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Brief report: assessment of barriers to mental health services among caregivers of children with rare disease

Kim Hager¹, Maria Martinez Calderon¹, Allison W. Rothschild¹ and James K. Luiselli^{2*} 

Abstract

Background Caregivers of children with rare disease experience obstacles to securing medical care including mental health treatment services. The question posed in this study was whether barriers to accessing mental health treatment services reported by caregivers of children with rare disease differed from caregivers of children with common medical and mental health conditions, and children with mental health conditions alone.

Method An online survey combining both quantitative and qualitative outcome measures was distributed to caregivers ($n=305$) who were biological, step, foster, and adoptive parents of 374 children under 18-years-old residing at home in the United States.

Results There were no statistically significant differences among the caregiver groups concerning barriers to accessing mental health services based on quantified measures from the Barriers to Treatment Participation Scale. Statistically significant main and interaction effects were found on three scale items (scheduling appointments, life stress, understanding treatment). Qualitative responses among caregivers of children with rare disease emphasized difficulty finding mental health treatment, lack of competent professionals, financial burden, and problems with insurance coverage.

Conclusion Despite non-significant findings, several implications for families of children with rare disease are noted, namely having access to knowledgeable and experienced practitioners, making in-home services available, integrating disciplines at outpatient settings, and overcoming the costs of mental health treatment to the care required for complex medical conditions.

Keywords Families, Mental health services, Rare disease

Introduction

In the United States, a rare disease is defined as a disease or condition that affects fewer than 200,000 people, about 80% from genetic origin, and approximately half among children [1, 2]. Pelentsov [3] reported that families of children with rare disease frequently are dissatisfied with

the support they receive from health professionals, for example, obtaining a formal diagnosis and implementing a service plan. Further, Allshouse et al. [4] concluded that children with complex medical conditions “require tailored systems of care and community supports, yet often experience fragmentation, inadequate insurance coverage, a lack of infrastructure for home- and community-based care, an inadequacy of home care training and support for families, a lack of self-care training for children, and lack of attention to overall health status and the impact of the social determinants of health” (p. S196).

Notably, chronic medical illness in children is a risk factor for anxiety and other psychiatric disorders,

*Correspondence:

James K. Luiselli
jluiselli@melmarkne.org

¹ Seven Hills Foundation, 81 Hope Avenue, Worcester, MA 01603, USA

² Clinical Development and Research, Melmark New England, 461 River Road, Andover, MA 01810, USA

possibly resulting from predisposing biologic mechanisms, genetic abnormalities, environmental factors, and irregular response to treatment [5]. Other research provides evidence that children designated with “special healthcare needs,” medical complexity, and neurodevelopmental disabilities often present with co-occurring mental health problems [6–8]. Regardless of diagnostic profile, many children in the United States and internationally do not receive necessary mental health services [9–11] and families struggle to overcome a multitude of service barriers that encompass economic disadvantage, limited knowledge about available treatment, parent wellbeing, and child compliance [12, 13]. These and related impediments fall under the category of mental health literacy, referring to caregiver recognition of illness symptoms, health-seeking options, prevention strategies, and treatment effectiveness [14, 15].

Barriers to mental health treatment judged by caregivers of children with rare disease have not been evaluated in previous research. In this brief report, we describe a survey administered to this population that evaluated the impact of rare disease on access to services provided by mental health practitioners. To expand data analysis, the survey also included (a) caregivers for children who had general (non-rare disease) medical conditions and a mental health diagnosis, and (b) caregivers for children solely with mental health diagnosis in order to compare and contrast survey responses unique to children with rare disease. As well, we conducted the survey during a heightened period of the COVID-19 pandemic which impacted and greatly curtailed access to and the quality of child and youth mental health services [16–18]. We hypothesized that compared to caregivers of children with medical conditions plus mental health diagnosis and children with mental health diagnosis alone, caregivers of children with rare disease would record a greater number of barriers to mental health treatment from a standardized instrument that assessed external demands and treatment expectations. Further, the survey produced qualitative comments from respondents as additional outcome measures.

Methods

Study design and participants

Study design entailed a multi-item survey the authors designed and distributed over a two-phase recruitment process that covered the period from September 2020 through May 2021. We judged survey research methodology as the most viable and productive approach to test the hypothesis that caregivers of children with rare disease would perceive more barriers to mental health treatment compared to caregivers who did not have a child with rare disease. As a prospective study, our objective was

to sample the largest number of participants as possible and compare survey results among three distinct groups. Third, available internet resources made it possible to distribute the survey electronically and facilitate return.

In phase 1, we created a one-page flyer describing a survey that assessed barriers to treatment perceived by caregivers of children with mental health, mental health plus common medical, and mental health plus rare disease conditions. Phase 2 consisted of sending the flyer via email to organizations, foundations, palliative care agencies, and community centers within the United States that served children with the three identified conditions, as well as every organization listed on the National Organization of Rare Diseases (NORD) website. Recruitment in this phase also included posting the flyer on parent Facebook groups for children with mental health, common medical, and rare disease conditions.

The email was sent to a total of 5,830 organizations, foundations, agencies, centers, and Facebook groups, requesting that they make the flyer available to caregivers who might be interested in completing the survey. The flyer designated an online link that enabled recipients to open, fill out, and return the survey anonymously. No incentives were offered for survey completion. Inclusion criteria were that the recipient responding to the survey (a) was the primary custodial caregiver (e.g., biological, step, foster, or adoptive parent) and legal guardian of a child under 18-years-old, and (b) indicated that the child needed mental health services in the past 12 months. Recipients who met these criteria and completed the survey formed a participant sample of 305 caregivers who self-reported without gender identification as mother (88.5%), father (5.2%), and other (6.2%). Any partially completed surveys were not included in the study. In total, these participants represented 374 children with different combinations of mental health, common medical, and rare disease conditions (see Results section below). Note that the number of children exceeded the participant sample because caregivers were able to report more than one child in their custody. Table 1 summarizes the participant demographic data.

Study approval and consent

The study originated within one division of a multi-state human services organization serving children and adults with neurodevelopmental disabilities, psychiatric disorders, medical problems, and traumatic brain injury. An Institutional Review Board (IRB) operated by the organization approved the study (Reference ID: “A Comparison of Caregivers Experiences in Accessing Mental Health Treatment for Their Children”), the procedures for distributing the survey, and acquisition-analysis of survey data. Participants were required to acknowledge understanding of the purpose of the study and record their informed consent before accessing the survey.

Table 1 Participant demographic data

Demographic Category	Percentage of Participants
Age	
18–24 years	1.0%
25–34 years	10.9%
35–44 years	43.2%
45–54 years	30.7%
55–64 years	10.9%
65 + years	3.1%
Race-Ethnicity	
White/Caucasian	90.1%
Black/African-American	1.5%
Hispanic/Latino	5.6%
Asian/Asian-American	1.0%
American Indian/Alaskan Native	1.0%
Native Hawaiian/Pacific Islander	1.0%
Other	1.0%
Geographical Area	
Metropolitan/Major City	18.2%
Suburban	54.6%
Rural/Country	27.0%
Marital Status	
Single/Never Married	8.2%
Married	72.0%
Living with Partner	7.7%
Separated/Divorced	11.9%
Language Spoken other than English	
No	85.8%
Yes	14.1%
Level of Schooling Completed	
None/Less than High School	1.0%
High School	13.0%
Certificate/Diploma Equivalent	2.0%
Trade/Technical/Vocational Training	4.1%
Associate's Degree	14.6%
Bachelor's Degree	31.9%
Master's Degree	27.2%
Doctorate Degree of Higher	6.2%
Employment Status	
Fulltime Wage Earner	47.8%
Parttime Wage Earner	12.6%
Business Owner	4.2%
Volunteer not Receiving Wages	1.0%
Unemployed	4.2%
Stay-at-Home Caregiver	25.2%
Retired	4.7%

Survey construction

The authors requested and received feedback on the initial version of the survey from three mental health professionals, however did not conduct a formal pilot phase to test survey administration and feasibility. Section 1 of the survey inquired about caregiver status, demographic information, and the number of children in their custody with a mental health, common medical, and rare disease condition. A mental health condition was defined as a disorder that affects a person's mood, thinking, and behavior. The definition of a common medical condition was physical disease that negatively impacts different organs in a person's body but is not classified as a rare disease. A rare disease condition was defined as a medical condition that affects fewer than 200,000 people in the United States. For each of these conditions, the participants could respond "yes" (the condition in present), "no" (the condition is not present), or the condition "Is in the process of being determined." There were 12 mental health diagnoses (e.g., attention deficit hyperactivity disorder, autism spectrum disorder), 31 common medical diagnoses (e.g., asthma, epilepsy), and 27 rare disease diagnoses (e.g., Gaucher disease, sickle cell anemia) listed per condition. Participants checked one or more diagnoses that applied and could write in diagnoses that were not listed.

In Section 2 of the survey, participants completed the Barriers to Treatment Participation Scale, an English-language instrument (Spanish translation available), which has been shown to have high levels of internal consistency [12], is based on parent and therapist ratings, and predicts involvement with, dropping out of, cancelling, and not showing up for treatment sessions among children 3 to 13 years old. Representative statements on the scale that inquire about respondent experiences with treatment barriers are "Treatment did not seem necessary", "My child had trouble understanding treatment", "Treatment added another stressor to my life", and "Treatment did not seem to be working." The scale requires respondents to endorse each statement with one of five Likert-type ratings (1: never a problem, 2: rarely a problem, 3: sometimes a problem, 4: often a problem, 5: very often a problem). In the present study, the only modification to the original scale developed by Kazdin et al. [12] was the addition of two statements, "My child lost interest in coming to sessions," and "I felt treatment did not focus on my child's life and problems."

Relative to survey construction, an Exploratory Factor Analysis (EFA) was conducted on the original items and added items ($n=2$) presented in the Barriers to Treatment Participation Scale using Principal Component Analysis with Varimax rotation. The EFA showed a two-factor solution with the subscales interpreted to represent Treatment Expectations ($\alpha=0.94$) and External Barriers ($\alpha=0.91$) consistent with the findings from Kazdin et al. [12]. This two-factor solution explained approximately 43% (42.500) of the total variance. Further, five of the forty-seven items from the Barriers to Treatment Participation scale were dropped from our survey as they had factor loadings below 0.3 on each factor [19]. The items were “I felt that treatment cost too much,” “I was billed the wrong amount,” “My child’s behavior seems to have improved, therefore treatment no longer seems necessary,” “Finding a place to park at the clinic,” and “Other barrier not mentioned.”

Finally, the third section of the survey posed the question, “Is there any additional information you would like to share about your experiences with your child’s mental health services?” Participants were able to write open-ended responses of any length at their discretion.

Analysis of survey outcome measures

Several steps were taken to ensure the integrity and security of the collected survey data. As noted previously, participants completed the survey anonymously without identifying information. The data and comments recorded from the online survey platform were converted to summary files in Microsoft Excel available only to the authors via a secure (encrypted) password. Electronic storage of files is maintained until a disposal date listed on the IRB approval form.

The data from Section 2 of the survey were quantified as the average Likert scale rating for each statement contained in the Barriers to Treatment Participation Scale among participants in the mental health condition, common medical condition, and rare disease condition groups. An average rating was computed by summing the Likert scale statement scores and dividing by the number of participants who endorsed a rating. Analysis of variance for the external barriers and treatment expectations subscales from the Barriers to Treatment Participation Scale and for the individual scale items was computed using SPSS statistical software (p value < 0.05).

The authors conducted independent qualitative analysis of any open-ended responses on the survey by caregivers of children with rare disease (not all of the participants wrote responses). These analyses produced code words and phrases that could be combined into larger categories of consistent narrative themes. The authors subsequently

shared their findings and through discussion, confirmed three thematic categories (reported below).

Results

The 374 children in the survey completed by 305 caregivers produced nine diagnostic groups listed in Table 2. A three-way ANOVA was conducted to examine the effects of mental health conditions, common medical conditions, and rare disease conditions on barriers to mental health treatment. As previously noted, these barriers were divided into two Treatment Expectations and External Demands subscales. The overall mean score for External Demands was just over 2 ($M=2.20$, $SD=1.19$), suggesting that overall, the impact of external demands on treatment was “rarely” a problem. The mean score for children with only a mental health condition was just over 2 ($M=2.11$, $SD=1.16$), and the mean score for children with a common medical condition was also just over 2 ($M=2.18$, $SD=1.10$). The mean score for children with a rare disease condition was slightly higher, with a mean score closer to 2.5 ($M=2.36$, $SD=1.22$), suggesting that these caregivers rated treatment barriers related to external demands between “rarely” and “sometimes” a problem.

The overall mean score for Treatment Expectations was about 2 ($M=2.09$, $SD=0.77$), suggesting that treatment barriers related to treatment expectations were rarely a problem overall. The mean score for children with only a mental health condition was slightly over 2 ($M=2.12$, $SD=0.80$), and the mean scores for children with a common medical condition or a rare disease condition were also just over 2 ($M=2.18$, $SD=0.77$; $M=2.08$, $SD=0.78$, respectively).

A three-way ANOVA was conducted to assess the effect of mental and medical health conditions on barriers to treatment related to Treatment Expectations and External Demands, as well as the total scale mean score.

Table 2 Child diagnostic group

Category	Percentage of Children
Mental health condition	40.0%
Mental health and common medical condition	20.6%
Mental health and rare disease condition	11.2%
Mental health, common medical, and rare disease condition	7.2%
Common medical condition	2.4%
Common medical and rare disease condition	0.8%
Rare disease condition	3.4%
Child in need of mental health services	7.2%
Child in process of mental health assessment	6.6%

However, the Levene’s test showed that the variances of the groups were not equal for Treatment Expectations ($F(12, 357)=2.55, p=0.003$), External Demands ($F(12, 312)=1.98, p=0.025$), or for the total scale ($F(12, 384)=2.06, p=0.019$). To address these violations, the data was transformed using a logarithmic transformation [20, 21]. Following the transformation there was homogeneity of variance as assessed by Levene’s test for all three scales; Treatment Expectations ($F(12, 357)=1.40, p=0.162$), External Demands ($F(12, 312)=1.29, p=0.224$), and the total scale ($F(12, 384)=1.15, p=0.315$).

The results of the factorial ANOVA on the transformed data showed that there was no statistically significant three-way interaction between child mental health condition, common medical condition, and rare disease condition on barriers to treatment related to and of the three scales; Treatment Expectations ($F(2, 357)=1.80, p=0.166$), External Demands ($F(2, 312)=2.34, p=0.098$), or the total scale ($F(2, 384)=1.30, p=0.275$). There were also no significant two-way interactions or simple main effects on any of these scales.

In addition to examining differences among these three groups along the two subscales, a three-way ANOVA was also conducted for each individual survey item. There was only one item with a very slight statistically significant three-way interaction, “Scheduling of appointment times for treatment” ($F(2, 382)=3.10, p=0.046$). There was also one significant two-way interaction between the mental health and rare disease condition for the item “During the course of treatment I experienced a

lot of stress in my life” ($F(2, 360)=6.30, p=0.030$). This item also had a significant main effect of the rare disease condition ($F(3, 360)=2.75, p=0.043$). One other item showed a significant main effect of the mental health condition, “My child has trouble understanding treatment” ($F(2, 360)=3.94, p=0.020$). No other significant interaction or main effects were found.

A sample of open-ended survey responses from caregivers of children with rare disease is presented in Table 3. Three key categories comprised these responses, which were consistent with findings from parent and caregiver mental health literacy research [14]. Specifically, our participants commented about difficulty finding mental health treatment [22], limited competencies of care providers [23], and financial burdens associated with payment for services and insurance coverage [24].

Discussion

This study emerged from prior research that reported caregivers of children with rare disease and/or medical complexity were dissatisfied with unknowledgeable service providers, receiving fragmented care, having unmet needs, and being excluded from some care settings [3, 4, 25]. We found similar concerns among caregivers of children with rare disease seeking mental health treatment. A notable finding was no statistically significant differences in barriers to treatment recorded among caregivers of children with rare disease and mental health

Table 3 Open-ended survey responses by caregivers of children with rare disease

Category	Response Examples
Access to Mental Health Services	<p>“We didn’t get any treatment because clinics won’t even call us back to do an assessment.”</p> <p>“It took me months to try and get a psychiatrist to see my daughter.”</p> <p>“My child is often too sick or too tired to get an appointment, or in need of emergency medical appointments that take precedence over anything else.”</p> <p>“Long wait times for responses. Still no provider for his neurological disorder.”</p> <p>“It took emergency crises in order to obtain mental health treatment for the oldest and youngest children, both with rare diseases.”</p> <p>“When my child has needed help or I suspected he needed mental health [treatment], it always fell on me as the parent to find him help, even when I asked his providers for assistance or social workers.”</p>
Competencies of Providers	<p>“Lack of knowledge or information from our service providers. His disorder is quite rare and no one knows about it.”</p> <p>“Friedreich Ataxia is a progressive, degenerative disease. We’ve found very few professionals are willing to work with teens facing this difficult future.”</p> <p>“Lack of knowledge of medical issues and mental health issues that goes with it.”</p> <p>“We need more services that are culturally competent and are willing to be flexible and meet the family’s needs.”</p>
Financial Costs and Insurance Coverage	<p>“We did find a great provider, but neither our primary nor secondary insurance covers a social worker, so all costs are out of pocket and prohibitive.”</p> <p>“After adoption, our local Medicaid group refused proper mental health services for our daughter.”</p> <p>“It is difficult to access and too expensive. Psychoeducational evaluations are out of reach for many families due to cost.”</p>

condition, common medical and mental health condition, and mental condition alone.

Nonetheless, qualitative survey findings suggested that caregivers of children with rare disease in need of mental health services will benefit from skilled and experienced practitioners who are knowledgeable about the complex conditions that come to their attention. The availability of in-home mental health services, including weekend and evening hours, and with a wider selection of providers is another needed resource for this child population. When travel to treatment locations is indicated and possible, having multiple practitioners at one setting also addresses a perceived barrier. Of course, covering payment for mental health treatment of children with rare disease that requires the costly input from multiple medical specialists is a necessary solution to service challenges.

Limitations

Interpretation of study findings may be limited by several factors. For example, there are likely common barriers to mental health treatment regardless of child medical conditions. Specifically, caregivers face obstacles locating appropriate services, paying for treatment, understanding therapeutic options available to their children, qualifying for health insurance, finding services outside of urban areas, and engaging culturally competent practitioners [18]. Second, the Barriers to Treatment Participation Scale [12] used in the study does not list barriers tailored specifically to medically complex children and their caregivers. Access-to-services challenges in this regard would be a compromised immune system that prevents treatment at outpatient settings, necessity for medical equipment, genetic or rare disease conditions affecting caregivers, and unique transportation exigencies (e.g., specialized wheelchairs and vehicles). Third, the survey was distributed at the height of the COVID 19 pandemic such that caregivers across the child diagnostic groups experienced the same reduction of mental health services evident at the time. Travel restrictions, reduced in-person contact with specialists, and inaccessibility of telehealth modalities among low-income and marginalized groups were dominant constraints occasioned by the pandemic [16–18].

We note too that this study included a relatively small and self-selected participant sample. However, it is unknown how many of the 5,830 organization, foundation, agency, and group contacts actually made the survey available to potential participants. Restricted access to the survey would have reduced the number of respondents because only caregivers who received the flyer announcement could complete the survey. At the same time, some caregivers may have looked at the survey but

chose not to complete it. The characteristics of study participants compared to non-respondents also is unknown. Thus, additional study limitations extend to the need for improved sampling rigor with statistical power analysis to determine a sufficient quantity of participants for a survey of this type and constraints imposed from analyzing the scale item-by-item.

Participant responses also were collected exclusively from an anonymous online survey and not in-person interviews. Face-to-face interviews with caregivers may have produced different outcomes, particularly the qualitative impressions that supplemented the quantitative ratings. Consider that additional qualitative analysis would have been possible by including more than a single open-ended question on the survey, for example, asking participants to recommend solutions to mental health treatment barriers and which of them were or were not successful. A further concern is that our qualitative analysis was author-driven and did not adhere to formal guidelines such as the consolidated criteria COREQ checklist [26].

Future directions

New research might distribute surveys to caregivers of children with rare disease and follow-up with focus groups to more precisely assess impediments to mental health treatment. Caregivers should be encouraged to suggest solutions to treatment barriers, including how digital mental health interventions can improve service accessibility and integrity with this vulnerable population [27].

Conclusions

Accessing mental health treatment services for children with rare disease often is a challenge for their caregivers. Delays scheduling appointments, finding qualified medical practitioners, and financial obligations are some of the common barriers that caregivers report. More research into treatment options is needed such as integration of disciplines at outpatient settings, provision of in-home services, and telehealth modalities.

Authors' contributions

All of the authors contributed equally to the design, implementation, data analysis, and writing of the study, as well as read and approved the final manuscript.

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Availability of data and materials

Data and materials are available upon reasonable request from the corresponding author.

Declarations

Ethics approval and consent to participate

The study was reviewed and approved by the human services organization IRB and adhered to the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Consent for publication

Not applicable.

Competing interests

The authors have no financial, non-financial, or competing interests to disclose.

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