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"Tell Me When 'Normal' Stops": How Parents Recognized Their Child's Mental Illness

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Many parents do not recognize psychological disorder, and current mental health service delivery programs are not sufficiently responsive to the early help-seeking dynamics of families. This mixed-methods study explored Colorado parents' experiences of recognizing their child's mental illness as a precursor to seeking treatment, revealing that the phenomenon of parental recognition was a process of "waiting to hear that 'normal' had stopped," wherein parents miscategorized symptoms as typical behaviors in a passing developmental phase. Prior experience with mental illness appeared to significantly decrease both the length of time and the level of distress necessary for recognition. Ultimately, recognition did not occur until someone in the parents' social network explicitly validated their concerns, which galvanized them to seek treatment. The results of this study can have wide applications for positive social change, because many chronic mental disorders manifest in childhood and benefit from early and sustained treatment. Further, mental health underscores many societal issues such as homelessness, school dropout rates, child abuse and neglect, foster care, and prison overpopulation. Positive social change and parental recognition can be promoted through public policies and programs such as universal mental health screening, mental health literacy, and school and health policies that are more supportive and responsive to the early help-seeking needs of children and families.

Keywords: *parental recognition, help-seeking, childhood mental health, social network, mixed methods, phenomenology, poetic inquiry*

The Paradox

Childhood mental illness is pervasive, with an estimated 15 million children in the United States suffering from a diagnosable mental illness (American Psychological Association, 2019). Despite mounting evidence that early identification and treatment can benefit both a child's long-term prognosis and quality of life (Koivunen, Van Alst, Ocasio, & Allegra, 2017), only a fraction of children in need actually receive professional treatment (Xu et al., 2018). This emerging public health crisis produces long-term negative consequences for individuals and communities (Villatoro, DuPont-Reyes, Phelan, Painter, & Link, 2018).

The paradox inherent in obtaining treatment is that many parents do not recognize the symptoms (Boulter & Rickwood, 2013). Although parents are typically aware that their child's behaviors may be unusual when compared to peers, they frequently do not define the problem as related to a mental illness that could benefit from diagnosis and treatment (Johnston & Burke, 2019). Although most models for help-seeking include recognition as an important step (Boydell, Volpe, Gladstone, Stasiulis, & Addington, 2013), few studies have inquired into the details of the recognition process itself.

Background

Explanatory Models

How parents contextualize their children's behaviors, and whether they seek treatment, will depend on how they explain the origins of those behaviors (Cairns, Yap, Rossetto, Pilkington, & Jorm, 2018). Explanatory models of illness are culturally bound (Kiropoulos & Bauer, 2011) and include an individual's beliefs about the etiology or causes of the illness, the meaning of symptoms, the course of treatment, and the expectations of affected individuals (Jacob, 2010).

The process of defining and conceptualizing mental illness is an ongoing and dynamic activity (Kiropoulos & Bauer, 2011). Attribution and explanatory models underpin parents' ability to make meaning of and understand their child's illness, and thus recognition becomes, in part, a narrative process (Johnson, Sathyaseelan, Charles, Jeyaseelan, & Jacob, 2012) that is tied to a person's self-concept (Tekin, 2011) and identity as a parent (Thomson et al., 2012).

Normalization and Distress

Normalization occurs when an individual redefines or minimizes abnormal or dysfunctional symptoms as within the range of typical everyday distress (Biddle, Donovan, Sharp, & Gunnell, 2007). While this phenomenon has been observed in relation to many medical conditions, normalization is particularly prevalent in mental illness cases because of the gradual onset of symptoms, coupled with the imprecision and subjective interpretation of terms like *depression* and *stress* (Biddle et al., 2007; Mechanic, 1995).

Recognition was consistently described as a protracted, evolving process of observation and worry, often building to a crisis where parents reached a breaking point (Wilson, Cruickshank, & Lea, 2012). Interestingly, it was not so much the child's distress that prompted recognition or treatment-seeking, but rather an accumulation of a seemingly insurmountable level of burden to the parents or the family (Zwaanswijk, Verhaak, Bensing, Van Der Ende, & Verhulst, 2003).

Social Network

For both recognition and help-seeking, parents rarely relied on their own perceptions and usually required confirmation or legitimization from their social networks (Thomson et al., 2012). These social networks could be composed of family members or friends and often also included other societal elements such as the Internet, media (Epstein et al., 2010), and the justice system (Watson, Kelly, & Vidalon, 2009).

Prior Experience

Mental health problems in the parent served as a predictor of recognition (Sayal, 2006). The converse was also supported—lack of experience with mental illness typically produced barriers or delays to recognition (Boydell et al., 2013). However, despite the improved effect on recognition, prior experience did not always correlate with actual treatment-seeking (Zwaanswijk et al., 2003), although it could predict intentions to seek help (Henderson, Evans-Lacko, & Thornicroft, 2013).

Purpose and Methodology

The researcher explored the process of how parents in the Pikes Peak region of Colorado recognized their child's mental illness before seeking treatment, specifically the effect and relationship of

variables that inhibited or enhanced parental recognition. Logan and King's (2006) model of parent-mediated pathways to mental health services for adolescents and Jorm's (2015) concept of mental health literacy provided the conceptual framework. A mixed-method, convergent parallel design synergistically integrated three methodologies throughout the data collection, analysis, and reporting phases to triangulate methods and thoroughly explore the multiple perspectives and realities inherent in this phenomenon.

Rooted in a phenomenological methodology, the qualitative strand was enhanced by incorporating elements of poetic inquiry (McCulliss, 2013; Prendergast, 2009). The use of Moustakas' (1994) transcendental phenomenology model was particularly important due to the researcher's personal experiences with the phenomenon of recognizing her own children's mental illnesses, to ensure identification and bracketing of preconceived ideas, judgments, experiences, and biases (Moustakas, 1994). In the quantitative strand, a cross-sectional survey technique and a frequency distribution analysis were employed to investigate the relationship of various factors to the process of parental recognition.

Significant debate continues about the ramifications of describing behaviors using medical terms and psychiatric diagnoses (Picco et al., 2018). Because this study focused on recognition as a component of treatment-seeking, *mental illness* was defined as the "term that refers collectively to all diagnosable mental disorders" (Satcher, 2000, p. 91). One overarching research question and three subquestions guided the exploration:

> *Research Question*: How do parents describe their experiences of recognizing that their child's behaviors are related to a mental illness that requires treatment?
> (a) What impedes or enhances parents' perception and initial treatment decisions?
> (b) How and why do parents overcome barriers to problem recognition?
> (c) Which factors will significantly contribute to the percent variance change accounted for in parental problem recognition?

The factors consisted of the independent variables of (a) normalization, (b) explanatory models, (c) stoicism, (d) stigma, (e) previous experience with mental illness, (f) social network, (g) media, (h) distress, and (i) crisis. All variables were hypothesized to significantly contribute to the percent variance change accounted for in parental problem recognition of their child's mental illness.

After institutional review board approval, flyers were distributed to reach participants who met the criteria for this purposeful criterion sampling: a caregiver responsible for making the medical treatment decisions for a child (under age 18) who had received a diagnosis of any psychological disorder (contained in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders*; American Psychiatric Association, 2013) within the past 5 years. The overriding assumption was that if the child had received a diagnosis, then the parent/caregiver had gone through the process of recognizing the child's mental illness.

The researcher served as the interviewer, and the protocol used a standardized open-ended interview format that incorporated both qualitative and quantitative tools. A validation exercise and a pilot study were implemented to enhance the validity and reliability of the researcher-developed instrument and protocol. The pilot study was conducted as a small-scale version of the main field study, and because the key elements of the main study were maintained, the data obtained from the pilot study were subsequently pooled with that from the full study (Thabane et al., 2010).

Within a 6-month period, at least 15 school districts statewide were contacted, and 46 agencies/individuals agreed to advertise in English or Spanish. This garnered eight responses from

prospective participants, six of whom met the criteria and agreed to participate, with five completing the entire study (one participant withdrew after the screening). Table 1 highlights demographic differences and also provides pseudonyms for the participants.

Table 1. *Demographic Differences Between Participants*

Name[a]	Age Range	Race	Children, N	Children With Mental Illness, n	Age of Child at Diagnosis	Diagnosis	Family With Mental Illness	Self With Mental Illness
Lisa[b]	51–60	Hispanic	1	1	14	MDD	Yes	Yes
Amy[b]	51–60	White	2	1	10	ADD	Yes	Yes
Susan	41–50	White	2	1	13	PTSD	No	No
Karen	51–60	White	7	3	7	ADHD	Yes	No
Debra	51–60	White	7	3	15	MDD	Yes	Yes

Note. MDD = major depressive disorder; ADD = attention deficit disorder; PTSD = posttraumatic stress disorder; ADHD = attention-deficit/hyperactivity disorder.
[a] For confidentiality purposes, pseudonyms are listed instead of participants' actual names. [b] Pilot study participant.

Prior to the interview, participants completed a telephone screening and a written survey pamphlet, which included a token monetary incentive of $2 and a request for a poem about recognizing mental illness (they had the option to compose a poem or find one that was meaningful to them). Each session was conducted at a semiprivate location approved by the participant, and informed consent was obtained in writing. All participants granted permission to video- and audio-record their 60-min interview.

Open-ended qualitative items included the following: "Share your story of how you learned to recognize that your child had this illness." "What were some of the things that helped you recognize that [child's] behaviors were related to a mental illness?" "Tell me about some of the things that got in the way of, or prevented, your recognizing the behaviors as related to a mental illness." These qualitative inquiries were interspersed with structured quantitative questions to augment and triangulate responses.

The quantitative items (e.g., "Please rank-order these [cards] starting with those things that helped you the most [at the top] to those that were the least help on your ability to recognize [bottom]") relied on the use of various cards that contained the independent variables, along with any other variables mentioned during the interview. This allowed the participants to sort, prioritize, and rank-order their responses and subsequently enabled the interviewer to probe for the deeper meanings behind the rankings and their relationship to the open-ended narrative responses by using questions such as "Tell me why you put them in this order. How important was [that variable] in helping you overcome that barrier?" and having participants point to a card with a Likert scale from 1 to 7.

Next, participants shared their poems by either reading them aloud or offering them in written form. The interviews were concluded with a request for the participants to suggest questions that had not been asked and the promised compensation of a $15 gift card was offered.

After transcribing the recordings and poems, the qualitative data were entered into precoded categories (nodes), and the quantitative data were extracted. Moustakas' (1994) transcendental phenomenological model served as the framework for the data analysis process. During each step (epoche, phenomenological reduction, imaginative variation, and synthesis; Moustakas, 1994), an iterative process was used, which involved melding, unmerging, and triangulating the qualitative

data with the quantitative data. This process was augmented by a variety of poetic inquiry techniques, including the technique of writing found poetry (Prendergast, 2009). This method—also known as data poetry or transcription poetry—involved the researcher using or representing the participants' words in poetic format, capitalizing on a variety of poetic formats, in the belief that changing the format would change the thought processes about the information and potentially reveal new perspectives or result in new ways to fracture and rearrange the data.

The data were then recoded, using an inductive system of open coding and constant comparison (Leech & Onwuegbuzie, 2007). Concurrently, the quantitative data were analyzed using a frequency distribution analysis and a Spearman's rank-order correlation (due to the small sample size). The patterns and contrasts revealed by these analyses served as a whetstone for inquiry, and triangulation back and forth between the quantitative and qualitative data continued during the process of data transformation, illuminating patterns and relationships and clarifying emerging themes.

Results

The findings suggest that the essence of the phenomenon of parental recognition for these mothers was a process of "waiting to hear that 'normal' had stopped." Their lived experience involved a period of watchfulness, during which they justified their increasing worry with the assumption that their child was progressing through a "normal" developmental phase or response, which would eventually pass. Due in part to the self-esteem they derived from being a good parent, their perception that this was a typical phase meant that they should be able to handle things, so they continued waiting, despite ever-increasing levels of distress to themselves and their family. This only ended when someone else used explicit terms, which abruptly realigned each mother's understanding, enabling her to reframe the behaviors, and galvanized her to obtain treatment.

Perhaps it was because their self-esteem was related to being an effective parent that the mothers expressed a sense of guilt for either not recognizing, or in some way having caused or exacerbated, their child's condition. Susan did not recognize her child's behaviors as related to mental illness until after a crisis required her daughter's hospitalization. She remembered that it felt

> Like I was the worst parent in the world! Yeah, it really did. It really, it was really devastating. Um, I was scared, all the time. All the time…it's hard to know that your child is hurting that bad, and there's really nothing you can do.

Impediments and Enhancements

The most palpable barrier to these mothers' recognition was their perception that their child's behaviors were attributable to either a "normal" (their words) developmental phase, or to a stressful event in their environment. Because they framed the problem as something that would be outgrown, or that was typical to the experience of parenting, they would reason that it was something that they could overcome or wait out—certainly, it was something they thought they could handle, despite their rising levels of distress or worry. Susan recalls that

> …she was not bathing as often, which we thought it was normal teenage stuff, um, a lot of isolation, staying in her room a lot, um. She was coming home with some injuries…"Oh mom, I scraped a tree." … Um, but like I said, it was easier to recognize it, after the fact, than before…

Two mothers explained how easy it was to find plausible explanations not only for their children's behaviors, but also for their own distress. Lisa described a combination of a stressful event and hormonal changes as her assessment of the cause of her daughter's change in behavior, and Karen shared several different things that appeared to explain her son's behaviors but that, in reality, were masking the problem:

> …when he was four we transitioned from Arizona to here. I mean nothing is more stressful in life than divorces, marriages, and moving.
> But the red dye, when he ate foods, or drank stuff, that seemed to have that, oh the behavior was worse…
> Oh, and a lot of times we do think, oh that's normal, all that rambunctiousness, and ants in the pants…

The most prominent correlational pattern in the quantitative data was the importance that all of the participants placed on their prior experience with mental illness. A Spearman's rank-order correlation revealed a moderately strong, negative correlation between prior experience as a help to recognition and the length of time to recognition, which was not statistically significant, $r_s(8) = -.649$, $p = .236$. There was a strong, positive correlation between no prior experience as a hindrance and the length of time to recognition, which was not statistically significant, $r_s(8) = .745$, $p = .148$. Finally, there was a very strong, negative correlation between prior experience as a benefit to overcoming barriers and the length of time to recognition, which was statistically significant at the .05 level, $r_s(8) = -.913$, $p = .030$.

When examining the relationship between the variable of prior experience with mental illness and the outcome variable of time between awareness and recognition, the correlational pattern continued. Again, the four participants who had a prior close relationship had shorter recognition timelines than the one participant with no prior close experience. This particular pattern was echoed and strengthened by the narratives of the two mothers who had older children with a diagnosis. The period to recognition for their first child was much longer, and much more distressful, than the recognition time for their younger (subject) child, and the length of time for the first child was similar to that of Susan, with no close prior experience. A comparison of the recognition timelines for each child, as described by the participants, is shown in Figure 1.

The qualitative data confirmed that across every timeline, each participant acknowledged some level of self-deception or avoidance throughout their recognition experience. Although this finding may have been exacerbated by the hindsight inherent in the retrospective nature of the interview process, all of the mothers indicated that during their recognition journey, they were cognizant—at some level—that they were putting off dealing with something more serious:

> *Lisa*: I think there was kind of a short period of…like hanging on to normalcy, like denial, or whatever…
> *Susan*: Um, we had seen, some things that were worrisome, but I don't know if we had our heads in the sand, or just didn't know.
> *Amy*: I think we would have lollygagged along.
> *Karen*: …so, self-denial really got in the way a lot I think, you know, making excuses, you know…
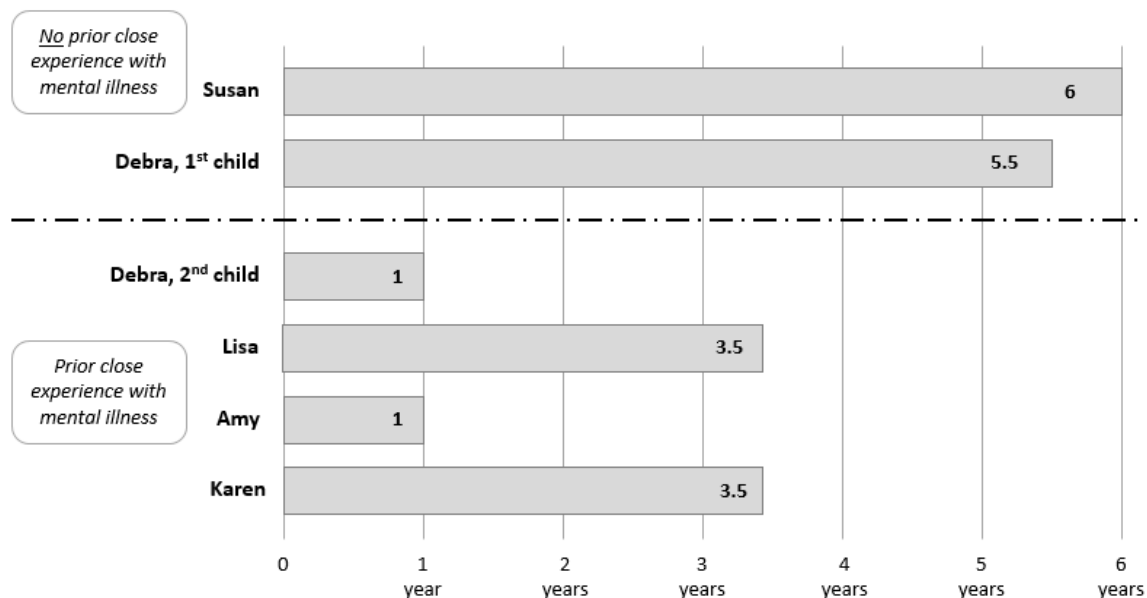
Figure 1. *Time (in years) From Initial Awareness to Recognition, and the Relationship of a Prior Close Experience With Mental Illness (estimates based on mothers' narratives)*

Overcoming Barriers

To successfully move from awareness to recognition, the mothers needed some sort of confirmation to validate their growing concerns or give a name to their distress. The aspects of intuition and the importance of a social network surfaced as prominent components of the lived experience. Three of the women referred to a guiding voice or intuition. Debra referred to an "internal voice," whereas Susan's intuitive sense was connected to her faith. Karen went through a process of denying her intuition until it became too compelling:

> We are the first ones to, to say, "Hmm. Something's a little off here." You know. We're also the first ones to dismiss all that. You know, and um, but, but we see it, and it's a red flag, and we know it. You know, and maybe we're not paying attention to the red flag, until there's six, or seven, 10 red flags. Then we say, "Hoo wee. I gotta fix this, I gotta do something."

The importance of hearing explicit words—something that connoted diagnosis or need for treatment—was evident in all of the interviews. In some cases it was a naming or renaming of the behaviors, and in some experiences, it was confirmation of suspicions or concerns. Lisa remembered,

> So, when that doctor said the word "depression"… I know about depression, and I have had depression, and have depression, you know, I mean I'm familiar with this, but to hear a doctor say it, which is what why it, you know I realize that I was in this cloud of not noticing…

Discussion

Mixed Effects of Self-Efficacy

There was evidence that high parental self-efficacy could be both an enhancement and a barrier to recognition. Amy ascribed her early recognition to her strong sense of parental competence, her watchfulness of her son's behaviors, and her desire to avoid denial about the possibility of mental illness. In contrast, Susan believed that her high levels of confidence in her parenting actually obscured her recognition "because I didn't think that could happen to my kid. That we had done a good job raising her."

Despite the conflicting evidence of its effect on recognition, self-efficacy appeared to be a strong component of treatment-seeking for all of the mothers in this study. Once they recognized the need for mental health services for their child, they were prompt in obtaining them, which seems to counter the findings of Dempster, Wildman, Langkamp, and Duby (2012), who inferred that parents with higher levels of self-efficacy were less likely to seek help.

Misclassification
All the mothers initially engaged in what Biddle et al. (2007) described as "lay diagnosis" (p. 998), where they failed to include the behaviors into their frame of reference for mental illness. This indicated that the overriding barrier was one of categorization of symptoms versus an inability to recognize them (Biddle et al., 2007). The mothers' misclassification of behaviors they saw as "normal" melded with their perceptions of self-efficacy and became an iterative and self-perpetuating cycle: Because they interpreted their child's behaviors as within the normal range, this interpretation reinforced their perception that they, as effective parents, could and *should* be able to wait until this phase passed and handle the behaviors without professional assistance.

However, contrary to previous research (Biddle et al., 2007), the majority ($n = 4$, 80%) of the Colorado mothers sought treatment for their child well before a crisis occurred. These participants' prior experience with mental illness may have had a mitigating effect on the level of input necessary from their social network to motivate them to seek treatment. Instead of a crisis, they needed a word.

Beginning the Conversation

Two interwoven aspects emerged—the mothers' intuition and their apparent need to hear explicit confirmation from someone else in their social network. Interestingly, both of these aspects paralleled parental recognition and help-seeking for other medical conditions. Ingram et al. (2013) noted that parents exhibited the need for sanctioning before seeking care for their child's cough. A noteworthy difference was that when confronted with uncertainty about a cough, parents were more likely to default in favor of consulting a professional (Ingram et al., 2013), yet the results of this study indicated that the default response to uncertainty about behavioral issues was to assume it was due to "normal" or environmental causes and to proceed with a form of de facto home care.

Preventing Conversations

New questions emerged when considering the factors that the participants did not rate highly as affecting their recognition. The mothers gave a lackluster endorsement of recognition help from teachers, pediatricians, and self-help resources, and (based on their rankings) waiting until a crisis occurred was more help to their recognition than inputs from these sources. Because teachers were found to be significantly better at recognizing children's mental health problems than parents (Arya,

Agarwal, Yadav, Gupta, & Agarwal, 2015; Bevaart et al., 2012), it raised this question: What is keeping these Colorado teachers and parents from communicating effectively on mental health issues?

For doctors, the results from this study were even lower, which was consistent with the literature. It points to the development of a downward cycle—if parents do not recognize mental illness, doctors will not receive the inputs they need to recognize the problem and cannot facilitate the parents' recognition.

Trustworthiness

The small sample size resulted from the researcher's limited time and financial resources. Along with the criterion sampling strategy, the small sample—combined with the relative homogeneity of the participants in gender, age, geographic location, race, and socioeconomic status—may reduce the power of the quantitative portion and constrain the transferability of the findings. Therefore, the results may not be representative of other Colorado parents, especially fathers and members of minority populations. Using retrospective interviews may have resulted in distortion of the data due to participant bias, recall error, reflexivity, asymmetric power differential, and the offer of a financial incentive. Although unintentional, two of the participants were acquainted with the researcher, so extra diligence was exercised to safeguard the participants' privacy and minimize reflexivity. The potential for bias from the researcher's personal experiences with the phenomenon were offset by additional bracketing and epoche (Moustakas, 1994). To enhance the credibility of the results, triangulation was inculcated throughout the entire study, and the conduct of both a validation exercise and a pilot study enabled use of outside experts and member checking to ensure the face validity of the protocol.

Implications for Research and Social Change

"Please Say the Word"

> Because I was voiceless, I became blind.
> Because I was blind, I became distressed.
> Because I was distressed, I became isolated.
> Because I was isolated, I almost lost hope for my child.
> But I heard you—glaring through my isolation—say THE word.
> Because I heard you, I could name it.
> Because I could name it, I could recognize.
> Because I could recognize, I could change.
> Because I could change, I found hope for my child.

(Researcher-created data poetry)

When asked to offer advice at the conclusion of their interview, the resounding refrain from all of the mothers was "You are not alone—reach out, connect, and empower yourself to help your child." This sends a strong message for social change: It is important for policymakers and practitioners to create ways to reach out to parents. We should find supportive ways to begin the conversations, and create opportunities for the words that can help re-frame parents' attributions of their children's behaviors.

School environments hold the greatest potential for assisting parents in the processes of both recognition and help-seeking. Teachers are typically the first, and sometimes the only professionals that parents or adolescents consult about their concerns (Boydell et al., 2013). The state of Colorado has set an example by implementing a pilot program for universal mental health screening in

schools (Schimke & Schimel, 2014), which is one means that policy makers can use to predict problems (Koivunen et al., 2017) and foster productive conversations in the school setting. Programs that promote children's mental health have shown to provide a fivefold return on investment within 5 years (McDaid, 2011).

This study should be continued to include diverse populations such as members of racial and ethnic minorities, different socioeconomic status levels, rural areas, and fathers or other caregivers. Because parental self-efficacy emerged as a qualitative theme in this research, use of an instrument like the Parenting Sense of Competence Scale (Johnston & Mash, 1989, as cited in Hankinson, 2009) could be used to quantify and correlate this variable with parents' time to recognition.

Conclusion

Parents—conscientious, caring parents—are struggling to recognize the difference between developmental behaviors and those related to treatable medical conditions. Engaging them in meaningful dialogue about childhood mental health issues is likely to facilitate recognition and treatment-seeking. It will also ensure that everyone heeds the poignant call for social change from Susan: "And that's, that's always the biggest thing, because it's frustrating to know… that there are other people out there, but no one talks about it."

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