al., 2012). The authors, Siu et al., used prior literature regarding MH stigma/discrimination (Byrne, 2000, 2001; Chong et al., 2007; Pinfold et al., 2003; World Psychiatric Association, 2005) and a team of MH experts (psychiatrists, social workers, and psychologists) to develop a 15-item scale to understand opinions, potential stigma, and MH myths related to enacted and anticipated MH stigma. The study used descriptive statistics for demographics, correlational analysis, *t* tests, and analysis of variance ($P < 0.05$) to assess relationships of demographic data to knowledge/stigma scores (Siu et al., 2012).

Outcomes of the study revealed that children had lower levels of knowledge (higher levels of stigma) than other age groups and that children should be of interest for MH

education and anti-stigma programs (Siu et al., 2012). An important aspect missing from this conclusion is that parents have a significant impact on children's understandings and perceptions and should be considered in how they affect children's health access, as well (C. Johnston & Ohan, 2005; Moses, 2010). This study provided a general MH stigma assessment within the community and considered the potential role of differing demographics, such as age and race/ethnicity, in the level of stigma within the community. A developed stigma scale should consider the role of such demographics in the community it is used in to help understand underlying causes of MH stigma and potential for individualized interventions. The use of a general MH stigma scale together with a specific perceived child MH stigma scale would provide better understanding of parental views overall—necessary in determining perceived child MH stigma levels before parents may be aware of a potential child MH issue with their own children.

Parents are the key component in recognizing and acting on a MH need of their child. While literature often focuses on the diagnostic process of child MH and the Centers for Disease Control and Prevention (CDC) emphasizes access to child MH care needing improvement (CDC, 2020b), there is a need to promote all aspects of child MH (CDC, 2020c), as well as understanding how to aid parents in recognition and knowledge of child MH prior to evaluation (Charles et al., 1999; Hallström & Elander, 2004; Mak et al., 2014). Measuring parents' perceptions of child MH issues and stigma would enlighten what factors—e.g. parental anticipated stigma or perceived responsibility (Landsman, 2009; McKeever & Miller, 2004)—impact the ultimate decision to have a child evaluated. Both general MH and child MH stigma assessments may provide a

clearer picture of parental understandings and decision making. A combination of the two into a singular tool may help capture a more accurate picture of parental perceived child MH stigma. This study aims to (1) develop a scale to measure general and parental perceived child MH stigma, (2) validate the scale, and (3) assess resulting factors and levels of stigma affecting parental understandings of child MH. Developing and validating this tool for use in a diverse population, such as that in Phoenix, Arizona, is important for future use of the stigma measure.

Method

Participants and Procedure

The study was approved by the Arizona State University Institutional Review Board (#2823). In order to understand general parental perceptions of child MH, recruitment did not focus only on parents or guardians who had children with a diagnosis. The stigma scale would be used to determine perceptions before any kind of problem recognition occurred and any decision making was done by parents or guardians. Therefore, participants were any parent or guardian over the age of 18 years, who currently had guardianship of a child or children under the age of 18 years. In this way, the study would include all parents/guardians from those who have never even considered child MH care access to ones who have gone through the process, potentially multiple times.

For the initial testing, participants were recruited by posted flyers or active recruitment in public spaces such as parks or libraries around the greater Phoenix (Arizona) metropolitan area. Future use of this tool in the Phoenix metropolis would focus on understanding potential differences in stigma perceptions by key demographic groups such as the large, Hispanic population. While a representative population (age, race/ethnicity, education) reflecting the region would be ideal, for the purposes of validation, a sample similar to King et al. would be sufficient for validation purposes of this study. The King et al. study included a majority white population sample for their validation testing, and noted the need for their survey to be further evaluated with a broader demographic, especially ethnic minorities (King et al., 2007). This study expected a larger sample size for other race/ethnicities than King et al., but recruitment was not targeted. While the posted flyers included information regarding the survey and the link and QR code for the survey, in-person recruitment entailed potential participants being approached by researchers and presented with physical handouts as well as verbal communication of the study and its aims. Participants were also provided with extra flyers to share with others who may fit the recruitment standards. Participants could then use the link or QR code to access the developed survey on the Qualtrics© platform, an online survey tool estimated to take about 10 to 15 minutes.

Recruitment occurred between January and October of 2018.

Measures

The parental perceptions of child MH and stigma survey, Full Stigma Scale, was created by adapting two existing, validated tools. Siu et al. validated their 15-item scale measuring MH stigma generally within a population, focusing on anticipated and enacted stigmas (Siu et al., 2012). Their scale was used for this study for the purpose of identifying parents' general MH stigma. No changes were made to its wording. King et al. validated a MH stigma tool, comprised of 28 prompts, measuring enacted and anticipated stigma of adults (King et al., 2007). For the purposes of this study, 27 of the 28 prompts were chosen, as a statement regarding police treatment was decided to be unapplicable to the target population by the research team after two initial 20 and 25-participant pilot studies. The 27 statements were then adapted to capture parental perceptions of MH statements regarding their child (see Table 2 for Siu et al. #1-17 and King et al. #18-44 statements). Specifically, the wording of prompts was changed from regarding a participant's personal experience to a parent's perception of what their child is experiencing: from "I worry about telling people I have received/will receive treatment" to "I worry about telling people *my child has* received/will receive treatment" (King et al., 2007). A total of 44 questions comprised the Full Stigma Scale. Participants respond to statements on a five-point Likert scale: definitely disagree, disagree, neither agree or disagree, agree, and definitely agree.

Basic demographics, such as age, race, and education, were elicited. Education and race options were provided as multiple choices. Education was broken down into categories of less than high school, high school degree, some college, college degree, and professional or graduate degree. Race/ethnicity included Black/African American, Native American,

Asian or Pacific Islander, White/Caucasian, and Other (allowing for free response to explain). At this time, ethnicity was not included in the captured data, following King et al.'s demographic inclusion.

Participants were asked to take the survey with their youngest child in mind, if they had multiple children under the age of 18. This directive was meant to help the study capture participant perceptions for more non-school-age children—a demographic that was difficult to find in earlier pilot testing—and help parents focus their answers on a single child. The result would be twofold: participants would take the survey with a specific child in mind (an issue discovered in piloting the study) and would help include parents with younger children where diagnosis of MH issues may be more difficult due to normal differences in development and lack of mastery of language skills. Under the premise that the youngest child would have generally less agency in their health care than an older sibling, the study helps parents focus on the (likely) most parent-reliant child in the household. Further, for stigma prompts regarding child MH, participants with children who did not have a diagnosed MH issue were asked to think about how they may feel if their child did have a diagnosed MH issue.

Analysis

Power analysis was run using SPSS v. 27 to determine how many participants would be needed for at least 0.90 power, 0.05 significance, with medium effect size (0.600) for the factor analysis and Pearson correlation yielding a preferred 60 participants. For the purposes of common (exploratory) factor analysis, a sample size of 50 was adequate to

determine whether factors from this adapted survey compared favorably to those from King et al (Thompson, 2004).

For the purposes of validation of the survey adaptation, analysis was kept similar to the King et al. study, especially, as that is where the most significant changes occurred during the adaptation. The use of Siu et al. prompts would help ascertain perceptions of MH stigma that would impact parental understanding of child MH, as well as decision making; these combined surveys would together capture parental perceptions, experiences, and fears more accurately. Though test-retest reliability was not used due to the format of sampling, distribution of responses, common factor analysis, internal consistency using Cronbach's alpha, mean scores of questions for the scale, and descriptive statistics were done. In addition to King et al. methods, Skewness, Kurtosis, and variance were considered when looking at descriptive analysis. All statistical steps were done using SPSS v27.0. Responses from positively worded statements had reverted scoring to ensure highest scores (four and five on the scale) corresponded to higher stigma levels. Common factor analysis using un-rotated and orthogonal rotation (Varimax) was done to look for patterns and relationships in the survey statements (King et al., 2007). A scree plot was used to guide factor cutoff. Internal consistency was assessed using Cronbach's alpha for the full scale, the potential sub-scales, and the two adapted scales, separately. Inter-item correlations were considered along with item-total score. Pearson correlation (two-tailed) was done to further validate and compare the Full Stigma Scale to King et al. results.

Results

Participant demographics

To test the combined survey, it was first disseminated to 25 participants and assessed against King et al. results to ensure functionality of the 44-question scale using the analysis steps. Results appeared similar to King et al. and dissemination was continued for a total of 65 surveys taken. Most survey respondents were white/Caucasian (61.3%), within 25-34 years of age, and with a college degree (51.6%), as shown in Table 1.

Demographics related to race were similar to those of King et al., and the sample's largest population groups reflected Phoenix's largest groups in the 2010 U.S. Census (age 25-34 as 16.2% and white as 76.7% of Phoenix population) (*Phoenix, AZ / Data USA*, n.d.).

Table 1: Demographic data from pilot of survey. Percent of valid sample (N) shown; rounded data do not always sum to 100.

Race	Percentage	N=62
White/Caucasian	61.3	38
Black/African	8.1	5
Other	8.1	5
Asian or Pacific Islander	19.4	12
Native American	3.2	2

Age	Percentage	N=64
18-24	7.8	5
25-34	46.9	30
35-44	25.0	16
45-54	9.4	6
55-64	9.4	6
65-74	0.0	0
75 and over	0.0	0
Education	Percentage	N=64
Less than HS	0.0	0
HS	9.4	6
Some College	20.3	13
College	51.6	33
Professional/Doctorate	18.8	12
Marital Status	Percentage	N=64
Married	68.8	44
Living w Partner	6.3	4
Single	15.6	10
Divorced	9.4	6
Widowed	0.0	0

Distribution of responses

The frequency of what participants chose as responses in the survey was considered along with basic descriptive statistics. The mean ranged from 2.85 to 3.59 (1.00 being lowest levels of stigma) amongst statements and 3.17 overall. The mode yielded majority

of statements at 3.00 and eight statements that were at or above 4.00 (statements bolded in Table 2). When looking at the distribution of answers for statements (Table 2), there is a notable trend (65.9% of 44 questions) toward participants choosing agree and strongly agree options, showing higher perceived stigma levels. Additionally, exploring groupings of low stigma (strongly disagree and disagree), neutral stigma (neutral), and high stigma (agree and strongly agree) by question shows which questions tended to yield higher levels of stigma by proportion (more than 5% difference from the other two groupings). By considering the prompts altogether (both Siu et al. and King et al. sections), results yield an understanding of actual levels of MH stigma.

Table 2: Percentage breakdown of participant choices per stigma statement. Statement results have been adapted so that agree and strongly agree refer to higher levels of stigma. Percentages do not all add up to 100 as incomplete answers are removed from total percentages. Bolded percentages of groupings of low stigma (strongly disagree and disagree), neutral stigma (neutral), and high stigma (agree and strongly agree) show where larger proportions (more than 5% difference from other groups) of the three groups were found.

#	Statement	Strongly Disagree	Disagree	Neither Agree of Disagree	Agree	Strongly Agree
1	It is difficult to communicate with people with mental illness	4.6	26.2	26.2	32.3	9.2
2	It is common for people with mental illness to have propensity for violence	10.8	20.0	13.8	33.8	20.0
3	The majority of people with mental illness can recover	1.5	23.1	40.0	23.1	9.2
4	People with mental illness are weak, they should blame themselves for their illness	24.6	7.7	3.1	20.0	43.1
5	The society should treat people with mental illness with a tolerant attitude	9.2	24.6	16.9	16.9	30.8

6	It is difficult to predict the behaviors of people with mental illness	6.2	26.2	33.8	24.6	9.2
7	It is difficult to predict the mood of people with mental illness	9.2	21.5	29.2	30.8	7.7
8	Everyone has the chance to develop mental illness	10.8	16.9	26.2	21.5	23.1
9	I would not tell others that I suffer from mental illness	9.2	23.1	24.6	27.7	10.8
10	People having a relative suffering from mental illness would be looked down upon by others	7.7	12.3	32.3	32.3	13.8
11	I feel afraid of talking to people with mental illness	13.8	18.5	15.4	30.8	20.0
12	I oppose the building up of residential hostels for people with mental illness near to my household	12.3	24.6	13.8	27.7	20.0
13	There are no medication treatments for mental illness	21.5	12.3	4.6	9.2	47.7
14	People with mental illness have very low chance of being recovered	6.2	27.7	13.8	27.7	23.1
15	It is difficult for me to make friends with people with mental illness	9.2	18.5	18.5	35.4	16.9
16	I would feel embarrassed to go out with my relative if my relative has/were to have mental illness	15.4	18.5	13.8	29.2	21.5
17	It is a waste of money to increase the expenditure on the service to care for people with mental illness	21.5	9.2	6.2	16.9	43.1
18	My child has been discriminated against (in education) because of their mental health problems	6.2	24.6	29.2	27.7	10.8
19	Sometimes I feel that my child is being talked down to because of his/her mental health problems	10.8	24.6	29.2	21.5	12.3
20	Having a child with mental health problems has made me a more understanding person	6.2	24.6	24.6	20.0	23.1
21	I do not feel badly about my child having mental health problems	10.8	20.0	23.1	27.7	16.9
22	I worry about telling people my child has received/will receive treatment	9.2	18.5	24.6	33.8	12.3

23	Some people with mental health problems are dangerous	12.3	26.2	24.6	21.5	13.8
24	People have been understanding of my child's mental health problems	1.5	29.2	38.5	20.0	9.2
25	My child's mental health problems have made me more accepting of other people	4.6	21.5	26.2	24.6	21.5
26	Very often I feel alone because of my child's mental health problems	10.8	16.9	26.2	29.2	15.4
27	I am scared of how other people will react if they find out about my child's mental health problems	12.3	16.9	30.8	29.2	9.2
28	My child would have had better chances in life if she/he had not had mental health problems	24.6	16.9	21.5	16.9	16.9
29	I do not mind people in my neighborhood knowing my child has had mental health problems	7.7	21.5	27.7	24.6	15.4
30	I would say my child has had mental health problems if she/he were applying for a job	12.3	20.0	26.2	26.2	12.3
31	I worry about telling people that my child takes medicines/tablets for mental health problems	9.2	20.0	26.2	27.7	13.8
32	People's reactions to her/his mental health problems make me keep the issues to myself	6.2	24.6	24.6	32.3	9.2
33	I have noticed people's reactions to her/his mental health problems make my child keep to him/herself	9.2	24.6	38.5	15.4	9.2
34	I am angry with the way people have reacted to my child's mental health problems	20.0	20.0	21.5	27.7	7.7
35	I have not had any trouble from people because of my child's mental health problems	7.7	30.8	29.2	21.5	7.7
36	My child has been discriminated against by health professionals because of her/his mental health problems	6.2	13.8	33.8	26.2	16.9
37	People have avoided her/him because of her/his mental health problems	7.7	23.1	33.8	20.0	10.8
38	People have insulted me and/or my child because of his/her mental health problems	7.7	23.1	33.8	26.2	6.2

39	Having had a child with mental health problems has made me/her/him a stronger person	6.2	23.1	30.8	18.5	18.5
40	I do not feel embarrassed because of my child's mental health problems	12.3	24.6	21.5	21.5	16.9
41	I avoid telling people about my child's mental health problems	6.2	32.3	27.7	18.5	12.3
42	Having a child with mental health problems makes me feel that life is unfair	10.8	18.5	24.6	33.8	9.2
43	I feel the need to hide my child's mental health problems from my friends	9.2	15.4	24.6	26.2	21.5
44	I find it hard telling people my child has mental health problems	9.2	21.5	20.0	29.2	15.4

Skewness and kurtosis trends were well-within expected range and support normal distribution of the sample and an effective sample size. Skewness values ranged between -0.58 and 0.40; kurtosis values ranged between -0.15 and -0.347. The scale showed good range in variance.

Factor analysis

Common factor analysis using no rotation and orthogonal (Varimax) rotation was done to compare to King et al. results (Table 2, Siu et al. #1-17 and King et al. #18-44 statements). An initial analysis yielded nine factors, unrotated, above an eigenvalue of 1.00, and the scree plot identified a potential for three or four factors of significance, accounting for 56.8% or 62.3% of the cumulative percentage respectively. Eigenvalues for the first four factors were 13.0 (29.5%), 8.2 (18.7%), 3.8 (8.7%), and 2.4 (5.5%). Inter-item correlation was looked at to ensure that orthogonal (Varimax) rotation was still appropriate for this scale before proceeding: though correlation (above 0.50) among

statements were seen, statements generally had low levels of correlation (below 0.50). Though King et al. did not explain whether common factor analysis was tested with specific constraints, results of the full nine factors along with constrained three and four factor analyses were considered when determining factor themes. The fourth factor was dropped due to its low eigenvalue, the scree plot results, and similarity to factors two and three upon review.

Factor loading was screened above 0.400 level, per King et al., and highest loadings were considered for each statement to identify sub-scales (Table 3). Highest loadings were most heavily considered when categorizing sub-scales: factor one dealt with interactions with MH (22 statements), factor two with discrimination (12 statements), and factor three with positive aspects (eight statements).

Table 3: Statements and their highest factor loadings. Bolded factors refer to where statement best fits among the three factors. Statements 30 and 35 did not load. Positively worded statements' scores were reversed to be consistent with higher scores relating to greater levels of stigma.

#	Survey Statements	(I) Interactions with MH	(II) Discrimination	(III) Positive Aspects
1	It is difficult to communicate with people with mental illness	0.594	0.322	0.107
2	It is common for people with mental illness to have propensity for violence	0.152	0.767	-0.065
3	The majority of people with mental illness can recover	-0.123	0.243	0.587
4	People with mental illness are weak, they should blame themselves for their illness	-0.246	0.873	-0.097
5	The society should treat people with mental illness with a tolerant attitude	-0.444	0.200	0.566

6	It is difficult to predict the behaviors of people with mental illness	0.723	0.042	0.098
7	It is difficult to predict the mood of people with mental illness	0.717	-0.008	0.005
8	Everyone has the chance to develop mental illness	-0.544	0.109	0.371
9	I would not tell others that I suffer from mental illness	0.473	0.290	0.346
10	People having a relative suffering from mental illness would be looked down upon by others	0.183	0.470	0.117
11	I feel afraid of talking to people with mental illness	0.111	0.887	0.009
12	I oppose the building up of residential hostels for people with mental illness near to my household	0.218	0.681	0.181
13	There are no medication treatments for mental illness	-0.272	0.877	-0.079
14	People with mental illness have very low chance of being recovered	0.047	0.843	0.084
15	It is difficult for me to make friends with people with mental illness	0.503	0.672	-0.032
16	I would feel embarrassed to go out with my relative if my relative has/were to have mental illness	0.110	0.886	-0.015
17	It is a waste of money to increase the expenditure on the service to care for people with mental illness	-0.281	0.882	-0.094
18	My child has been discriminated against (in education) because of my mental health problems	0.764	-0.047	0.014
19	Sometimes I feel that my child is being talked down to because of his/her mental health problems	0.830	-0.283	0.027
20	Having a child with mental health problems has made me a more understanding person	-0.588	-0.067	0.449
21	I do not feel badly about my child having mental health problems	0.352	-0.112	0.467
22	I worry about telling people my child has received/will receive treatment	0.673	0.407	0.237
23	Some people with mental health problems are dangerous	0.658	0.015	0.062
24	People have been understanding of my child's mental health problems	0.191	-0.349	0.440

25	My child's mental health problems have made me more accepting of other people	-0.597	-0.018	0.518
26	Very often I feel alone because of my child's mental health problems	0.550	0.364	-0.076
27	I am scared of how other people will react if they find out about my child's mental health problems	0.701	0.225	0.238
28	My child would have had better chances in life if she/he had not had mental health problems	0.745	-0.552	-0.125
29	I do not mind people in my neighborhood knowing my child has had mental health problems	0.215	-0.095	0.619
30	I would say my child has had mental health problems if she/he were applying for a job	0.254	-0.220	0.375
31	I worry about telling people that my child takes medicines/tablets for mental health problems	0.589	-0.051	0.285
32	People's reactions to her/his mental health problems make me keep the issues to myself	0.747	0.175	0.118
33	I have noticed people's reactions to her/his mental health problems make my child keep to him/herself	0.749	0.104	-0.181
34	I am angry with the way people have reacted to my child's mental health problems	0.683	-0.238	-0.275
35	I have not had any trouble from people because of my child's mental health problems	0.373	-0.264	0.218
36	My child has been discriminated against by health professionals because of her/his mental health problems	0.322	0.452	-0.188
37	People have avoided her/him because of her/his mental health problems	0.871	0.050	-0.045
38	People have insulted me and/or my child because of his/her mental health problems	0.489	0.448	-0.077
39	Having had a child with mental health problems has made me/her/him a stronger person	-0.187	-0.002	0.675
40	I do not feel embarrassed because of my child's mental health problems	0.080	0.020	0.684
41	I avoid telling people about my child's mental health problems	0.800	0.198	0.141

42	Having a child with mental health problems makes me feel that life is unfair	0.678	0.305	-0.008
43	I feel the need to hide my child's mental health problems from my friends	0.527	0.600	-0.009
44	I find it hard telling people my child has mental health problems	0.873	0.156	0.030

Internal consistency of adapted scale and sub-scales

Cronbach's alpha for all items (44), Siu et al. (17), and adapted King et al. (27) were 0.89, 0.88, and 0.88, respectively. Deletion of items 17 and 28 would have yielded higher Cronbach's alpha (above 0.90), overall.

Mean scores of the full scale, separate survey sections, and sub-scales follow: Full Stigma Scale 136.3 (s.d. 28.8), Siu et al. section 54.6 (s.d. 14.3), King et al. section 81.7 (s.d. 19.7), interactions with MH sub-scale 66.6 (s.d. 16.5), discrimination sub-scale 39.4 (s.d. 13.3), and positive aspects sub-scale 24.6 (s.d. 6.3). Results of the Pearson correlation showed mean sub-scales scores had higher correlations with the Full Stigma Scale (and either of the two separate survey sections) than with themselves, similar to King et al. results.

Table 4: Correlation between Full Stigma Scale, separate survey sections, and sub-scales scores. ** Pearson Correlation is significant at the 0.01 level (2-tailed).

Scales	Full Stigma Scale	Siu et al. Section	King et al. Section	(FI) Interactions with MH	(FII) Discrimination	(FIII) Positive Aspects
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Siu et al. Section	0.782**	-	.418**	.448**	.948**	.368**
King et al. Section	0.893**	.418**	-	.948**	.358**	.635**
(FI) Interaction with MH	.872**	.448**	.948**	-	.358**	.462**
(FII) Discrimination	.716**	.948**	.358**	.358**	-	0.208
(FIII) Positive Aspects	.618**	.368**	.635**	.462**	0.208	-

Discussion

Addressing study aims

This study has developed and validated a survey to measure parental perceived child MH stigma. Due to its adaptation and use of two previously validated MH stigma surveys, the Full Stigma Scale measures both general MH stigma as well as parental-perceived MH stigma. Results of the validation of the scale consistently compared favorably to those from King et al. (i.e., discrimination, disclosure, and positive aspects) and even resulted in closely related sub-scales of interactions with MH, discrimination, and positive aspects.

By developing a scale that measures both general and parental-perceived MH stigma, the tool can be used to identify key areas of child MH stigma, while still retaining King et al.'s ability to examine underlying influences on perceived and enacted stigmas such as fears in interaction and discrimination. More importantly, the use of the two surveys (Siu

et al. and King et al.) together may more accurately represent actual parental perceived child MH stigma: overall MH stigma still impacts parental perceptions of child MH stigma. For example, while there were high stigma levels regarding violent tendencies of people with MH issues (overall stigma, 53.8%), parents presented lower levels of stigma when a similar question regarding danger (35.3%) in the context of the section specifically regarding their child; however, that high level of stigma regarding violence is still present and impactful of how parents perceive any discussion of MH, and thus, is necessary to be included for an accurate measure of parental perceived child MH stigma. To ensure the actual connotation of the words (violence and dangerous) are not affecting these results, future iterations should consider using the same word in both instances to test whether there is any impact. This example illustrates the importance of using this tool together, rather than separated into general (Siu et al. section) and child MH stigma (King et al. section).

Additionally, the tool takes about 10 minutes to complete and can be used as a base for deeper investigation into parental perceptions and stigmas revolving about child MH. A Flesch-Kincaid reading level of 7.0 was achieved for the scale. The application of this novel tool can help understand parental fears and MH understandings that directly impact their decision-making on behalf of their child (Charles et al., 1999).

Child mental health stigma and parental perceptions

The parental role in the process of identifying a potential MH issue and choosing to have their child evaluated is a crucial and complex one. Socially, parents shoulder the responsibility of the care and wellbeing of their child, and a child who is not viewed as “normal” may not only impact the child but the parents and the family as a whole (Dinos et al., 2004; Landsman, 2009). Now parents not only feel internal pressure to ensure the good health of their child but the social pressures promoting feelings of guilt, shame, and stigma (Watson et al., 2007). Fears relating to such stigma can affect progress in coping and healing (Corrigan, 2005; Quinn & Chaudoir, 2009) and even prevent desire to seek appropriate evaluation and treatment (Earnshaw & Quinn, 2012). As MH conditions often are not visible or easily identified, there is space for concealment of the MH issue and even suppressing symptoms (Joachim & Acorn, 2000; Jones et al., 1984).

Concealment is driven by anticipated stigma in this scenario, and while concealing MH issues from others may alleviate felt stigma, it decreases the quality of life for those affected and cuts off the family from social support as well (Danckaerts et al., 2010; Pérez & Marqués, 2018). This stigma scale considers concealment (11 statements across subscales) and may be useful as a first step in any research methodology to understand general feelings toward concealment and disclosure in the study population. Meanwhile, the tool can provide a base for understanding what aspects of MH stigma—interactions, discrimination, and positive aspects—are at the forefront for a population.

Parents deal with more than just the enacted, anticipated, and self-stigma in such scenarios. Their decision-making is affected by their level of knowledge and understandings on MH and child MH conditions (Thurston et al., 2015; Zimmerman,

2005). This survey paired with interviews or free response questions on this topic would be able to address such factors. For example, misdiagnosis and overdiagnosis—of young children, especially—may lead parents toward fears of incorrectly labeling their child with a health issue as well (Bruchmüller et al., 2012; Cuffe et al., 2005; Vitztum et al., 1995). Recent studies show that parents and professionals cannot identify potential MH issues for young children the vast majority of the time when calculating rates of problem recognition (Alakortes et al., 2017; O. G. Johnston & Burke, 2020). In 2018, Villatoro et al. results specifically show that stigma may impact problem recognition and help seeking when parents consider their child’s MH (Villatoro et al., 2018). Per Villatoro et al. and other existing literature, greater parental MH exposure/experience, lower stigma levels, male gender, and the older age of the child appear to affect problem recognition positively (Bussing et al., 2003; Villatoro et al., 2018).

Results from the Full Stigma Scale tool show that while average and mode scores show fairly neutral levels of stigma, 65.9% of statements had greater portions of agree and strongly agree responses from participants: there is an underlying level of MH stigma that was found in the study population. Regarding interactions with MH, 54.6% of the statements had responses that leaned more toward higher levels of stigma. While positive aspects had 50.0% of statements in a similar fashion, the discrimination sub-scale had 100% of its statements with larger portions of higher stigma responses. Overall, results of the tool in this population show that parental fears of discrimination is a key underlying cause of child MH stigma—both relating to anticipated stigma regarding their own perceptions of MH and of their children facing discrimination. MH discrimination is a

well-recognized problem as it affects not just a sense of self and identity but all aspects of life and decision-making. (Link et al., 2004; PENN & WYKES, 2003) Further, as a tool measuring perceived and experienced child MH stigma, this survey shows interventions focused on alleviating fear of and actual discrimination (Peterson et al., 2007) may have the most powerful impact on parental perceived child MH stigma (Amering, Michaela; Dunne, Simon; McGabhan, Liam And McGowan, Paddy, 2018). That said, the importance of interactions with MH and positive aspects should not be diminished: the near majority presence of higher levels of stigma in these two subscales bolsters the need to include their consideration. Because discrimination can be easier to identify, the two other subscales may be just as influential in how child MH stigma develops but not as readily apparent. Further study of these subscales using interviews may help to understand the level of impact they have on overall child MH stigma. As King et al. recommend, the scale should be further tested in clinical and research populations of interest to better understand population and demographic differences in stigma levels and child MH understandings.

Limitations

While this study developed, tested, and validated the Full Stigma Scale with a small study population, the study is compared to results from King et al. to ensure integrity of the tool was maintained: the tool ultimately yielded similar results. Additionally, for the purposes of factor analysis, a minimum sample of 50 individuals was surpassed (Henson & Roberts, 2006; Mundfrom et al., 2005). While the demographics of the population were

not ideally diversified, breakdowns of the sample population's race were similar to King et al. In future use of this tool, researchers should consider the addition of ethnicity to demographics, especially due to the large Hispanic population found in the Phoenix metropolitan area (over 40% of the population) (*Phoenix, AZ / Data USA*, n.d.; Soto Vega & Chávez, 2018). With the validation of the Full Stigma Scale, we recommend additional demographic questions relating to socioeconomic status, basic child information (e.g., age, gender, whether evaluated), the topic of child MH evaluation, and three open-ended questions relating to thoughts and understandings of mental illness, MH, and child MH. A consideration of the age and gender of the child may yield further understanding of parental perceptions as there is evidence that they are factors in the evaluation and diagnosis process (Bruchmüller et al., 2012; Mandell et al., 2005). Inclusion of further context regarding the family situation such as experience with MH could be instrumental in finding and understanding any trends resulting from the stigma scale. The survey would then provide mixed-methodology results of quantitative measurements (Full Stigma Scale) and qualitative assessments (free response questions). Focusing on a larger study population will also allow for understanding whether socioeconomic status elements show trends in child and general MH stigma.

Conclusion

The development and validation of a parental perception on child MH stigma tool is a necessary step in creating a standardized process for evaluating MH trends in the U.S. The multi-functional aspect of the tool (assessment of sub-scales and general and child

MH stigma) makes it ideal for studying the multifaceted topic of child MH. Researchers plan to apply recommendations noted above and test a larger, more diverse population of parents to supplement the results found in this study. While decision-making is a difficult topic to gauge through survey, pairing the Full Stigma Scale with parent interviews may provide insight into this much needed field of study.

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Footnotes

Declaration of interest

None.

Parental Perceptions of Child Mental Health and Stigma Levels: A Mixed Method Survey

Parents and guardians are the key decision makers on behalf of their children (under the age of 18 years). Their own perceptions of child mental health and potential stigma impacts their reasoning and decisions. This study aims to measure levels of perceived child mental health stigma in a diverse urban environment, to determine whether parents view child mental health differently than general mental health, and to understand whether parental identities affect levels of measured stigma. Using a previously validated survey paired with free response questions, this study recruited parents and guardians in the Phoenix metropolitan area using traditional and electronic recruitment. A total of 623 participants were recruited. Results show neutral levels of child mental health stigma, but significant interactions among race/ethnicity, income, and education with stigma scores. Content and thematic analysis showed parents perceived child MH differently from general mental health. Development of successful interventions to help parents navigate

their children's mental health must take into account parents' individual identities and needs.

Keywords: child mental health, stigma, mixed method

Introduction

Child mental health (MH) is an issue the Centers for Disease Control and Prevention (CDC) has garnered attention for, especially as they estimate only about 20% of children diagnosed with mental, emotional, or behavioral disorders—herein discussed under the umbrella term MH issues or conditions—actually receive care from a MH care professional (CDC, 2020; Martini et al., 2012). These stark numbers are even more troubling when understanding they come from those already diagnosed: many children not only have issues in accessing proper MH care but also the knowledge that such help may be needed. Of course, children under the age of 18 years must look to their parents or guardians for this accessibility. Recognizing parents are gatekeepers to child MH evaluation and care, the issue then becomes one of understanding parental knowledge and perceptions of child MH and what potential factors, such as stigma, may impact their decision-making in how and when to seek evaluation and care.

Research has demonstrated that early evaluation and diagnosis of MH issues, especially in early childhood, lead to better outcomes for the children and family (National Research Council (US) and Institute of Medicine (US) Committee on the Prevention of Mental Disorders and Substance Abuse Among Children et al., 2009b). Yet, research also shows time from first symptom to initial diagnosis can take several years for children (Costello et al., 1996). Due to this lag-period, interventions focused on parent education regarding MH issues and recognition have been supported by National Research Council (US) and Institute of Medicine (US) Committee on the Prevention of Mental Disorders and Substance Abuse Among Children, Youth, and Young Adults (National Research Council (US) and Institute of Medicine (US) Committee on the Prevention of Mental Disorders and Substance Abuse Among Children et al., 2009a). Additionally, as a 2015 study showed, parents' perceived MH stigma impacts willingness to consider accessing MH care for their child, even with low levels of stigma (Polaha et al., 2015). This study found that greater perceived stigma correlated to less willingness to access care through health centers and schools (Polaha et al., 2015). Considering that seminal studies have shown the public—of which parents are a part of—often hold stigmatizing views of child MH (Pescosolido et al., 2008), a consideration of its levels and potential impact on parental decisions is necessary. While some parents may report potential MH issues in their children early (Gilliam & Shahar, 2006), the estimate that only 20% of children with MH conditions receive appropriate levels of care, overall, leads toward a conclusion that parents are either unable to recognize when a child needs to access MH care or are unwilling to access care due to certain factors, such as stigma (Martini et al., 2012; Villatoro et al., 2018). Thus, research and intervention focused on the parents or

guardians in how to identify and promote MH wellbeing at an early age as well as overall parental understandings may be crucial (Petrie et al., 2007; Polaha et al., 2015; Ulferts, 2020). However, successful interventions need to be based on a solid foundation of understandings regarding parental perceptions of the issues at hand.

Current studies on child MH often highlight the importance of social understandings (Pescosolido, 2013; Pescosolido et al., 2008), especially when considering stigma (*Causal Theories of Mental Disorder Concepts*, n.d.). Parents base their decisions on their knowledge of MH and child development, notions reinforced by their acquired social understandings (Hess et al., 2004; Landsman, 2009). Per modified labeling theory, social understandings are often based on expected, normative behaviors, and conversely, non-normative behaviors are ostracized socially (Perry et al., 2010). When an individual exhibits non-normative behaviors due to a MH issue, the threat of social rejection may increase the likelihood of avoidance and concealment behaviors (Jones et al., 1984). Modified labeling theory also considers social network theory in that strong relationships (i.e., family) help support while peripheral relationships (i.e., colleagues) reject the labeled individual (Kelner & Wellman, 2014). Such interactions paired with ideas of normality regarding childhood and parenthood play a critical role in parental perceptions (Landsman, 2009). Specifically, deviation from the perceived, socially-accepted ‘normal’ for parents may inspire feelings of fear and stigma, even as they feel the weight of responsibility to make the right decisions for their child and family (Broady et al., 2017; Landsman, 2009; McKeever & Miller, 2004). As ultimate responsibility lies with the decision-making individuals, parents’ guilt, shame, or embarrassment may increase levels

of perceived/anticipated child MH stigma (Landsman, 2009). Additionally, with a potential increase in perceived child MH stigma, parents may experience their circumstances in a more negative light (than if they had lower levels of perceived stigma), manifesting a situation where their fears and misunderstandings bolster their higher levels of stigma (Green et al., 2005; McKeever & Miller, 2004).

While studies show parents seeking help experience barriers in finding appropriate professionals (Hansen et al., 2021), there is also a need to understand social and perceived barriers parents face even before this step (Mukolo et al., 2010). A 2018 study by Zuckerman et al. found that not only was stigma associated with unmet needs for MH care but that sociocultural differences potentially had an impact on the severity of stigma perceived by parents (Zuckerman et al., 2018). The study developed an English/Spanish bilingual parent-reported scale of perceived community Autism Spectrum Disorder (ASD) stigma focused on Latino and non-Latino white parents (Zuckerman et al., 2018). According to the study, parents with minority and vulnerable identities, such as those related to race/ethnicity (Latino parents) and income (low income) such as publicly-insured families and Latino parents without English literacy, may be experiencing more perceived community stigma than non-minority, non-vulnerable identities (Zuckerman et al., 2018). While the study focused on parent-perceived MH stigma regarding ASD (Zuckerman et al., 2018), there is also a need to understand parental perceptions of child MH stigma overall, as parents just entering into the realm of child MH make decisions for evaluation and diagnosis based on their preconceived understandings. Both general views of MH and views on specific MH conditions are important in determining impact

of MH stigma on decision-making and outcomes. Specifically, an overall child MH stigma scale would be able to capture parents' perceptions prior to and before any problem recognition of MH symptoms may occur, generally within the community, as well as using as a tool to combine with later screening and decision-making by parents: the times when parental decision-making to access child MH care is critical in moving toward formal evaluation, diagnosis, and treatment.

As the Zuckerman et al. study noted the impact of race/ethnicity on perceived MH stigma, a 2020 literature review and meta-analysis by Eylem et al., mental illness stigma (for common mental disorders) found MH stigma to be higher among ethnic minorities than majorities (Eylem et al., 2020). Literature shows that negative consequences of MH stigma are increased for minority populations due to multiple layers of structural adversities faced such as poverty and gender (Eylem et al., 2020; Nadeem et al., 2007). Specifically for the Hispanic population, those with lower socioeconomic status (lower income, lower education level) are less likely to seek access to MH care (compared to non-minorities) due to MH stigma. Considering Hispanics are one of the largest ethnic minorities in the U.S., such trends regarding MH stigma and MH care seeking behaviors are troubling and require further investigation (Lopez et al., 2018). Further, there is a need to consider how perceived child MH stigma may impact parental decisions to access or not access MH care and whether aspects other than ethnic minority identities interplay meaningfully regarding levels of perceived stigma.

This study aims to (1) test a validated parental-perceived general and child MH stigma scale on a diverse population in the Phoenix metropolitan area, (2) determine whether

parents' identities relating socioeconomic status (*i.e.*, race/ethnicity, income, education) affects their perceived stigma levels, and (3) assess differences in how parents view MH and child MH. Based on intersectionality frameworks and modified labeling theory, this study will focus on testing whether minority groups such as Hispanic/Latinx parents may have higher perceived child MH stigma when considering other factors of their identities such as socioeconomic status (education, income). Exploratory analysis to determine whether such interactions exist is a first step in the process of individualizing effective intervention and policy to lessen perceived child MH stigma.

Materials and methods

Participants and study site

Similarly to Ivanova et al. (Paper I), the focus on understanding all parental perceptions of child MH meant that our target population included all parents regardless of whether their children were diagnosed with any type of MH issue or not. The stigma scale was developed to be used by any parents from those who have never considered child MH issues to those who have potentially gone through the process of diagnosis and treatment for their children. As this study tried to capture parents and guardians in the liminal spaces of the problem recognition, evaluation, diagnosis, and treatment schema—and specifically before and after the problem recognition step—participant recruitment included any parent or guardian over the age of 18 years, who currently had guardianship

of a child under the age of 18 years. Parents who had multiple children under the age of 18 years, including infants, were asked to take the survey with their youngest child in mind. This step was done to help increase information on parental perceptions of child MH of younger, non-school age children: the youngest children have the least amount of agency in child MH care access and often benefit the most from early intervention. Age of child was not a factor of interest at this time as this study focuses on overall parental perceptions of child MH at any point of childhood,

Recruitment was done through convenience and respondent-driven sampling. While recruitment was done throughout diverse areas of the Phoenix metropolitan area, no targeted recruitment occurred (i.e., race and ethnicity, education, and income were not targeted characteristics in any way). Participants were recruited by physical and virtual flyers as well as active recruitment in public spaces (parks, libraries, recreational facilities, etc.) by researchers around the Phoenix metropolitan area between May 2019 and August 2020. Flyers were placed in any public space allowed including café and recreational facility bulletins. In-person recruitment entailed potential participants being approached and presented with physical handouts, as well as verbal communication about the study. Participants would use the link or QR code to access the developed survey on the Qualtrics© platform, an online survey tool. Participants accepted the consent form online before moving forward to the survey section. All participants were asked to let people in their social network know about this study and were given information for such purposes via extra flyers. Participants provided consent online by accepting the consent and moving forward to the survey questions.

This process occurred as COVID-19 began, which required an additional type of recruitment. The survey was disseminated through Mechanical Turk, which compensates participants for their time (\$0.50). The platform allows the restriction of the survey to people within the target region (Phoenix, Arizona) and participants went through a similar consent process as in the first round of recruitment (English speaking adults over the age of 18 years with children under the age of 18 years).

While the initial iteration of the stigma scale survey did not include ethnicity in its demographics (Ivanova et al. Paper I), Hispanic/Latinx ethnicity was included in the race selections. Importantly, the Hispanic/Latinx ethnicity was included as there is a large Hispanic population in Phoenix, Arizona (43.2% of the Phoenix population). (*Phoenix, AZ / Data USA*, n.d.) Notably, this Hispanic/Latinx population identifies predominantly as white, Hispanic (35.3%). (*Phoenix, AZ / Data USA*, n.d.) Use of “Hispanic/Latinx” was meant to be an inclusive step for racial and ethnic identities that “refers foremost to an ethnic identity that is often associated with a brown racial identity, but it can also refer to a white or black racial identity, as well as an indigenous identity (not to mention how multiraciality complicates this simple schema).” (Soto Vega & Chávez, 2018) While use of Latinx for ethnicity is contested outside of academic use, this study uses the terminology with the intent of providing a more inclusive term than either Hispanic or Latino/a. Though this study includes all race/ethnicity in demographics and descriptive statistics, there is a focus on the two largest race/ethnic populations of the Phoenix metropolis: white non-Hispanic/Latinx and any participant who identifies as

Hispanic/Latinx (regardless of other race (s) chosen). Focusing on the two largest race/ethnicity populations in Phoenix was to identify perceived child MH stigma where results may have (initially) the most impact.

The study was approved by the Arizona State University Institutional Review Board (#2823).

Survey

An online survey was developed using a validated stigma scale measuring parental perceptions of general and child MH (would cite Paper I here). (King et al., 2008; Siu et al., 2012) The tool features 44 statements on a five-point Likert scale and includes three subscales capturing factors of interactions, discrimination, and positive aspects pertaining to MH stigma. As mentioned in the above section, race/ethnicity was included among the demographic questions as well as education, income, age, marital status, and relationship to child (see Table 1 for breakdown of demographic categories). An additional three free-response questions were added asking participants to answer “what do you think when you consider the term” MH, mental illness, and child MH, separately. Participants were allowed unlimited space to respond to these open-ended questions. The survey was estimated to take about 10-15 minutes online.

Analysis

Based on a recent literature review on MH stigma and effect size of 80 different MH stigma studies, (Mehta et al., 2015) this study expected a medium effect size, though at least one study reported a large effect size of MH stigma. (Mehta et al., 2015) Power analysis was run using SPSS v. 27 to determine how many participants would be needed for at least 0.90 power, 0.05 significance, with medium effect size (0.600) yielding a preferred 60 participants per demographic group of interest (race/ethnicity, income, education). With a focus on the white, non-Hispanic/Latinx and Hispanic/Latinx groups, recruitment was monitored to ensure sufficient sample size was achieved—though monitored, recruitment was not targeted toward specific groups—for running common (exploratory) factor analysis and analysis of variance (ANOVA). Additionally, skewness and kurtosis trends were considered to ensure normal distribution and effective sample size for factor analysis.

As recruitment occurred through two substantially different modes, survey responses would be kept separate until demographic results could be compared. If deemed similar based on descriptive statistics of survey responses, the two groups would be combined for further assessment. Descriptive statistics was done using Excel v. 16.46 and SPSS v. 27 to understand demographics of participants and further test for trends among parental identities and levels of stigma. Responses having more than four missing responses were removed from summation (less than 90.0% complete). Using race/ethnicity (white, non-Hispanic/Latinx; Hispanic/Latinx) income (\$0-32,999; \$33,000-59,999; \$60,000-99,999, and

>\$99,999), and education (less than college degree, college degree, and professional/doctorate degree) as independent variables and overall and factor-score sums as dependent variables, an overall variance of analysis, ANOVA, was run. (Note, additional dummy variables were used within race/ethnicity to help categorize any race associated with Hispanic/Latinx ethnicity coding for white, non-Hispanic/Latinx and Hispanic/Latinx.) As the white, non-Hispanic/Latinx and Hispanic/Latinx communities were of most interest in this study, race/ethnicity was constrained to those two groups for ANOVA. Income and education were reduced from the categories gathered in the survey for the purposes of having a sufficient sample size for running the ANOVA (Table 1). Of specific interest were two-way and three-way interactions, though it was expected that these results would be exploratory due to loss of power with increasing interactions. The purpose of running ANOVA was to determine whether a larger-scale study may yield further light on how intersectionality can be operationalized and analyzed in a mixed-method framework.

To ensure scale functioning with a larger, diverse sample population, common factor analysis, and Cronbach's alpha was done and compared to prior validation results (King et al., 2008) (paper I). Total and subscale scores were summed and assessed for levels of MH stigma. Results showed whether there were noticeable levels of child MH stigma and potential connections among demographics.

Qualitative analysis of the three free-response questions (*what do you think when you consider the term (1) MH, (2) mental illness, and (3) child MH*) was done using the MAXQDA 2020 platform. Analysis took part in three separate steps.

Firstly, content analysis was used to determine the way in which parents discussed the three topics (Bernard, 2011). The unit of analysis was meaningful phrases. Therefore, this unit could include anything from single, meaningful words such as “depression” to full sentences such as “any disorders that can hinder a person’s cognitive abilities.” This was done due to the results of the free responses varying from full sentences and paragraphs to single word answers or lists. Two *a priori* themes were utilized in the qualitative analysis: *diffuse MH descriptors* of the three topics and *DSM 5 criteria language that used any key words* (specific disorders, clinical terminology, symptomology) from the DSM 5. Any phrasing attempting to describe MH, mental illness, or child MH outside of disorder-specific terminology was categorized as *diffuse MH descriptors*. These two codes were applied to all free responses.

A secondary step of further analyzing the diffuse MH descriptors was taken by using thematic analysis: coding per participant entry, themes were then organized by concepts and frequency over three iterations by one author (Bernard, 2011; Braun & Clarke, 2006). While thematic analysis was done for all responses coded as diffuse descriptors, the resulting emergent themes were primarily used in this study to guide the next step of analysis.

Finally, as diagnoses appeared to be a major response for both *diffuse MH descriptors* and *DSM 5 criteria language codes* for all three free response prompts, diagnoses were chosen as a way to identify whether there were differences in how participants discuss child MH and mental illness/MH. A go-list was developed (Appendix B) based on diagnoses mentioned from the actual data and run for the purposes of then doing a complex coding query (intersection) on the MAXQDA 2020 platform. This analysis was used to determine whether parents conceptualized diagnoses differently for MH/mental illness and child MH.

Results

Demographics

A total of 623 surveys were taken (376 through traditional recruitment; 247 through Mechanical Turk). Demographics of race/ethnicity, age, education, marital status, relation to child, and income were compared between the two groups: due to great similarity in descriptive statistics and perceived stigma scale results, the groups were combined (Table 1).

Table 1: Participant demographics (%) of all 623 surveys taken. Please note that not all participants answered all questions (N in parentheses for each category).

	Traditional	Mturk	Combined
Race/Ethnicity			
	N=293	N=219	N=512

White/Caucasian	66.9 (196)	62.1 (136)	64.8 (332)
Black/African	11.6 (34)	12.8 (28)	12.1 (62)
Other	2 (6)	3.2 (7)	2.5 (13)
Asian or Pacific Islander	7.2 (21)	3.2 (7)	5.5 (28)
Native American	1.7 (5)	4.6 (10)	2.9 (15)
Hispanic/Latinx	10.6 (31)	14.2 (31)	12.1 (62)
Age			
	N=302	N=219	N=521
18-24	5.6 (17)	11 (24)	7.9 (41)
25-34	45.7 (138)	51.1 (112)	48 (250)
35-44	29.1 (88)	21.5 (47)	25.9 (135)
45-54	15.2 (46)	14.2 (31)	14.8 (77)
55-64	3.3 (10)	1.8 (4)	2.7 (14)
65-74	1 (3)	0.5 (1)	0.8 (4)
75 and over	0 (0)	0 (0)	0 (0)
Education			
	N=293	N=219	N=512
Less than High School	0 (0)	0.9 (2)	0.4 (2)
High School Degree	7.2 (21)	9.1 (20)	8 (41)
Some College	21.8 (64)	21.5 (47)	21.7 (111)
College Degree	52.2 (153)	55.7 (122)	53.7 (275)
Professional/Doctorate Degree	18.4 (54)	12.8 (28)	16 (82)
Marital Status			
	N=293	N=219	N=512
Married	72.7 (213)	67.6 (148)	70.5 (361)
Living w Partner	9.9 (29)	12.3 (27)	10.9 (56)
Single	12.6 (37)	16.4 (36)	14.3 (73)
Divorced	4.8 (14)	2.3 (5)	3.7 (19)
Widowed	0 (0)	1.4 (3)	0.6 (3)
Relationship to Child			
	N=289	N=219	N=508
Mother	56.7 (164)	45.2 (99)	51.8 (263)
Father	36 (104)	46.6 (102)	40.6 (206)
Guardian	2.8 (8)	4.6 (10)	3.5 (18)
Grandfather	0.3 (1)	0 (0)	0.2 (1)
Grandmother	0.7 (2)	0.9 (2)	0.8 (4)
Other	3.5 (10)	2.7 (6)	3.1 (16)

Income			
	N= 293	N=219	N=512
<\$10,000	3.4 (10)	5 (11)	4.1 (21)
\$10,000-24,999	7.5 (22)	11 (24)	9 (46)
\$25,000-32,999	14.7 (43)	14.2 (31)	14.5 (74)
\$33,000-59,999	24.6 (72)	30.1 (66)	27 (138)
\$60,000-99,999	24.6 (72)	25.1 (55)	24.8 (127)
\$100,000-149,999	14.3 (42)	10.5 (23)	12.7 (65)
>\$150,000	7.2 (21)	2.7 (6)	5.3 (27)
Prefer Not to Say	3.8 (11)	1.4 (3)	2.7 (14)

Survey functioning

The survey took, on average, 16.5 minutes to complete for both recruitment formats together. To ensure the validated survey was indeed measuring levels of stigma as expected, common factor analysis and Cronbach's alpha were done to compare with prior cited results of King et al. and Ivanova et al (King et al., 2007).

Common factor analysis for the two different recruited samples was done with similar results, further showing the two sample sets could be combined. The combined sample yielded similar components to Ivanova et al. and King et al., supported by scree plot, of (1) interactions with MH (accounting 29.8% of variance), (2) discrimination (9.0% of variance), and (3) positive aspects relating to MH (7.6% of variance). When comparing how the 44 statements from the survey broke down into the three components, 12 were

found to not be loading in the same components found in Ivanova et al. However, the 12 different loadings were nearly all related to slight changes in previously high factor loadings across two components with switches between interactions with MH and discrimination or between now-negatively loading statements moving between the first two components and positive aspects. Subscales from Ivanova et al. were thus kept consistent for subscale summation of stigma levels.

Cronbach's alpha for the full survey was 0.901, also similar to prior results.

Distribution of frequencies and summation of scale

All acceptable responses (completion of 90% or more of survey) were summed and yielded a mean of 129.71 (SD 17.27, lowest possible being 44.00, highest possible being 220.00). Mean score of the entire survey was 2.95 (SD 0.62; scale of 1.00 to 5.00, with 3.00 being neutral). Average median score was 2.93.

All acceptable responses (90.0% completion) were summed by factor: interactions with MH (F1) had a mean of 70.8 (median 70.0, SD 10.02), discrimination (F2) had a mean of 33.5 (median 32.0, SD 10.68), and positive aspects (F3) had a mean of 21.3 (median 22.0, SD 4.19). Interactions with MH was the only factor that had a mean and median score above its neutral midpoint of 66.0. Discrimination and positive aspects scored slightly below the neutral midpoints of 36.0 and 24.0, respectively.

Table 2: Frequency distribution of Likert-scale responses per statement. Strongly agree and agree relate to higher levels of stigma. Positive statements (bolded) have been flipped so that they are read similarly. Bolded sections of strongly disagree and disagree, neither agree or disagree, or strongly agree and agree show distribution tended toward higher, neutral, or lower stigma levels per statement. Responses may not sum to 100 percent due to missing answers or rounding.

#	Statement	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
1	It is difficult to communicate with people with mental illness	4.2	18.8	22.8	34.0	7.1
2	It is common for people with mental illness to have propensity for violence	6.7	25.0	23.9	23.0	8.2
3	The majority of people with mental illness can recover	10.4	33.1	27.6	14.0	1.3
4	People with mental illness are weak, they should blame themselves for their illness	39.8	15.9	10.6	12.2	8.2
5	The society should treat people with mental illness with a tolerant attitude	23.0	43.2	14.8	3.5	2.1
6	It is difficult to predict the behaviors of people with mental illness	1.0	11.7	20.7	43.5	9.5
7	It is difficult to predict the mood of people with mental illness	1.0	11.6	21.7	38.5	13.5
8	Everyone has the chance to develop mental illness	18.6	43.3	18.1	5.5	0.5
9	I would not tell others that I suffer from mental illness	5.3	22.3	23.3	24.1	11.1

10	People having a relative suffering from mental illness would be looked down upon by others	13.8	18.3	24.1	23.0	7.2
11	I feel afraid of talking to people with mental illness	14.0	27.9	16.4	22.8	5.0
12	I oppose the building up of residential hostels for people with mental illness near to my household	12.4	25.0	21.8	17.3	9.5
13	There are no medication treatments for mental illness	28.3	22.8	13.3	16.1	5.6
14	People with mental illness have very low chance of being recovered	15.1	26.8	19.7	16.4	8.2
15	It is difficult for me to make friends with people with mental illness	12.8	23.0	22.8	20.5	6.9
16	I would feel embarrassed to go out with my relative if my relative has/were to have mental illness	20.4	29.9	12.5	18.6	4.3
17	It is a waste of money to increase the expenditure on the service to care for people with mental illness	28.7	27.0	12.8	8.5	8.8
18	My child has been discriminated against (in education) because of my mental health problems	5.0	12.7	21.2	38.4	8.7
19	Sometimes I feel that my child is being talked down to because of his/her mental health problems	3.5	10.9	18.9	41.3	11.2
20	Having a child with mental health problems has made me a more understanding person	17.8	37.7	23.0	5.1	2.1
21	I do not feel badly about my child having mental health problems	10.9	26.5	15.1	25.2	7.7
22	I worry about telling people my child has received/will receive treatment	9.3	16.2	22.2	27.1	10.6
23	Some people with mental health problems are dangerous	2.2	6.1	20.2	43.2	13.6

24	People have been understanding of my child's mental health problems	10.4	24.4	33.4	14.8	2.2
25	My child's mental health problems have made me more accepting of other people	15.2	43.0	21.5	3.9	1.8
26	Very often I feel alone because of my child's mental health problems	6.7	22.5	17.8	29.9	8.0
27	I am scared of how other people will react if they find out about my child's mental health problems	6.3	15.9	20.7	33.1	9.1
28	My child would have had better chances in life if she/he had not had mental health problems	2.4	7.1	17.5	38.5	19.6
29	I do not mind people in my neighborhood knowing my child has had mental health problems	13.5	32.7	22.0	14.4	2.4
30	I would say my child has had mental health problems if she/he were applying for a job	8.5	27.6	27.3	16.2	5.5
31	I worry about telling people that my child takes medicines/tablets for mental health problems	5.6	18.0	19.4	33.7	7.9
32	People's reactions to her/his mental health problems make me keep the issues to myself	4.3	14.3	24.2	31.6	10.3
33	I have noticed people's reactions to her/his mental health problems make my child keep to him/herself	3.0	10.3	28.4	31.8	10.8
34	I am angry with the way people have reacted to my child's mental health problems	1.4	7.4	19.4	35.8	20.5
35	I have not had any trouble from people because of my child's mental health problems	6.9	20.2	24.1	26.6	6.4

36	My child has been discriminated against by health professionals because of her/his mental health problems	6.9	21.5	19.7	29.5	6.3
37	People have avoided her/him because of her/his mental health problems	2.6	10.9	25.5	34.5	10.6
38	People have insulted me and/or my child because of his/her mental health problems	2.9	14.0	27.3	31.8	8.0
39	Having had a child with mental health problems has made me/her/him a stronger person	18.8	36.1	22.6	4.7	1.9
40	I do not feel embarrassed because of my child's mental health problems	17.7	35.6	16.4	12.5	1.8
41	I avoid telling people about my child's mental health problems	5.1	18.1	24.9	27.4	8.3
42	Having a child with mental health problems makes me feel that life is unfair	6.6	18.0	25.0	25.0	9.0
43	I feel the need to hide my child's mental health problems from my friends	11.9	23.8	20.5	19.4	8.0
44	I find it hard telling people my child has mental health problems	7.7	14.8	20.7	32.3	8.5

ANOVA of Survey Results

To run the ANOVA, the three independent variables of interest were reduced down from the demographics captured in Table 1: race/ethnicity (white, non-Hispanic/Latinx versus Hispanic/Latinx), income (\$0-32,999; \$33,000-59,999; \$60,000-99,999, and >\$99,999), and

education (less than college degree, college degree, and professional/doctorate degree). Overall and factor-score sums were dependent variables.

For overall survey score sum, education was determined to be a main effect ($P=.004$), and there was a statistically significant two-way interaction between race/ethnicity and income ($P = .036$) and race/ethnicity and education ($P = .003$); however, R squared was low (R squared = .205) (Table 3). Lower income brackets and higher education brackets relating to race/ethnicity correlate with higher levels of stigma (Appendix C). Low R squared scores may be due to smaller sample size when demographic variables are broken down—specifically, the Hispanic/Latinx group was significantly smaller than the white, non-Hispanic/Latinx group. As mentioned in methods, race/ethnicity, education, and income categories were further compartmentalized for effective analysis and ANOVA results are considered in an exploratory fashion to determine future directions of research framework.

Looking at results of specific factor scores, education was a main effect for F1 and F2 scores (Table 3). No significant main effects or interactions were noted for F3 and no factor showed main effect of race/ethnicity on its own. Again, though, R squared values were low. Overall, higher brackets of education level correlated with higher levels of stigma (Appendix C).

Table 3: ANOVA results for overall survey score sums and for three factors' survey score sums.

Tests of Between-Subjects Effects					
Dependent Variable: Survey Results Sums					
Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	27266.088a	57	478.352	1.829	0
Intercept	657561.288	1	657561.288	2513.666	0
Race	1065.408	5	213.082	0.815	0.54
Income	1591.216	4	397.804	1.521	0.195
Education	3494.467	3	1164.822	4.453	0.004
Race * Income	6976.089	15	465.073	1.778	0.036
Race * Education	6178.635	8	772.329	2.952	0.003
Income * Education	2626.941	8	328.368	1.255	0.266
Race * Income * Education	4822.416	13	370.955	1.418	0.148
Error	105945.769	405	261.594		
Total	8194453	463			
Corrected Total	133211.857	462			
a R Squared = .205 (Adjusted R Squared = .093)					

Tests of Between-Subjects Effects					
Dependent Variable: SumF1					
Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	7564.758a	57	132.715	1.41	0.033
Intercept	191983.726	1	191983.726	2040.196	0
Race	298.774	5	59.755	0.635	0.673
Income	314.29	4	78.572	0.835	0.503
Education	850.726	3	283.575	3.014	0.03
Race * Income	2337.771	15	155.851	1.656	0.057

Race * Education	1812.129	8	226.516	2.407	0.015
Income * Education	930.197	8	116.275	1.236	0.277
Race * Income * Education	1557.262	13	119.789	1.273	0.226
Error	38110.763	405	94.101		
Total	2368454	463			
Corrected Total	45675.521	462			
R Squared = .166 (Adjusted R Squared = .048)					

Dependent Variable: SumF2

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	13074.246a	57	229.373	2.337	0
Intercept	38722.192	1	38722.192	394.568	0
Race	387.231	5	77.446	0.789	0.558
Income	447.497	4	111.874	1.14	0.337
Education	1300.975	3	433.658	4.419	0.005
Race * Income	1974.145	15	131.61	1.341	0.174
Race * Education	2146.098	8	268.262	2.734	0.006
Income * Education	638.747	8	79.843	0.814	0.591
Race * Income * Education	1376.113	13	105.855	1.079	0.376
Error	39745.974	405	98.138		
Total	589341	463			
Corrected Total	52820.22	462			

a R Squared = .248 (Adjusted R Squared = .142)					
Dependent Variable: SumF3					
Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	1489.483a	57	26.131	1.589	0.006
Intercept	18509.386	1	18509.386	1125.41	0
Race	109.523	5	21.905	1.332	0.25
Income	18.491	4	4.623	0.281	0.89
Education	33.313	3	11.104	0.675	0.568
Race * Income	214.408	15	14.294	0.869	0.6
Race * Education	195.874	8	24.484	1.489	0.159
Income * Education	202.934	8	25.367	1.542	0.141
Race * Income * Education	211.056	13	16.235	0.987	0.463
Error	6660.953	405	16.447		
Total	217192	463			
Corrected Total	8150.436	462			
a R Squared = .183 (Adjusted R Squared = .068)					

Qualitative Analysis

Results of the qualitative analysis revealed a total of 1,830 codes with 1,375 of them being diffuse descriptors from 512 individuals who answered all three of the free response questions (Figure 1, Appendix A). Responses varied in length and depth from

single word answers to lists (often of diagnoses and symptoms) and full paragraphs discussing topics from causality of MH issues to explanations of specific diagnoses. Content analysis was used to yield an initial set of codes before thematic analysis was applied to determine emergent themes in response to what participants thought when considering MH, mental illness, and child MH as terms.

The two *a priori* codes for the content analysis were applied (Figure 1, DSM 5 criteria language and diffuse descriptors). Participants responded to the three prompts in an array of only DSM 5 criteria language or diffuse descriptors or a combination of both. DSM 5 codes, any key words (specific disorders, clinical terminology, symptomology) from the DSM 5, were used by 163 participants for MH, 161 for mental illness, and 127 for child MH, while diffuse descriptors were used by 216 participants for MH, 233 for mental illness, and 199 for child MH. Meanwhile, both codes were used together by 59 participants for MH, 64 for mental illness, and 35 for child MH. Of these, 104 participants used both DSM 5 criteria language and diffuse descriptors together at least once as seen here: “*Autism, ADHD, challenges to parenthood, love, understanding, tolerance.*”

Diffuse descriptors fell into four subcategories: *related to DSM 5 disorders* (n=808), *norm/normal* (n=329), *opinions & experiences* (n=138), and *causality of MH* (n=100) (see Figure 1). The majority (58.8% of diffuse descriptors) of codes fell within *related to DSM 5 disorders*—containing information that was both DSM 5 criteria language and also diffuse descriptors that explained DSM 5 criteria language further—followed up by

discussion of norms and normal behaviors (23.9%). Participants who replied with diffuse descriptors provided complex understandings of the topics, such as this discussion on mental illness: *“I think of people who need help dealing with emotions, who have trouble controlling thoughts, who are easily provoked. I know that mental illness can have many different forms, some that are easier to treat than others. There is a definite stigma associated with mental illness and a lack of recognition and appropriate treatment that puts this population at a significant risk to find it difficult to fit in with our societal ‘norms’ and increases their risk for isolation.”* Indeed, the complexity of the responses required further analysis using thematic analysis not included in this paper due to the wide variety of emergent themes within the four diffuse descriptor codes (Figure 1).

Briefly, emergent themes of interest were found within the four main topics of diffuse descriptors. Thematic analysis results are reported as the number of unique codes applied in each category (Figure 1). Within *related to DSM 5 disorders*, six separate themes were found (Figure 1) providing many explanations directly related to diagnosis and treatment discussed in the DSM 5: *“[Regarding child MH] Complex; I am more against giving medication to children. Interactions are very different and less well-studied, and they are still developing.”* Within *norm/normal*, participants’ language regarding MH often touched on the binary nature of normality: from *“a variety of diagnoses describing functioning outside the statistical norm”* to *“not normal, acting crazy, IQ is low”* and *“...brain does not function as it is supposed to.”* The use of *norm/normality* appears to act as a descriptor of MH issues by participants and was combined repeatedly with the

related to DSM 5 disorders theme to further frame definitions and explanations of MH issues as outliers.

For *opinions and experiences*, three types of themes were found with many focused on MH stigma: *“I think there is still a stigma attached to it. Like if someone had cancer or some other awful disease people would feel sorry for them and want to help but if it is a mental disease somehow it is the persons fault and not willing to help.”* Within *causality of MH*, participants considered causes of MH issues in their free responses with the majority focusing on biological, mental, or genetic reasons such as *“a chemical imbalance that one can’t control.”* Few participants (4 codes) pointed to parents or children as causes of MH issues (subsection of socioeconomic status): *“I think it’s a shame and difficult situation—possibly the parents fault.”* Other discussions of *causality of MH* included socioeconomic, environmental, and spiritual/religious mentions: *“...I believe a child’s environment has a great deal to do with mental illnesses manifesting in young people, and that often, an environment change can alleviate some of the symptoms of a mental health disorder”* and *“God does things for a reason to make each and every one of us stronger in our life.”*

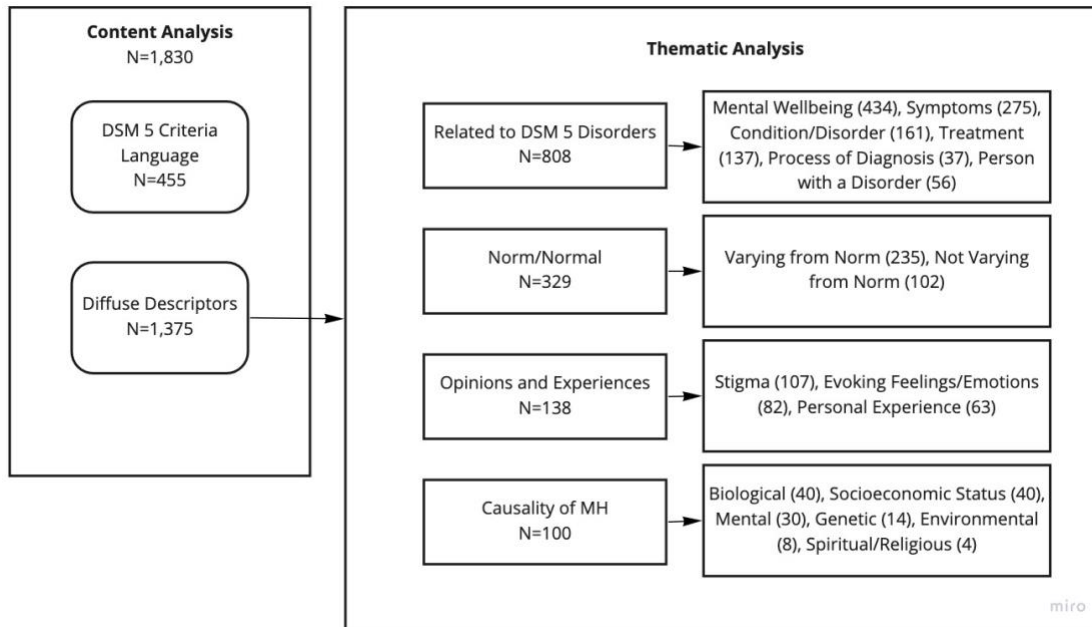


Figure 1: Results of content analysis using DSM 5 criteria language and diffuse descriptors and thematic analysis of resulting diffuse descriptors. N counts the number of instances within each code. Note subcode totals from thematic analysis do not add up to parent code totals.

While diffuse descriptors were further analyzed using thematic analysis (and its results informed the following analysis as discussion of symptoms and diagnoses were common in both diffuse descriptors and DSM 5 codes), this study focused on a content analysis to determine whether participants discussed child MH differently from mental illness and MH in the free responses. A targeted analysis of the diagnoses mentioned within the three free-responses allowed for a systematic way to identify what types of MH disorders participants considered for each of the three free responses. As the below results show, diagnoses were commonly mentioned in both diffuse descriptors and DSM 5 codes,

frequency of specific diagnoses for a complex coding query would provide insight in how participants think about child MH and mental illness/MH.

When considering items from the DSM 5 criteria language go list that included terminology of specific diagnoses and symptoms directly used in the DSM 5 (Appendix B), frequency of diagnoses were of particular concern (some diagnoses refer to broader types of diagnoses such as behavioral disorders, Table 4). Predictably, DSM 5 codings included the majority of instances diagnoses were mentioned. However, there were some diagnoses that were proportionally common across both diffuse descriptors and DSM 5 codes such as ADD/ADHD, anxiety, autism spectrum, and depression. While schizophrenia, a predominantly adult-onset disorder, was mentioned (N=4 for DSM 5 codings) under child MH, the vast majority of participants included it only within their considerations of MH and mental illness. Similarly, certain diagnoses were brought up more often in MH/mental illness rather than for child MH such as anxiety, bipolar, depression, and OCD. On the other hand, other diagnoses such as ADD/ADHD, autism spectrum, and behavioral appeared more often when considering child MH. Note that while down syndrome is not a mental health diagnosis, it was mentioned three times under child MH for DSM 5 codings.

Results point to differences in how participants think about MH/mental illness and child MH based on the observed trend in categorization.

Table 4: Diagnoses by coding and type. Other category includes any diagnoses that were only named once within the type (MH, MI, CMH). ^aNot a DSM diagnosis, though increased likelihood of having a diagnosis. ^bOtherwise known as antisocial personality disorder.

Diagnoses	Diffuse Descriptors			DSM 5		
	MH (N)	Mental Illness (N)	Child MH (N)	MH (N)	Mental Illness (N)	Child MH (N)
ADD/ADHD	5	10	6	43	37	66
Addiction			2	2		2
Anosognosia		2			2	
Anxiety	9	10	5	49	47	24
Autism spectrum	5	2	3	19	17	26
Behavioral			3	4		10
Bipolar	5	6		26	21	3
Borderline				2		
Depression	17	16	7	72	67	28
Dissociative					2	
Dyslexia					2	
Down syndrome ^a						3
Learning disability					2	
Multiple personality					3	
OCD		2		9	7	5
Oppositional defiant				2		
Other	4	4	2	5		
Phobias					2	
Psychosis					4	
Schizophrenia	3	9		25	27	4
Sociopathy ^b		2			3	
Suicide	2		2	3	3	2

Discussion:

Addressing study aims

Results show the survey functions as expected with similar outputs as Ivanova et al. and King et al. (King et al., 2007) even with a more diverse sample of participants than these prior studies (King et al., 2007). While stigma levels appeared to be slightly below neutral, specific questions appeared to elicit greater levels of stigma. Interactions with MH (F1) was the only factor that resulted in slightly greater scores—and thus, slightly higher levels of stigma—than neutral. In the results from the two-way ANOVA, the overall survey showed race/ethnicity and income together influence levels of perceived child MH stigma. Education was shown to have a significant influence on level of stigma in both the overall survey and for the two largest factors of interaction with MH and discrimination. Considering the free response portion of the survey, participants showed trends that certain diagnoses such as schizophrenia, depression, and anxiety were more prevalent when thinking about MH/mental illness than child MH. These differences in diagnoses require further consideration as they show parents associate certain disorders as more prevalent and impactful for children. This type of MH understanding and knowledge can impact perceptions, stigma, and decision-making.

Usability and Assessment of Stigma Survey Tool

While the tool has been previously validated in a similar, though smaller, participant sample, the focus had been solely on the Likert scale prompts and their ability to measure parental-perceived MH stigma regarding child MH (Ivanova et al.). This study not only

supports prior results and suitability of the tool (Ivanova et al.) (King et al., 2007; Siu et al., 2012) but also includes a free response section to further aid in parental-perception evaluation. In doing so, the mixed method approach results in an even stronger tool for researchers, as quantitative results measure stigma levels and qualitative results yield systematic measurements and of participants' opinions on child MH. Further consideration of open-ended answers from the survey may provide even more context to results. Qualitative frameworks not only provide their own quantifiable results but can also provide another dimension of understanding in a study.

Parental identities' impact on stigma levels

This study determined there is potential for parental identities affecting levels of perceived child MH stigma. Using the results as an exploratory platform for intersectionality in perceived child MH stigma, there is evidence that parental identities connected to ethnicity may be interplaying with factors of socioeconomic status such as income. When looking at overall MH stigma using total scale scores, race/ethnicity (white, non-Hispanic/Latinx and Hispanic/Latinx) and its connection to income for participants affect levels of perceived stigma. Results point to lower income brackets among Hispanic/Latinx participants correlating to higher levels of stigma. Education, by itself, influenced levels of stigma in the overall survey scores and in the factor breakdown. Specifically, participants in the higher education brackets tended to show higher perceived stigma scores in these instances. In this study, education seems to operate outside of the intersectional framework, while income and race/ethnicity appear

together to influence perceived stigma levels. Intersectional frameworks support these findings: certain combined identities may be more sensitive to perceived MH stigma. (P. Collins & Bilge, 2016) As social identity and social network loss is a potential outcome of MH stigma, (Lonardi, 2007; Varul, 2010) intersectionality highlights that combinations of identities may be more at risk of this loss than others. As a result, sensitivity toward and awareness of perceived/anticipated or enacted stigma toward their child or family may be higher. While our study focused on factors of socioeconomic status and racial/ethnic factors, current intersectionality research tends to focus on gender and racial/ethnic differences (Rosenfield & Mouzon, 2013). Future work for parental perceived child MH stigma should consider additional key identities that may be at play in outcomes of perceived child MH stigma such as gender, as well as relationship to child and marital status.

While many MH stigma scales show higher education correlating with lower levels of stigma (Bonabi et al., 2016; Liu et al., 2016; Xu et al., 2018), some studies have found no or weak evidence of such a correlation (Bhavsar et al., 2019; Villatoro et al., 2018) or altogether conflicting results. Specifically, Lopez et al. showed greater levels of stigma toward use of antidepressants associated to higher education in Hispanic women (Lopez et al., 2018). Similar trends in this study were found for participants when looking at education brackets for overall stigma scores and factor stigma scores. Such results spotlight a potential negative trend in higher education processes impacting parents' thinking about MH, specifically child MH (Gallego et al., 2020). There is a possibility that the form of MH education—e.g. formal teachings on MH stigma or exposure to

people treated for MH issues— may be of more importance on MH stigma than of the level of education. After all, higher education does not guarantee study of, knowledge of, or exposure to psychology, MH, or overall wellness. Labeling theory’s emphasis on social network frameworks may also help answer the results of this study: higher education brackets often result in socially desirable careers and social networking connections; however, these employment connections may be more susceptible to socially rejecting individuals as well (Kelner & Wellman, 2014). Therefore, parents may be in a socially precarious position of having higher education but increased pressure to adhere to socially normative behaviors and experiences thus increasing levels of worry and perceived stigma (Kelner & Wellman, 2014). Considering that race/ethnicity in this study did not influence perceived levels of stigma by itself, such an affect may indeed be present and highlighting the importance of intersectionality framework in MH stigma research. Further qualitative frameworks of research should be employed to understand this potential interaction as results would have consequence on intervention planning.

Meanwhile, increased income, tied to access of resources, appears to coincide with lower levels of stigma, a result seen in prior literature for both stigma and parental problem recognition (Villatoro et al., 2018). Villatoro et al. note income brackets may effect parental thresholds and sensitivity of what may be viewed as “problematic” for their children’s behaviors (Villatoro et al., 2018). Income brackets affect parental accessibility for MH treatment processes. This accessibility may play a role in parental knowledge of MH as well as recognition of disorders (Salgado, 2019). However, while education played a significant role in stigma levels for overall and specific factor scoring, income

only influenced overall stigma scoring. Such a result may show that income (and its complex interaction with other demographic standards) has a smaller effect size that cannot be seen easily in specific factors of MH but is tangible in their summation. Interestingly, F3 (positive aspects) results showed no significant impact of income, education, or race/ethnicity. While this factor was the smallest of the three (and thus has a smaller weight in the overall scores), it also included prompts that stated child MH experiences in a positive light. The positive wording, itself, may have resulted in the slightly lower stigma scoring found (only factor to be below the neutral point in both median and mean of scores), and this same effect may be influencing the results seen in the ANOVA. By discussing child MH in a positive manner, underlying connections to socioeconomic status and race/ethnicity may be offset. Evidence shows that positive attitudes toward MH is a critical step in decreasing levels of MH stigma. (Thornicroft et al., 2016) Based on these results, education plays a more decisive role in child MH stigma and potential interventions than income.

Child MH perceived differently

Content analysis yielded three main ways participants discussed MH topics: utilizing DSM 5 language, using diffuse descriptors of MH, or a combination of the two.

Unsurprisingly, when DSM 5 language was used it was often a list of DSM 5 diagnoses or symptoms (Appendix C) such as “*Depression, anxiety, ADHD, schizophrenia, bipolar, antisocial, etc.*” While the code diffuse descriptors sometimes included diagnoses or symptoms as examples, participants touched on four main themes of (1) related to DSM 5

disorders, (2) norm/normal, (3) personal experiences and opinions regarding MH, and (4) causality of MH.

The concept of normality regarding MH was the second most common theme discussed in the free response. Participants' language regarding MH touched on the binary nature of normality: "*a variety of diagnoses describing functioning outside the statistical norm.*"

Abnormality brings up the issue of otherness, as well: "*Not normal, acting crazy, IQ is low*" and "*...brain does not function as it is supposed to.*" Socially constructed ideas of MH norms and what is deviant cause stigma for children and parents (Landsman, 2009).

Specifically, parents' preexisting views of what is normal and what their perception of parenthood and childhood are can affect their decision making, experiences, and expectations (Landsman, 2009). Perceptions of an abnormal childhood can coincide with parental responsibility and, damagingly, with perceived parental fault leading to stigmatization of the parent (s) and child (Landsman, 2009; McKeever & Miller, 2004).

The cause of a perceived departure from the norm of MH may be of importance regarding views of responsibility and MH stigma. Future research should also consider how parental identities and their factors (such as education, income, race/ethnicity) affect these causal beliefs and understandings.

Participants considered causes of MH issues in their free responses with many focusing on biological, mental, or genetic reasons (69/100 codes) such as "*a chemical imbalance that one can't control.*" Causal models of MH issues are intimately related to MH stigma (Hagmayer & Engelmann, 2014; Knettel et al., 2021) and attitudes toward seeking and

receiving treatment (Knettel et al., 2021; Nolan & O'Connor, 2019). Prior literature notes biological explanations tend to correlate with receiving treatment and lower levels of stigma, though some MH diagnoses linked to a person's genetic biology appear to show increases in stigma with such an explanation (Larkings & Brown, 2018; Mannarini & Rossi, 2019; Pescosolido et al., 2010). The free response resulting in higher instances of biological explanations of MH supports the overall lower levels of stigma measured by the survey portion. Even so, while six of eight instances of parent/childhood causal explanations for MH were within the child MH free response, only nine of 54 instances of biological causal explanations occurred for the same section. This difference in perception is further seen in the types of diagnoses used to describe the three free response sections, as well.

The predominant use of MH issues such as ADD/ADHD and ASD within the free response relating to child MH as opposed to other disorders shows participants' awareness of which MH issues are more commonly associated with children. The emphasis of these disorders for child MH (and others such as schizophrenia for MH/mental illness) demonstrate participants focused on typical onset and general age of diagnosis for these disorders rather than what disorders can affect children and adults. Awareness of these different disorders, in and of itself, may affect overall perceived child MH stigma. Additionally, pairing condition-specific perceived stigma tools with this survey may also help understand whether parents may be using ADD/ADHD and ASD as their baseline for MH issues when considering all child MH. Follow-up work should consider opinions and understandings of these listed diagnoses to determine level of

knowledge and feelings toward those specific diagnoses. For example, emphasis on behavioral disorders for children fails to consider the impact of these same disorders on adults' lives and wellbeing. This same situation also means an increased chance of parents missing warning signs of a different MH issue such as depression or anxiety. Ultimately, a difference in perception of child MH disorders can lead to a difference in how parents approach decision making and disorder recognition—a consideration when developing any intervention.

In the context of COVID-19

While this study took place partly during the beginning of the COVID-19 pandemic, the survey did not gather specific information regarding how the unfolding pandemic affected parents and children; however, research since 2020 has shown a significant increase in MH diagnoses for children, specifically in anxiety and depression (Panchal et al., 2021). While this study reported that anxiety and depression were diagnoses more commonly considered by parents when thinking about general MH and mental illness rather than child MH, COVID-19 may have already changed this trend. The impact of lockdowns and other consequences of the pandemic on child MH are still being researched as many MH issues can take longer to manifest, such as post-traumatic stress disorder (Panchal et al., 2021). Meanwhile, UNICEF reported “that significant barriers, including stigma and lack of funding, are preventing too many children from experiencing positive mental health or accessing the support they need” (*Impact of COVID-19 on Poor Mental Health in Children and Young People ‘Tip of the Iceberg,’*

n.d.). While this study focuses on parental understandings that may impact the path to MH access, COVID-19 is having a visible impact on parents' ability to actually access care for their children. With the isolation brought on by lockdowns and quarantine protocols, parents are further burdened in being able to identify a need for accessing child MH care. This isolation may have unknown effects: MH symptoms may be more easily concealed due to lack of socialization, but MH stigma may also decrease due to society's increased discussion of MH issues. This study could be used as a baseline to determine impact of the pandemic on parental perceptions of child MH stigma in the future.

Future directions and limitations

This study utilized a validated survey to measure levels of perceived child MH stigma and expounded on the tool with the inclusion of free responses for additional context and breadth of understanding. As recruitment for this study occurred during the beginnings of the COVID-19 pandemic, impact of the pandemic on levels of perceived child MH stigma are unknown. Additionally, due to the pandemic's effect on recruitment processes, paid participants were a necessity in reaching a large enough sample size; however, use of MTurk for data has been shown to result in framing effect biases especially regarding topics of money and risk (Goodman et al., 2013). Because this study included traditional recruitment for half of its study sample, researchers were able to compare and check for unusual trends from the MTurk population results prior to combining the data. Though a larger, more diverse sample size would be a next step to further investigate the relationship among income, education, and race/ethnicity and their impact on perceived

child MH stigma, this study was able to reach adequate sampling for groups of interest and provide future direction through exploratory analyses. Future dispersal of the survey tool should include targeted recruitment for all race/ethnicity categories so that all race and ethnicity combinations can be considered in the analysis leading to better understanding of how intersectionality affects perceived child MH stigma. Additional manipulation of present data such as further compartmentalizing of race/ethnicity, education, and income and inclusion of other potentially impactful variables such as gender or marital status may provide better insight into how parental identities affect perceived stigma.

Further analysis of the quantitative measurement tool in tandem with the quantifiable free response data may help in deciphering the complex relationships mentioned in this paper. Specifically, pairing the demographic data with the qualitative data is necessary in understanding intersectionality and results from analyses of variance. Further reduction and analysis of the three free-response prompts is necessary to situate differences among child MH, mental illness, and MH topics for parents. Additional qualitative measures, such as one-on-one interviews, are necessary to map and understand parental decision making regarding child MH before any fruitful interventions can be developed or recommended.

Conclusion

Though levels of perceived child MH appear to be overall low, there are still domains of child MH that result in higher levels of stigma that interact with race/ethnicity, income, and education of parents. This study showed that race/ethnicity may become an important factor when interacting with income or education: the need for considering parental identities in tandem to measurable outcomes is a necessary step in developing effective interventions and policies. Understanding that parents view child MH categorically different from MH generally can impact efficacy of general interventions in place to lessen MH stigma and/or support evidence-based parental decision making. This study determined parental identities factor into child MH knowledge and perceptions. These interactions are of significant importance as they highlight the need for personalized interventions for different communities, groups, and individuals. Perceived child MH affects parents' reasoning and, ultimately, the decision pathway for evaluation, diagnosis, and treatment.

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Declaration of interest

None.

Parental Decision-Making on Child Mental Health Care in the Context of Stigma: Narrative Analysis and Process Map

Keywords: child mental health, narrative analysis, decision making, process map

Introduction

The process of seeking mental health (MH) care is often presented in psychology as a straightforward, linear schema of recognition of a MH issue, evaluation, diagnosis, and then treatment (Dishion & Stormshak, 2007). Unfortunately, barriers exist at all four of these checkpoints: from the difficulty in recognition of MH symptoms to the problems of diagnosis (Johnston & Burke, 2020; Teagle, 2002; Vitztum et al., 1995). When it comes to child MH—MH issues include mental, emotional, behavioral, and developmental disorders (CDC, 2020; Cree, 2018)—there is an additional burden added to these barriers of working with a gatekeeper to accessing MH care: the parent (s) or guardian (s) (Johnston & Burke, 2020). Handling the agency and context of minors and their guardians lead to a more complex situation in accessing the traditional MH care pathway that yields potential for barriers in liminal spaces not often considered.

While MH issues often begin in early childhood, statistics on child MH rely on numbers from children who are diagnosed. Though 17.4% of children between two and eight years of age have been diagnosed with a MH issue, the number of children who are not evaluated and do not have a chance to receive MH care is difficult to find (CDC, 2019). With the COVID-19 pandemic disrupting typical child development and ultimately MH (Imran et al., 2020), figures will be updated to reflect the unknown impact of pandemic life. With such context, understanding how children access and where barriers may be located in MH care is crucial.

Research has consistently shown that early treatment of child MH issues lead to better outcomes for the child (Green et al., 2015; National Research Council (US) and Institute of Medicine (US) Committee on the Prevention of Mental Disorders and Substance Abuse Among Children et al., 2009; Shire et al., 2017). Green et al. demonstrated that early recognition of risk markers, within the first year of life, and intervention for autism spectrum disorder (ASD) showed positive developmental outcomes for children in comparison to no intervention (Green et al., 2015). Further, Shire et al. showed that early treatment is effective in community, real-world interventions, not just in clinical trials. (Shire et al., 2017) Literature bolsters these results and provides the groundwork reasoning that early evaluation and intervention are integral to solving the child MH crisis currently seen in the U.S. (CDC, 2020; French & Kennedy, 2018). Indeed, the Centers for Disease Control and Prevention (CDC) estimates only 20% of children with MH issues actually receive appropriate care in the U.S. (CDC, 2020). With the further

negative impact of the COVID-19 pandemic on child MH, (*Children and the COVID-19 Pandemic.*, n.d.) addressing the gap in child MH care is a national necessity.

As parents and guardians can be considered the initiators in child MH care access, research should focus on their perceptions and decision-making on behalf of their children. With the positive impact of early intervention in child MH care (French & Kennedy, 2018; Green et al., 2015; Shire et al., 2017), recognition of when care is needed and of the steps to acquiring such care are necessary for parents. Recognition of a MH issue is intimately connected to MH outcomes (Johnston & Burke, 2020; Teagle, 2002). If parents do not recognize “red flags” (e.g. symptoms) their child may be exhibiting, then even if they would be willing to quickly access MH care, they would not know to do so. For parents who have children in school, there are more opportunities to be alerted to a potential issue and recognize a problem, though the impact of all these increased interactions may be difficult to separate. For example, in a 2018 study using a mixed-method study of surveys (N=159) and semi-structured interviews (N=18), Haack et al. recruited 159 school-aged children and parents to determine barriers in ADHD problem recognition and help seeking (Haack et al., 2018). The study identified parent ethnicity, problem domain (in relation to the diagnosis), and child age all factor in MH problem recognition, specifically for ADHD (Haack et al., 2018). Interestingly, Latino parents were more likely to disagree with teacher problem recognition in younger children and appear to be a group that interventions should be tailored to for increasing problem recognition (Haack et al., 2018). By focusing on parental understandings and decision-making, this study lessens focus on other outside determinants such as teacher and school

involvement. Additionally, prior studies show that parent-teacher communication tends to be lower for Latino families when compared to non-Latino families (Wong & Hughes, 2006) and may be caused by a combination of being more trusting but less comfortable with teachers and schools (Chavkin, 1993). Furthermore, Haack et al. identified that single-informant evaluation (singular report of potential problem recognition to parent) is not effective in parental problem recognition of ADHD—meaning a single teacher identifying a “red flag” situation may not precipitate child MH care access by parents where repeated incidences and reporting may (Haack et al., 2018). Further research should be done to understand how problem recognition may or may not precipitate parental decisions to move forward with child MH evaluation.

The effect of MH stigma, causing an individual to be perceived as abnormal or less than (Goffman, 1963), on parental decision making regarding child MH care access may lead to negative outcomes such as choosing to conceal or avoid a diagnosis (Jones et al., 1984; B. G. Link et al., 1989). In the case of child MH, the parent has the agency to access MH care on behalf of their child, and thus, parents are the responsible party for MH care decisions (Landsman, 2009). Their navigation of problem recognition, evaluation, diagnosis, and treatment is susceptible to their own understandings and perceptions of child MH and child MH stigma (Dishion & Stormshak, 2007; McKeever & Miller, 2004). Parents are thus laden with the pressure of making decisions on topics that they are sometimes unaware of in the interest of their children: parents often find themselves ill-prepared when faced with the uncertainties around child MH issues (Gray, 2002; McKeever & Miller, 2004). Measuring parental perceived child MH stigma prior to

parents facing such a situation may provide answers as to baseline understandings before and after problem recognition, the first step of entering MH care.

In an earlier part of this study, a 44-prompt survey tool was used to measure stigma levels of parents and guardians in the Phoenix metropolis, a diverse urban and suburban area.

With 623 participants recruited, the study determined neutral levels of parental perceived child MH stigma. However, exploratory analysis of variance also showed significant ($p < .05$) influence of higher education levels relating to higher levels of stigma, with lower income among Hispanic/Latinx participants influencing higher levels of perceived stigma. While some qualitative data did provide context regarding parental understandings of child MH, more in-depth consideration of this population's MH understandings and decision-making is necessary to understand where parental perceptions of child MH may impact the process of accessing child MH care. Results of the prior study identified that while parents may not have high perceived child MH stigma, the level of stigma was not low. Stigma and MH discrimination directly impact decision making (Alakortes et al., 2017; B. Link et al., 2004); therefore, measuring levels of parental perceived child MH stigma is necessary in assessing barriers to problem (MH issue) recognition and accessing MH care. This final phase of the study aims to provide this needed qualitative context regarding processes of decision making and parental understandings. Ultimately, the earlier parts of the study identified the presence of perceived stigma and potential trends of parent identities that may be more at risk in perceiving child MH stigma. This study will identify specific areas where stigma may have the greatest effects on decision making and the process of accessing MH care.

This study aims to (1) identify a simplified parental decision-making pathway for accessing child MH care, (2) determine areas of consequence in the pathway that may be key for future interventions, and (3) consider where in the pathway parents are most likely to access a formal MH care path. Using the diverse sample population of the prior survey study and knowledge of stigma levels, this qualitative analysis of follow up semi-structured interviews will provide context as to how parents and guardians make decisions on behalf of their children's MH.

Materials and methods

Participants and study site

Recruitment occurred between May 2019 and August 2020. As the COVID-19 pandemic began in the middle of recruitment, additional methods of virtual recruitment were added to the protocol.

Participants were recruited either by physical and virtual flyers as well as active recruitment by the study team in public spaces such as parks, libraries, and public university campuses around the Phoenix metropolitan area or via Mechanical Turk restricted to the Phoenix, Arizona region. In-person recruitment entailed potential participants being approached and presented with physical handouts, as well as verbal communication about the study. Participants would use the link or QR code provided to

access a parental-perceived child MH stigma survey (cite Paper I and II) on the Qualtrics© platform, an online survey tool. The survey was a tool to measure perceived child MH stigma and upon completion of the survey, participants were invited to provide contact information for an hour long, paid (\$10/hour) semi-structured interview.

All participants who provided contact information were contacted by the interviewer to set up an in-person, telephone, or virtual interview at a time of their choosing. The survey was strictly used as a way to consent potential interviewees, as accepted by the Institutional Review Board (IRB). Though the IRB did not require it, due to the amount of time between participating in the survey and interview, the interviewer provided a verbal version of consent prior to recording of interviews and ensured that participants confirmed consent once the recording started. Participants' survey information was not linked to their interviews in any capacity as survey data could only be reported in aggregate due to the sensitivity of the topic, per the IRB. In-person interviews were done in public spaces such as parks or cafes. Telephone and virtual interviews (via Zoom) were done with the request that participants felt comfortable to have a discussion regarding MH and child MH. All interviews were recorded with the consent of the participant.

As this final phase of the study was focused on helping understand decision making prior to or directly after problem recognition of a child MH issue by parents, all parents with children regardless of a diagnosis were included. Participants included parents or guardians (over the age of 18 years, fluent in English) of a child under the age of 18

years. As the Phoenix metropolitan area has a significantly large Hispanic/Latinx population (Lukinbeal et al., 2012; *Phoenix, AZ | Data USA*, n.d.), recruitment continued until a sufficient sample size of this community was included for the initial phases of the study. Due to the sensitive nature of the topic, demographic information was not asked of participants for the interview. Demographics of the survey sample pool from the prior survey study show a considerable level of diversity that interviewees were recruited from.

Malterud et al.'s information power was used to determine required sample size for the purpose of this study (Malterud et al., 2016). Due to the specificity of the research aim for this study (determining a process flow for initial parental decision-making based on specific questioning), the initial recruitment of interview interest through the survey process, the use of the parental perceptions of child MH stigma framework, the thorough descriptions through the interview process, and the specific analytic methodology, a provisional number of 15 participants was determined. This study appears to have a high information power based on the Malterud et al. model and thus a smaller sample size may be sufficient (Malterud et al., 2016). Because the initial piloting of the questions provided insight into efficacy of the interviewer and the research framework, researchers believed theme saturation would be achieved with 15 participants. Information power was appraised at every fifth interview to determine whether sufficient sample size was acquired.

The study was approved by the Arizona State University Institutional Review Board (#2823).

Interview

Interviews were semi-structured, emphasizing participants' knowledge, understanding, and experience of child MH issues (Table 1). Questions were developed based on a prior literature review on the topic of child MH and parental perceptions of child MH.

Questions were piloted in 2017 on three parents who fit the inclusion criteria to determine whether questions elicited the information needed for the study. Authors went through three iterations of these questions resulting in the eight seen in Table 1. As mentioned above, due to the sensitive nature of the interviews, identifying information was not asked of the participants. Interviews centered on parental decision-making in how they may react or have previously reacted to suspicions of child MH issues (Table 1).

Participants were asked to consider prompts with their youngest child in mind if they had more than one child. This was done for two main reasons: (1) participants would provide focused responses for one child and thus lessening potential for confusion and (2) potentially increasing the responses with younger, non-school aged children in mind.

Based on the assumption from pilot data that parents being recruited were more likely to have an older child (between the ages of five and 18 years), such a directive would thus help include more responses focused on non-school age children for the study in how parents make decisions. Questions were generally asked in the order listed in the Table; however, should the interviewee provide answers to a question that would be asked

further down, the interviewer allowed for the comfortable flow of discussion to supersede question order.

Table 1: Semi-structured interview prompts.

Prompts	Topic Theme
What experiences have you had with mental health issues?	Experience, Understanding
What are your experiences with child mental health issues?	Experience, Understanding
What would you do if you believed your child may have a mental health issue?	Decision-making
If a trusted person, such as a teacher, shared with you that your child is exhibiting abnormal behavior during recess, how do you think you would respond?	Decision-making
If mental health evaluation were provided for free for your child, would you consent to an evaluation?	Decision-making
Can you tell me about the steps you might take in navigating the mental health care system?	Decision-making
What are the most notable disadvantages you have seen for children facing mental health issues? What do you believe is most helpful for children with mental health issues?	Experience, Understanding
What are your thoughts about this topic that previous questions may not have touched upon?	Understanding

All interviews were recorded with consent. Participants were compensated based on length of interview (\$10/hour) immediately after the interview was completed. In-person interviews were compensated with cash (with a signed receipt), while telephone and virtual interviews were compensated using Venmo (privately compensated with a request for participants to confirm receipt via phone or virtual connection). Participants were

debriefed on the aim of the project, overall, and asked whether they would be interested in receiving further communication regarding results. Any questions participants may have were answered at this time.

Recordings were then transcribed by the research team. Transcriptions were checked for accuracy before recordings were deleted to ensure confidentiality of participants. All transcriptions were deidentified prior to being uploaded to MAXQDA 2020, a qualitative coding platform. Interviews were recorded, and upon transcription, recordings were deleted to ensure maximum confidentiality of participants. Interviews were not linked to the survey in any way.

Analysis

Qualitative analysis of the transcribed interviews was done using the MAXQDA 2020, a qualitative coding platform. Along with the appraisal of information power for every fifth interview Exploratory thematic analysis was done by one researcher to ensure theme saturation before undertaking next steps. Narrative analysis was used specifically regarding decision-making prompts, making these prompts the unit of analysis (Table 1) (Nollaig, 2011). Over three iterations, one researcher identified, defined, and amended codes for each interview. The analysis yielded meaningful phrases with step-by-step codes following participant narration of how they may access MH care for their children. Words such as “then” and “next” were commonly used as indicators of a new step to

code (Bernard, 2011; Nollaig, 2011). Narrative codes were then exported to Excel and color-coded to help identify presence of distinct decision-making processes. Patterns via repetition and frequency of codes were developed into a decision-making process map.

Results

Demographics

A total of 623 participants were asked whether they would consider participating in a paid interview at the end of their survey to discuss the topic of child MH. One-hundred-ninety-one participants provided contact information, with the majority being emails or phone numbers and some being requests for direct messaging via social media platforms. All participants were contacted at least once throughout the study timeline. Participants were contacted twice before being marked off as uninterested. Note: many phone numbers provided appeared to be fake or incorrect, and there were multiple cases of emails bouncing back to the researcher attempting to make contact. A total of 29 interviewees were scheduled but only 15 interviews were completed and used for this study. Narrative analysis was begun upon confirmation of theme saturation. As noted in the methods section, no demographics were collected due to the sensitivity of the topic and survey demographics could not be used for providing such data per IRB request. Of the 15 parents interviewed, seven parents had a child who was diagnosed with a MH issue, and they discussed the process of accessing child MH care based on their own experiences and in terms of what they might do hypothetically.

Narrative Analysis

The initial coding of the interviews yielded 37 codes as to how participants would make decisions in accessing MH care. On average, participants yielded six steps (codes) with a minimum of three (parent of child diagnosed with condition) and maximum of nine (parent of child diagnosed with condition). Detail and length of steps taken did not appear to be related to whether a parent had a diagnosed child. After three iterations of narrative analysis and refining the codebook, participants yielded an average of five steps with three as the minimum and seven the maximum (see Figure 1). All (100%) participants began with *awareness of MH* and *notice issue* as the basis of their decision-making process (Table 2). All parents considered the situation where a trusted person, such as a teacher, would comment on their child’s abnormal behavior as the medium of problem recognition, though parents also included their own experiences of problem recognition as well.

Table 2: Code definitions and examples after three iterations of narrative analysis.

Code	N	Definition	Example
Awareness of MH	15	Consideration of child MH	Anyways, I guess if it was something like that, like what it was that my daughter was doing, in fact I think a teacher did tell me that they saw her doing it, with the scissors on the back of her hand, that’s when we started saying ‘what’s that about’? (<i>parent of child diagnosed with condition</i>)

Notice Issue	15	Recognition of a MH issue, symptom, or possibility of MH issue	Yeah, like right now if I noticed maybe like she's throwing tantrums or something or like just seemed super sad.
Research	7	Investigation, often using the internet, into MH (e.g. symptoms, diagnoses, treatments) to help decision making	I would probably, first of all, I would look it up online, but I would also, you know, because not everything is true online, I would um, I'll get a book on it. Maybe talk to someone else who has a child who's dealing with this, the same thing.
Context for Issue	8	Investigation of circumstances surrounding a red flag event	I think a lot of times, initially [I would respond], by responding negatively, like 'that's not my child.' But, um, I think I would have to ask that teacher, you know, what specific traits are being exhibited? And what do they think, in their opinion, are the causes of those symptoms being exhibited?
Talk with Child	12	Discussion with the child to determine cause of behavior and how to move forward with decision making	I would just talk to my son about what caused it and try to come to my own conclusions of, like I don't know, what initially started the [fight].
Medical Expert	16	Any health professional being sought out by parents including pediatrician, counselor, therapist, specialist, psychologist	I'd probably want to take him to some sort of like therapist or psychologist or psychiatrist to figure out if there's other options that are also available...maybe if you're able to talk to someone or if there's some kind of medication--which I'm somewhat against medication for younger kids...
School Support	7	Any type of health being sought out by parents from the school including	Having a certain diagnosis on a piece of paper meant we could browbeat the school into offering some service.

		school counselor, principal, teachers	
Help Group	2	Any type of community forum developed to help parents and children--not necessarily MH specific	There's a lot of Facebook groups or parents who, you know, parents of autistic kids and different you know just of any, anything that you can reach out to. So, I would probably talk to someone who's been in this similar situation and yeah. <i>(parent of child diagnosed with condition)</i>

Initially, two types of processes were considered: one for parents of children diagnosed with a condition and one for parents of children not diagnosed with a condition; however, only one major difference was discovered—within the formal MH access section (circle section of Figure 1). While only two parents (2/7, 28.6%) of children diagnosed with a condition discussed *school support*, five (5/8, 62.5%) parents without a child diagnosed with a condition discussed this topic extensively. As this step was part of the formal access to child MH care and not in a sequential fashion, one process flow was maintained for the study. The most common pattern (6/15, 40%) showed parents moving from *awareness of MH*, *notice issue*, *context for issue*, *talk with child*, and then moving to either *medical expert*, *school support*, or *help group* (or a combination of the last three, Figure 1). The other participants included *research* (7/15, 47%) within their steps or did not include certain common steps such as *context for issue* or *talk with child*. Only three participants—with children who were 3, 6, and 13 years old—did not discuss *talk with child* as an option in any of their steps, whether at the beginning or end of the process.

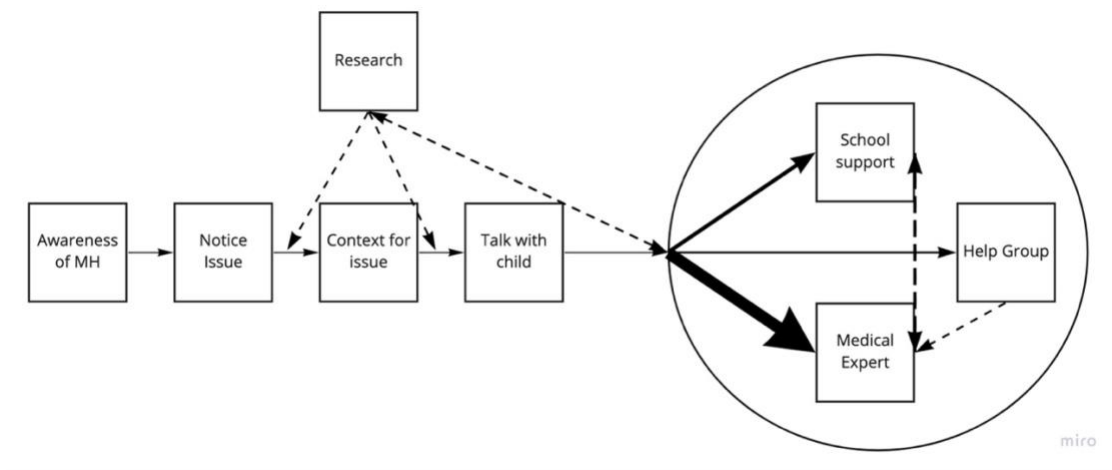


Figure 1. Parental decision-making process map. Steps within circle are formal steps in accessing MH care. Size of arrows within circle correspond to number of parents choosing to go to one option over another.

Research appeared to be the most erratic code to fit into the pattern as some parents (3/15, 20%) chose to do research immediately upon the step of *notice issue*, while others (3/15, 20%) consider *research* only after they *talk with child* or meet with a *medical expert*. *Research* was occasionally discussed as a way to help self-treatment (i.e., at-home informal treatment done by parent). One participant noted that while their first instinct was to do research to help engage with their child, their initiative did not yield ideal results: “*I would look up articles, and try [to] talk to [my child], but I think [they] kind of said you know you're my mom and you're not an expert, and the talking to this [counselor] helped*” (parent of child diagnosed with condition). Indeed, *research* was discussed with some frustration, as well: “*...I felt like it was more urgent if my [child] was cutting [themselves]. So, um, I think it was that event that prompted me to look for information. But I, I didn't even know what word to use to look up information or things*

like that” (parent of child diagnosed with condition). Of note, research was also a consideration by one participant after seeking a medical expert with plans to seek out more medical expertise afterward: “....always looking on the internet for things as well. Like, what kind of services are out there?” (parent of child not diagnosed with condition).

Thirteen participants brought up medical experts, with six being parents of children diagnosed with condition. When participants discussed *medical experts*, they referred to two specific subgroups usually. Six (40%) participants discussed doctors, with five specifically noting they would involve their pediatricians. All five participants who talked about going to their pediatrician looked to them as a source of information—for a referral to a specialist—rather than a definite source of diagnosis for their children. The other subgroup participants (10, 67%) named includes mental health professionals such as counselors, therapists, and psychologists. Notably, only four (27%) participants expressly noted seeking both subgroups of medical experts. The interplay of the two commonly involved referrals:

I'd probably go to [their] pediatrician right now because [they are] so young and it might just be like [their] brain's not, you know, developed yet. So it might just be super common. So...with them being so young, I would definitely like [to] try [to] figure it out and work with [them] before like going to a psychiatrist. A psychiatrist would be more like if my doctor told me or if there was a huge like thing that happened in like their lives to make

them need to go to one. But yeah, not right now, a little bit too young.

In the case of discussing mental health professionals, only one parent discussed the process of finding a therapist/counselor who was a good fit for their child: *“But it was really hard for the reason I just said, you know, like counselors who had a good recommendation and were taking the insurance but weren't able to see her...at least a month or so. And I felt like it was more urgent if my daughter was cutting herself”* (parent of child diagnosed with condition). Six parents (five with a diagnosed child) mentioned the constraints of insurance and availability of such a medical expert: *“In our case, we didn't have insurance for the kids, even when we were supposed to. So that's the other thing, it depends on what resources do you have. I think if I was really in that situation, I would probably go to a pediatrician--see we didn't have a pediatrician at that point either--or my own doctor and say ‘what do I do?’”* (parent of child diagnosed with condition).

Nine (60%) participants discussed the process of finding medical expertise including referrals and pursuing a MH care team for their children. Four (27%) participants directly named evaluation for a diagnosis as an important step in finding the right *medical expert*, but one pointed out the importance of evaluation for gaining *school support*, as well:

And I thought about this with the older kids as well, when we fight for diagnoses. You know, there's a part where you're fighting for your own peace of mind to make yourself feel better. It has no other...no value to the child. Sometimes

diagnoses may tell you what's wrong, but don't give you any action, you know. And so, to me, it only really mattered if it was actionable in some way. That means you know if you know there's a treatment because of something, then okay, that's obviously good. And oftentimes, that was really a political issue. Having a certain diagnosis on a piece of paper meant we could browbeat the school into offering some service. (parent of child not diagnosed with condition)

In this case, the parent talked about the situation based on their own experiences with child MH but did not have a diagnosed child. Only one participant chose to discuss the evaluation, diagnosis, and treatment pathway. Many participants (6, 40%, one of whom had a child who was diagnosed) stopped discussion of their decision-making steps once they arrived at *medical expert*. The majority of parents with a diagnosed child ended their decision-making steps with some form of family engagement whether it be monitoring of the situation (2 parents), engaging treatment (2 parents), seeking parental help (1 parent), or simply talking with their child (1 parent).

Some parents noted that their decision-making may change depending on the age of their child, feeling that their proposed pathway may be inappropriate for their child:

...My one year old, I guess almost two, like [they] wouldn't really be able to talk to a psychologist or psychiatrist and [they don't] really have as much interactions with other kids because [they're] kind of on [their] own... when [they're] a little older

we'd find ways to help [them] out I guess if I were to find out that [they had] mental health issues. I would do more stuff myself, of like me researching how to help out my two year old child going through that and maybe less of [them] talking to a therapist or psychologist or psychiatrist. (parent of child not diagnosed with condition)

While the parent provided their ideal pathway of how to address a MH issue, they ultimately noted their plans may change if they believe the child may not benefit as much as they would like from these more formal steps of seeking *medical experts*.

Some parents discussed how *context for issue* and *talk with child* affects their decision making and whether they ultimately seek formal MH care:

I can give you a specific example. My wife and I, we recently went through a divorce, through a separation, my youngest daughter began to pee on herself, a lot. She was exhibiting different behaviors at school, acting out, specifically being more introverted. There's a whole bunch of different telltale signs, so I think if we pay attention to our children, they can tell us everything that's going on, I think" (parent with undiagnosed child).

In this case, the parent points out context that explains the changes in their child's behavior. Because they were able to identify and explain

the potential MH issue, formal MH care was never sought and was not discussed in their own decision-making process either.

Three participants (20%, two with diagnosed children) would look for *school support* after finding *medical expertise* and four (27%, one with diagnosed child) would do vice versa. Participants also explained what these categories may include as “next steps” in more detail. Nine participants (60%) noted further actions to take after either *school support* or *medical expert* such as utilizing treatment strategies (6, 40%) monitoring (3, 20%), and parental engagement (2, 13%). One parent noted that “...*there's so much responsibility that falls on the parenting that I would want to see and talk to someone what I can do to change my parenting techniques*” (*parent of child diagnosed with condition*). This parent explained their personal experience as a child guided them to this realization: “*It's just, I grew up overweight and weight is something I always struggled with and now looking at it through an adult perspective...it's not the child's fault at all*” (*parent of child diagnosed with condition*). Overall, one process pathway (Figure 1) appears to fit the way both parents without and with diagnosed children would access child MH care. While level of detail in parents’ decision-making did not appear to be reliant on whether they had a diagnosed child, the majority of discussion regarding types of barriers in accessing care were broached by parents with diagnosed children.

Discussion

Main findings

As one linear pathway of recognition of a MH issue, evaluation, diagnosis, and treatment is often discussed in MH intervention strategies, this study shows that parents have multiple routes to consider when making decisions regarding their children's health care. While results demonstrate that the process map is applicable for both parents with and without diagnosed children, parents with diagnosed children were far more likely to point out barriers to their decision-making process. Results show that upon recognition of a MH issue, if parents ultimately choose to access formal MH help for their children, they do so either via *medical experts* (9/15, 60%) or *school support* (4/15, 27%). Parents discussed the two modes of formal MH help differently in that *medical experts* were expected to treat a MH issue, while *school support* provided an environment that monitored or mediated MH care access. However, parental decision-making up to the formal MH care access includes key steps that may impact arrival to that point: finding and understanding *context for issue*, engaging with the child (*talk with child*), and undertaking *research* are key steps that often occur before the formal access to MH help. Outcomes of these steps affect parents' abilities to move to the next step: if a parent determines that their child is exhibiting normal behavior or is provided with a contextual causal explanation for a MH issue, that parent will be unlikely to pursue further steps leading to formal MH help. While all parents who discussed *context for issue* remarked on the importance of gaining more circumstantial clues to the behavior they are being made aware of, there was an underlying assumption that *context for issue* is pivotal in moving forward. Parents' focus on *context for issue* and *talk with child* specifically

exhibits such a concern as parents point out that depending on *context* and the result of their discussion with their child, no formal MH care needs to be accessed. Considering that 87% (13/15) participants named *medical experts* (16 total codes) as part of their formal MH care access, a parental decision to not move past informal methods such as *talk with child* or *research* results in the MH care access pathway being a dead end. This conclusion means that parental perceptions of child MH are integral in these key decision-making steps and that perceived child MH stigma may be especially impactful in whether parents access formal MH care.

Impact of findings on literature

Much literature has focused on the consequence of MH issue recognition and its impact on outcome disparities (Haack et al., 2018; Johnston & Burke, 2020; Teagle, 2002). Without appropriate problem recognition by parents or guardians, children often do not have access to receiving MH care. In our study, we specifically ask parents what they would or have done once there is a suspicion of a MH issue, which is why *awareness of MH* and *notice issue* were unanimous as first steps of accessing MH care. While some parents had gone through this process before with their kids or from their own experiences, some also noted that they had never thought about how to find MH care for their children. Indeed, problem recognition as a first step is critical, especially when considering that “red flags” may be difficult to recognize and vary greatly depending on child age and development. Haack et al. focused on problem recognition of ADHD with

Latino families decidedly for this reason: parents are gatekeepers to not only accessing MH care but identifying a need (Haack et al., 2018). Indeed, they found that Latino “families may be influenced by a nuanced interweaving of perceptions regarding ADHD manifestations (including impairment and symptoms), causes (including psychological/emotional, contextual, and biological factors), and reactions to ADHD identification” (Haack et al., 2018). While Haack et al. determined that single-informant evaluation of ADHD was not effective (Haack et al., 2018), this study used such a scenario successfully to help prompt parents’ decision making regarding MH care access—with many parents noting that such a scenario caused their problem recognition in actuality.

Thankfully, such studies have developed multiple modes of recommendations in how to help parents and guardians through this process. As our own study found significant interaction among race/ethnicity, income, and education on stigma levels via results from the survey, problem recognition of MH issues with effective follow-up is a necessary consideration. Further work to determine whether there is a compounding effect of these factors and having a diagnosed child on decision-making is needed. Prior literature clearly shows the interaction of stigma on parental understandings and views on MH (Landsman, 2009; Polaha et al., 2015). Additionally, our results also show another point of interaction for parents as they make decisions for MH care access: participants provided information to develop their ideal decision-making process map, but they also point out that the age of their child may impact whether they actually follow it. For example, one parent noted that because their child is “...*a little bit too young*,” they

would not consider seeking out a psychiatrist unless they felt the problem was especially severe. However, child psychiatry and mental health professionals specializing in child MH are integral in appropriate evaluation, intervention, diagnosis, and treatment (Green et al., 2015; *Prevention and Early Intervention of Anxiety Disorders in Inhibited Preschool Children*. - *PsycNET*, n.d.; Shire et al., 2017). Parents may not realize that early interventions—as early as infancy—can lead to reduced risk of MH issues such as ASD (Green et al., 2015). Further work needs to be done to determine parental perceptions on the usefulness of bringing their child to a MH specialist, especially as it appears as though age of child may impact this factor. While MH screenings—including behavioral screening—can take place as early as infancy and are supported by the National Alliance on Mental Illness (NAMI) and American Academy of Pediatrics (AAP) in taking place at a primary care provider’s office or in school, NAMI also notes that even the legally required Medicaid screenings do not get follow through in many cases (*Early and Periodic Screening, Diagnostic, and Treatment / Medicaid*, n.d.; *Mental Health Screening / NAMI: National Alliance on Mental Illness*, n.d.). Considering that the average time delay between onset of symptoms for children and their first intervention is 11 years (*Mental Health Screening / NAMI: National Alliance on Mental Illness*, n.d.), screening and MH evaluation services should be done early and often as recommended. While pediatricians routinely do developmental delay screening as early as 9 months old, their MH screening is less systematic and guided by their AAP Mental Health Tools for Pediatrics (“Surveillance, Screening and Psychosocial Assessment for Behavioral Health Concerns,” n.d.). Proper evaluation by specialists (not pediatricians, for example) may lead to averting serious problems such as misdiagnoses, especially in the younger age

range for children. However, pediatricians are increasingly taught to consider MH in their overall health evaluations and act as a resource for directing parents to further care; the new emphasis of coordination of care—all health professionals from different domains exchange patient information to provide superior, holistic care—may improve these trends described above (Foy et al., 2019). Though there is a serious discussion to be had regarding misdiagnoses, underdiagnoses, and overdiagnoses with child MH, having a professional in the behavioral health field do the evaluation and following diagnosis may mediate such trends such as not diagnosing borderline cases and instead monitoring them for such disorders as ADHD (Kazda et al., 2021). Coordination of care may help bridge this issue by making specialist care more attainable through a typical pediatric visit. Evaluation processes should be led by experts in the field, who may also be more aware of such dynamics as overdiagnosis. Considering that the DSM 5 can be difficult to follow for child MH diagnoses, even by MH experts (Bruchmüller et al., 2012), a way to ensure parents know and understand the importance of seeking professional expertise is vital to early intervention success.

A common step that was revisited throughout the process map was *research* regarding MH and potential next steps. Once parents recognized a potential problem, many tried to understand what their next step options could be, whether it be about the type of MH issue and its treatments or what expert may be available to them in the area. *Research* occurs throughout the process map, and participants noted different approaches whether it be scouring for information online or in a recommended book. While one participant noted that “*not everything is true online*” as a good reason to also find further information

from books, not many parents commented on the veracity of internet research or were able to say what type of information-finding their investigation would entail. A literature review from 2021 on prevalence of health misinformation on social media showed that literature focused mainly on misinformation on topics such as vaccines, drugs, and diet, with nothing recent specifically on mental health information (Suarez-Lledo & Alvarez-Galvez, 2021). No study appears to attempt to quantify or detect the amount of mental health misinformation that may be available via social media, blogs, and other platforms that appear on the first page of an online search query. Participants admitted they often do not know what words to use in their query, making their *research* step even more at risk of uncovering misinformation unknowingly. This study highlights the need for providing reliable MH and accessibility information for parents and guardians to support effective decision-making through the MH care process map.

As mentioned in the introduction, causality of a MH issue has an important interplay in perceptions of MH, stigma, and decision-making. Results showed that the majority of parents (8/15, 53%) looked for *context for issue* and were interested in understanding the potential causality of the issue: “...*And what do they [teacher] think, in their opinion, are the causes of those symptoms being exhibited?*” Causal cognition is especially important in attributing responsibility for a MH issue (Schreiber & Hartrick, 2002). Outcomes from free responses in this study’s survey portion showed a definite focus on understanding causality of an issue, often with a focus on biological causes such as biochemical pathways or genetic predisposition. Interestingly, while most psychological and biological causal cognition tends to temper stigma (Mann & Contrada, 2020; Schreiber &

Hartrick, 2002), genetic biological causality may result in the opposite (Larkings & Brown, 2018) as cause and responsibility is attributed to the parent(s). Though there appears to be an increase in stigma due to biogenetic causal beliefs, some research also shows that people believe medication would be an effective treatment (Kemp et al., 2014; Read et al., 2014). For the one parent in this study (parent without a diagnose child) who discussed medication, specifically, it was the last step of their decision process.

Therefore, while certain types of causal cognition may positively impact perceptions of MH, attributing MH issues to certain causes, by themselves, is not a definitive solution for MH stigma even as it may help encourage certain treatment pathways. While parents in this study did not explicitly discuss feeling responsible or guilty in these scenarios, they did utilize causal beliefs to determine how they make their decisions. As mentioned previously, parents who could attribute a causal explanation during a problem recognition moment may not move into formal MH care access and remain in the informal space. Thus causal beliefs play a significant role in how parents decide to move within the decision making process flow:

This study is the first of its kind to consider MH as a whole—rather than specific diagnoses such as depression or anxiety disorders—regarding impact of parental stigma and decision-making in accessing MH care. Considering that parents and guardians may not recognize what kind of MH issue may be impacting their children and may not know how to approach MH care when faced with such ambiguity, determining parental first steps via the decision-making process map is necessary in identifying when and how effective interventions could be introduced. Results show that the liminal spaces where

research occurs may be most effective as they may determine how parents finalize their decisions toward the next step of (or lack thereof) MH care. This study previously reported low, but present levels of child MH stigma in the parental population (cite Paper II). This qualitative analysis of semi-structured interviews shows the key spaces where interventions, led by health professionals, schools, and other organizations, focused on preventing stigma, misinformation, and other barriers would be most effective for this population.

With this study occurring during the beginning of the COVID-19 pandemic, there was some limited discussion from parents regarding the impact of the pandemic on their children's MH. While these discussions were focused on the actual MH state of their children, the pandemic appears to be having lasting effects on MH care and access, overall, as well. There has been a significant increase in telemedicine usage, especially for MH care, due to lockdowns and quarantine procedures; though there has been a significant increase in diagnoses of anxiety and depression during the pandemic , telemedicine services have been making MH care more accessible to more people (Arafat et al., n.d.). While this development may not impact the process flow to *medical experts* as much, the ability for parents and children to seek care via *school support* may be at significant risk even as schools race to develop their own non-contact methods to support their community (*Impact of COVID-19 on Poor Mental Health in Children and Young People 'Tip of the Iceberg,'* n.d.). Further, when considering the issue of screening for children, the pandemic may have caused changes in how such screenings/evaluations are performed by pediatricians and other medical experts. As screenings are a key step in

helping aid awareness to MH issues, the impact on access to care may be significant. Even as something trivial as being unable to attain a referral for a psychiatrist from a pediatrician may bottleneck the care pathway. COVID-19 will certainly cause changes to how parents make decisions and access child MH care, and this study's results may become a baseline metric to help understand these changes.

Limitations

Though this study focused on a small sample size, theme saturation was reached allowing for development of a decision-making process map. Notably, while parents were asked to provide as much detail as they could regarding what they would or have done to access MH care for their children, certain steps may have been overlooked or assumed as obvious by parents and thus not included in the discussion. This limitation is also a benefit, though, as the purpose of this research is to determine what parents would do when first faced with making decisions for their children's MH care. The resulting process map includes steps that are of most consequence to parents as they develop their decision-making plans. The next step in further testing the decision-making process map for child MH care access would be to include demographic information to be paired with a larger sample size of interviewees for the purposes of a mixed method study to validate the process map developed here. Additionally, the interview data should be considered through thematic analysis to provide context for this study's process flow. There is a need to understand how parents may recognize a "red flag" scenario and what their thoughts

on child MH stigma may be as well as how they feel about evaluation and screening. By providing this richer context, the decision-making process map can serve to pinpoint key barriers for MH care access.

Conclusion

Parents and guardians are effectively their children's MH care access gatekeepers. This study showcases the importance of parents being able to recognize MH issues or have exposure to a trusted individual who may be able to help them recognize any potential issues. Additionally, the parental decision-making process map may help researchers and other stakeholders develop interventions and policy to alleviate burdens in decision making. For example, identifying simple, effective research methods for parents to utilize before, during, and after accessing the process map would help ease parental worry over finding correct and useful information for their situation. Having a simplified process map will also identify ways to individualize the MH care pathway different parents may take based on their beliefs and understandings.

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Declaration of interest

None.

Conclusion

This study considered three main aims of (1) developing and validating a tool to measure parental perceived child mental health (MH) stigma, (2) determining whether perceived stigma levels corresponded in any way to parental identities, and (3) producing a decision-making process flow identifying where barriers such as perceived child MH stigma may affect families dealing with child MH issues. While the study was able to address these aims, a significant shift in the landscape of MH needs to be addressed: with the beginning of the COVID-19 pandemic, child MH risk and care access has drastically changed. Major takeaways from the three key phases of this study will be placed in perspective of these changes.

COVID-19

The arrival and continuation of varying levels of the pandemic have left an indelible, multidimensional impact on child MH. UNICEF reported in October 2021 that more than one in seven children aged 10-19 is living with a diagnosed MH issue globally and that a large gap between MH needs and funding exist (*Impact of COVID-19 on Poor Mental Health in Children and Young People 'Tip of the Iceberg,'* n.d., p. 19). UNICEF pointed out that due to lockdowns and the change to daily behaviors and habits, children were forced outside of key social elements of childhood such as school, friends, and family gatherings, with 1.6 billion children suffering some loss of education (*Impact of COVID-*

19 on Poor Mental Health in Children and Young People 'Tip of the Iceberg,' n.d.). Use of online schooling techniques, though critical in continuing the education for children, brought about unique issues as child behavior and expectations changed drastically between in-person and online courses. The role of parental oversight and guidance and expectations by teachers and schools for online courses created additional confusion and difficulty (O'Connor Bones et al., 2021). Further, while protective factors such as positive peer relationships and loving caregivers counteract to some degree the many negative factors brought on by COVID-19 (e.g. health emergency), UNICEF's report warned "that significant barriers, including stigma and lack of funding, are preventing too many children from experiencing positive mental health or accessing the support they need" (*Impact of COVID-19 on Poor Mental Health in Children and Young People 'Tip of the Iceberg,' n.d.*). Such trends seen in accessibility of MH care ultimately translated to the lack of support and care people receive.

There is the direct impact of the pandemic to child MH in terms of diagnostics, as well. Based on a recent literature review by Panchal et al., effects of the lockdown measures worldwide included a significant increase in anxiety, depression, irritability, and anger—among other behavioral and psychiatric issues—for children under the age of 18 years (mean age in the review of 11.3 years, 49.7% female) (Panchal et al., 2021). The review also found that while new psychiatric disorders were appearing for children, preexisting disorders may reappear (such as with eating disorders) or worsen (such as with ADHD and sleep disorders) in the pandemic environment (Panchal et al., 2021; Spettigue et al., 2021). While many MH issues were documented in the 61 articles reviewed, certain

disorders such as post-traumatic stress disorder (PTSD) can take much longer to appear and the level of diagnoses were expected to rise with the continuation of the pandemic (Panchal et al., 2021). Another literature review of 28 empirical studies also focused on impact of the lockdowns on children's MH and showed that such measures were significantly related to negative general MH outcomes among children and sleep habits showed an increase in sleep duration (Bussières et al., 2021). Similarly to levels of PTSD in the Panchal et al. review, the results of increased sleep duration was an unknown level of risk requiring longitudinal study to determine impact on children (Bussières et al., 2021). Sleep problems and sleep disturbances are linked to MH as risk factors for worsening certain conditions such as ADHD as well as being indicators of poor MH, overall (Bussières et al., 2021; Panchal et al., 2021). Diagnostic impacts were not the only results found. One study by Kerr et al. determined parental perceptions of the COVID-19 pandemic's psychological impacts affected parental burnout as well as reported children's behavior (Kerr et al., 2021). Another study showed the importance of family resiliency in the status of child MH as it has a mediating effect on pandemic stressors

Access to MH care was also drastically changed by the pandemic. In a large study looking at nearly 2.5 million children between the ages of 3 and 17 years in Ontario, Canada, initial rates of MH outpatient visits plummeted, but by April 2020 above-expected rates of visits were sustained through the end of the study in February 2021 (Saunders et al., 2022). This increase in care was also done via non-traditional methods of virtual care (70.0-90.1% of all care at different points during the pandemic) (Saunders

et al., 2022). While virtual care expanded access of MH care to some, especially during lockdowns, the sudden increase in need for MH care has left a demand for services that is not being filled (Benton et al., 2022). As practices become filled up with the new demand, they are forced to turn away others seeking those same services. Additionally, while insurance providers may have been covering telemedicine visits at the same or greater rate than traditional in-person visits, this coverage status remains unknown due to the developing standards and policy for telemedicine (Gantz, n.d.). Even without the complexities of telemedicine insurance coverage, current insurance practices are a barrier for families trying to find medical experts who not only have availability for new patients but are also accepted by the insurance provider. Compounding the issue of insurance coverage was also job loss and reduced income: low income was a significant deciding factor on psychological impact and children's stress levels during the pandemic (Kerr et al., 2021). Such a trend means that while we see a global increase in numerous MH issues for children, we will also see an increase in unmet needs. Indeed, schools showed ingenuity in developing interventions and virtual MH care access for their students to alleviate the negative effects of the pandemic (*Impact of COVID-19 on Poor Mental Health in Children and Young People 'Tip of the Iceberg,'* n.d.).

The COVID-19 pandemic has and is leaving a mark on child MH from the increase in diagnosed disorders and unmet needs to paving the path for virtual MH care access. As the pandemic continues, child MH and MH care will continue to change. Therefore, the results of this study will not only be affected by these changes but may also be helpful in identifying community needs.

Results of Study in Context of Pandemic

As the UNICEF flagship report stated, MH stigma continues to be an active barrier in children gaining access to the care they need (*Impact of COVID-19 on Poor Mental Health in Children and Young People 'Tip of the Iceberg,'* n.d.). The development and validation of the parental perceived child MH stigma scale may be especially useful in determining changes in overall and child perceived stigmas in communities, using this study as a baseline due to its recruitment timing. Though the population of the Phoenix metropolitan area is diverse and the survey tool was adapted from ones also applied to diverse, urban populations, the baseline from the MH stigma scale should be used as a suggestion for other populations such as rural communities. Considering this study's results, minority populations in lower income brackets should be of particular focus as they face greater risk for higher levels of perceived MH stigma. As some COVID-19 research shows, low income can be a deciding factor in psychological impact (Kerr et al., 2021), there is a dearth of research on impact of income and race/ethnicity on perceived MH stigma at this time. Use of this study can identify underlying causes of perceived stigma such as discrimination and whether certain combinations of parental identities may increase likelihood of perceived child MH stigma. Additionally, this tool has been used in a diverse population that includes urban and suburban populations, sites where the pandemic caused the most drastic changes in daily behaviors and habits.

In testing intersectionality frameworks within the second part of the study, the tool determined neutral levels of perceived child MH stigma among parents. These results show that the Phoenix community does not have low levels of perceived child MH stigma. Though the resulting levels were not high levels of stigma either, such results still show the presence of underlying child MH stigma and the need for intervention. With isolation due to lockdowns and quarantines, the chances for concealability and avoidance of child MH issues increases for social contacts outside of the immediate family. While child MH has become a topic of greater discussion within the U. S. because of the pandemic (*Teen Mental Health*, 2022), the reach and actual impact of this discussion is unknown regarding MH stigma. While children, agency dependent on their age, may have had some direct access to certain MH care through the school they attended, with lockdowns, MH care access has been further restricted. Though schools may be providing virtual MH care access (*Impact of COVID-19 on Poor Mental Health in Children and Young People 'Tip of the Iceberg,'* n.d.), not all students are able to reliably access internet let alone find private space and time to access such care—consideration of confidentiality practices as well (Iyengar et al., 2020). Additionally, study results appear to show that self-identifying as Hispanic/Latinx paired with higher education and lower income brackets may increase the likelihood of higher levels of perceived stigma. Within Phoenix, AZ and United States overall, the Hispanic/Latinx population is large and greatly impacted by the pandemic in terms of physical health disparities and also greater economic stress (Macias Gil et al., 2020; Vargas & Sanchez, 2020; Wilder, 2021). Using the perceived child MH stigma tool may be useful in seeing whether there have been any changes to the levels of perceived child MH stigma in the community since the first years

of the pandemic by using this study as a baseline for future tool application. Dispersal of the tool would also be of interest in the qualitative data: with an increase in anxiety and depression disorders due to COVID-19, an increase in discussion of these MH issues within the child MH free response would be expected (Panchal et al., 2021).

The most significant impact COVID-19 may have on the results of this study would be seen in the decision-making process flow. The flow itself may not change drastically, but the details of how parents access child MH care will certainly change. Barriers such as insurance may no longer be as stressful as telemedicine has been subsidized and is at times covered 100% by insurance; however, access to a therapist whom the child trusts and bonds with may be more difficult to attain due to the lack of availability. Thankfully, literature shows that telemedicine's patient satisfaction and patient-provider trust is high, meaning that upon virtual access to a medical expert those two factors are not negatively affected, though these results were for adults (Orrange et al., 2021). Some literature exists showing high satisfaction of telemedicine for older children (12-17 years of age) (Sequeira et al., 2022), but more data needs to be gathered to determine whether telemedicine would be successful for much younger children with a MH need. Of course a critical part of the decision-making process flow may be affected: the awareness of MH, notice issue, and context for issue steps may change in how they occur. While in the study, participants considered an outside trusted source such a teacher potentially remarking on a MH issue and beginning the process, with lockdown measures and increasingly working-from-home parents, the critical step of problem recognition becomes even more important as fewer trusted people may be interacting with their child.

Thus, the need for parents to recognize a potential MH issue becomes stronger. Currently, little information in the literature is available understanding whether the actual baseline for “normal” child behavior has changed, though based on this study’s participant commentary (see below), parents are aware that their children’s routines have been upended and consequently their behaviors. Additionally, it is unknown how the increase in time spent with their children may impact parental understandings of this “normal” as well. There is a need to gather more ethnographic data regarding parents’ experience and views on child MH since the pandemic began.

Commentary on COVID-19 from Participants

A handful of parents made comments regarding the situation as it was unfolding in 2020. One parent (without diagnosed child) stated their feelings on impact of COVID-19 on MH: *“It hasn’t changed my perception on mental illness at all. It’s just that I worry about people you know who out of all the different illnesses, I, I worry the most about people dealing with anxiety and with depression.”* Another parent (without diagnosed child) shared their personal, eye-opening experience in how COVID-19 has changed their own perceptions: *“...And one of the things we had to do was like a volunteer program and I did it on a website called seven cups and it’s like an online website. And so, I had to like to talk to people who just needed somebody to talk to. Before necessarily seeing a therapist and a lot of people like were experiencing depression and anxiety just due to everything going on with the pandemic. So definitely opened my eyes up more...”* Only one parent (without diagnosed child) identified a change in their child due to the

lockdown of the pandemic, “[*With*] COVID, she's gotten a little more anxious and a little more testy, you know, because she can't do the things she wants to do.” Overall, all parent comments allude to changes in other people regarding anxiety, one of the diagnoses that increased during the pandemic, initially (Panchal et al., 2021). Finding more current snapshots due to the quickly fluctuating circumstances around the pandemic may be necessary for any future work.

Key Takeaway

While this study has developed, validated, and used a measurement for parental perceived child MH stigma and explored parental decision-making in accessing child MH access, COVID-19 has certainly caused changes in parental thinking, child MH wellness, and social infrastructure supporting MH care access. Future work using these mixed-methods will provide concrete results as to how the pandemic has affected the population of Phoenix, Arizona.

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APPENDIX A
CONTENT ANALYSIS CODEBOOK

Code	Definition	Example
DSM 5 Language	Participant uses words found directly within DSM 5 regarding mental health, mental illness, or child mental health.	“bi-polar, adhd, add, autism, schizophrenia”
Diffuse Descriptors	Participants describe elements of the topic without using specific DSM 5 language, often done in full sentence (s)	“A child's ability to cope and understand the world around them.”
Related to DSM 5 Disorders	Participant describes a person with the illness/disease or the effects of illness/disease in non-medical terms regarding symptoms, treatment, or wellbeing.	“I think of someone that is unstable without medical intervention, a different psychological capacity.”
Norm/Normal	Discussion of a standard or typical (expectation, socioculturally based) characteristic, behavior, aptitude that is expected. Use of language that presupposes a normal or standard (a comparison is assumed) such as "excessive" or "stable"	“I think of mental health as being in a "normal" mental state where emotional and behavioral functioning is not an issue in life. I also consider not having mental health as being detrimental to life in a big way. I think about the stigma of not being mentally healthy.”
Opinions and Experiences	In regards to how people perceive people with mental health conditions or perceive diagnoses/issues.	“I think about how people are so wrong about it. When someone mentions mental illnesses, most people will think about the person being violent or aggressive. It is not always true, not at all actually.”
Causality of MH	Discussion of why or how someone may have come to have a mental health issue	“A misfiring in the brain, a chemical imbalance, heredity.”

APPENDIX B
GO LIST FOR ANALYSIS

borderline
bipolar
behavioral
autism
attachment disorder
asperger
anxiety
anosognosia
anorexia
alcohol
adjustment disorder
addiction
add
SMI
ADHD
phobias
panic disorder
oppositional
ocd
neurosis
narcissistic personality
multiple personality
learning disability
dyspraxia
dyslexia
drug addiction
down syndrome
dissociative
depression
cerebral palsy
bulimia
suicide
substance use
speech disorder
sociopath
schizophrenia
psychosis
polio

APPENDIX C

MEANINGFUL ANOVA RESULTS: ESTIMATED MARGINAL MEANS FOR
OVERALL, F1, AND F2

Race * Income					
Dependent Variable: Sum					
Race	Income	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
0	0	127.478	4.532	118.568	136.387
	1	132.905a	2.32	128.345	137.465
	2	130.094a	2.03	126.103	134.086
	3	128.099a	2.677	122.837	133.362
	na	105.500a	6.225	93.262	117.738
1	0	137.900a	4.752	128.558	147.242
	1	135.143a	4.556	126.186	144.1
	2	137.250a	6.873	123.74	150.76
	3	127.000a	9.904	107.529	146.471
	na	b	.	.	.
2	0	136.394a	5.267	126.039	146.749
	1	132.893a	5.984	121.128	144.657
	2	130.208a	5.043	120.294	140.122
	3	113.056a	7.3	98.705	127.406
	na	137.000a	11.437	114.517	159.483
3	0	111.833a	9.338	93.476	130.19
	1	144.000a	16.174	112.205	175.795
	2	139.500a	11.437	117.017	161.983
	3	139.222a	6.455	126.534	151.911
	na	b	.	.	.
4	0	111.643a	8.645	94.648	128.638
	1	141.000a	9.338	122.643	159.357
	2	141.000a	9.904	121.529	160.471
	3	b	.	.	.
	na	b	.	.	.
5	0	125.400a	8.859	107.985	142.815
	1	126.000a	11.437	103.517	148.483
	2	123.000a	16.174	91.205	154.795
	3	132.000a	16.174	100.205	163.795
	na	120.000a	16.174	88.205	151.795

a Based on modified population marginal mean.

b This level combination of factors is not observed, thus the corresponding population marginal mean is not estimable.

Race * Education

Dependent Variable: Sum					
Race	Education	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
0	0	125.631	2.855	120.019	131.244
	1	125.1	2.52	120.146	130.054
	2	127.81	2.852	122.203	133.416
	9	107.000a	16.174	75.205	138.795
1	0	123.050a	5.272	112.686	133.414
	1	140.583a	2.819	135.042	146.125
	2	142.732a	6.573	129.81	155.654
	9	.b	.	.	.
2	0	118.614a	5.486	107.829	129.399
	1	130.682	4.387	122.058	139.306
	2	138.167a	7.624	123.178	153.155
	9	.b	.	.	.
3	0	119.667a	9.338	101.31	138.024
	1	140.042a	5.622	128.989	151.094
	2	122.500a	11.437	100.017	144.983
	9	.b	.	.	.
4	0	106.500a	9.904	87.029	125.971
	1	144.429a	6.55	131.552	157.305
	2	.b	.	.	.
	9	.b	.	.	.
5	0	130.450a	7.233	116.231	144.669
	1	118.000a	11.437	95.517	140.483
	2	120.000a	16.174	88.205	151.795
	9	.b	.	.	.

a Based on modified population marginal mean.

b This level combination of factors is not observed, thus the corresponding population marginal mean is not estimable.

Race * Education

Dependent Variable: SumF1					
Race	Education	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound

Race	Education	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
0	0	68.005	1.712	64.639	71.371
	1	67.013	1.511	64.042	69.984
	2	68.39	1.711	65.027	71.752
	9	59.000a	9.701	39.93	78.07
1	0	63.825a	3.162	57.609	70.041
	1	74.264a	1.691	70.94	77.587
	2	77.018a	3.943	69.268	84.768
	9	.b	.	.	.
2	0	65.261a	3.29	58.793	71.73
	1	71.91	2.631	66.737	77.082
	2	74.500a	4.573	65.51	83.49
	9	.b	.	.	.
3	0	61.333a	5.601	50.323	72.343
	1	76.558a	3.372	69.929	83.187
	2	66.500a	6.859	53.016	79.984
	9	.b	.	.	.
4	0	58.250a	5.94	46.572	69.928
	1	76.984a	3.929	69.261	84.707
	2	.b	.	.	.
	9	.b	.	.	.
5	0	69.200a	4.338	60.672	77.728
	1	63.000a	6.859	49.516	76.484
	2	65.000a	9.701	45.93	84.07
	9	.b	.	.	.

a Based on modified population marginal mean.

b This level combination of factors is not observed, thus the corresponding population marginal mean is not estimable.

Race * Education					
Dependent Variable: SumF2					
Race	Education	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
0	0	29.778	1.749	26.341	33.216
	1	32.334	1.543	29.3	35.368

	2	31.786	1.747	28.352	35.22
	9	23.000a	9.906	3.525	42.475
1	0	27.600a	3.229	21.252	33.948
	1	41.438a	1.726	38.044	44.832
	2	41.679a	4.026	33.764	49.593
	9	.b	.	.	.
2	0	26.778a	3.36	20.173	33.384
	1	32.702	2.687	27.42	37.985
	2	32.167a	4.67	22.986	41.347
	9	.b	.	.	.
3	0	31.333a	5.72	20.09	42.577
	1	39.692a	3.444	32.922	46.461
	2	35.000a	7.005	21.229	48.771
	9	.b	.	.	.
4	0	21.500a	6.066	9.574	33.426
	1	42.206a	4.012	34.319	50.093
	2	.b	.	.	.
	9	.b	.	.	.
5	0	31.000a	4.43	22.291	39.709
	1	24.500a	7.005	10.729	38.271
	2	25.000a	9.906	5.525	44.475
	9	.b	.	.	.

a Based on modified population marginal mean.

b This level combination of factors is not observed, thus the corresponding population marginal mean is not estimable.