

## Article

# Adolescents Hospitalized for Psychiatric Illness: Caregiver Perspectives on Challenges

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**Abstract:** Adolescents with psychiatric illness severe enough to be hospitalized experience many challenges that are also experienced by their caregivers and other family members. The purpose of this study was to explore the challenges experienced by these adolescents and their families from the perspective of the caregivers. A cross-sectional survey with open-ended questions and standardized measures was administered to caregivers while their children were in hospital. Caregivers ( $n = 24$ ) reported significant challenges related to the psychological problems their adolescents were experiencing, and additional burdens that influenced the family context in which the adolescents were developing. Adolescents with psychiatric illness may be contributing to and developing in stressful family contexts. Implications include the need for interventions for caregivers alongside the psychiatric care provided for their children and specialized supports for their complex situation.

**Keywords:** caregiver burden; psychiatric illness during childhood

## 1. Introduction

Mental illnesses are a major global burden [1], and mental illness in children and adolescents is a growing concern. Approximately 18% to 22% youth are reported to have a mental illness [2,3] and the prevalence is increasing as is the need for specialized care including hospitalization [4]. There has been a 65% rise in hospitalization rates for mental illness in children and adolescents [5]. Mental illness during childhood and adolescence can seriously disrupt development; it can have adverse impacts on interpersonal relationships [6], and thwart academic [7,8] and employment goals [9,10].

Children and adolescents with mental illness can experience many difficulties that may also affect their families. It has been consistently reported that the onset of mental illness in children and adolescents is experienced as disturbing and stressful [11,12]. Caregivers and family members may also have difficulties with psychosocial and financial challenges and barriers to accessing formal services stemming from managing the youth's mental illness [13]. It has also been reported that mental health problems among caregivers or parents is associated with mental health problems of the children in their care [14].

Caregiver burden is defined as the negative impact on psychological, emotional, physical, social and economic domains that affects caregivers of people living with some sort of impairment [15,16]. Caregiver burden consists of two domains: an objective burden consists of tangible and easily identifiable responsibilities and consequences, while a subjective burden is concerned with the thoughts, perceptions and feelings of caregivers [17]. The parents of adolescents with psychiatric illnesses are at most risk for high levels of caregiver burden, in contrast to siblings and child caregivers [18,19]. Approximately 11% of the general population is composed of parents who experience increased caregiver burden related to their children's mental illnesses [20]. Parents are also at increased risk for elevated parenting stress, depressive symptoms, social withdrawal [21], and internalized strain, such as grief, worry, sadness, guilt and fatigue [18,19,22].

High levels of caregiver burden can have damaging effects on caregivers. The adverse effects of elevated caregiver burden include depression [23,24], anxiety, perceived stress,



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lower quality of life [24], decreased well-being, impacts on relationships within and outside of families, and the restriction to pursuing personal activities [19]. Therefore, increased caregiver burden could have detrimental consequences for caregivers which could affect entire families. In addition to perceived parental stress, youth symptoms and youth school refusal may adversely affect caregiver burden in parents.

Psychiatric symptoms are related to psychosocial functioning and behaviors in youth, which can increase the demands placed on parents. Caregiver burden can be influenced by the type and intensity of symptoms present in care recipients, as well as the level of assistance and supervision needed from caregivers [16–18,20,21] and the duration of time spent in the caregiver role and accommodating the needs of care recipients [19]. Therefore, caregivers involved in close relationships and/or mutual living conditions are at an increased risk for high caregiver burden because of the increased exposure to, and expectation of, taking on primary caregiving duties related to youth symptoms, functioning and behaviors [17,23]. Youth who experience increased severity of symptoms and impairment often require more time, energy and resources from caregivers, and so, the caregiver role can become more demanding [22]. Parenting stress can be especially elevated when symptoms and behaviors are disruptive to others [21]. Additionally, psychosocial impairment in youth is related to anger, embarrassment and resentment in parents [22], which could also impact adolescents and parent-adolescent relationships.

School can be a major stressor for youth with psychiatric illnesses. The social and academic contexts and the difficulty of managing symptoms can be overwhelming for youth [7,25]. These youth have reported that their mental illnesses and associated stigma, impacted their ability to engage in school [7]. Youth school refusal could increase caregiver burden and tension within parent-adolescent relationships. Parents may also need to manage the effects school can have on their children and ensure that their children are attending school and/or receiving adequate supervision when avoiding school. Caregiver burden is significantly high in parents who spend increased amounts of time and energy finding cooperative schools, decreasing work hours and taking leaves of absence or resigning from jobs to accommodate their children's needs [21]). Families have reported a lack of understanding by school personnel amplifying parents' feelings of frustration and abandonment [26]. Thus, perceived stress and youth symptoms including school refusal have been shown to be important influences on caregiver burden.

The admission of youth into psychiatric units can potentially offer breaks and relief to parents; however, it may also be considered another contributor to the caregiver burden and family stress. Most children and adolescents (90%) are admitted at a time of crisis with suicide risk as the most prevalent problem precipitating admission [27]. Thus, admission to inpatient care often occurs when caregivers and their child are already in a state of crisis and many are also experiencing conflict [28–30]. Very few studies have been focused on the perspectives of caregivers of children hospitalized for psychiatric care, and sample sizes within these studies have been small, for example, ranging from 12 in-person [28] to 44 telephone [31] interview surveys with caregivers. In these studies, caregivers have reported the need for knowledge of strategies to help their child and emotional support, to improve their relationships [31], and reported exhausting all other mental health care options before admission, worries related to discharge during admission, and a vacillating recovery after discharge [28]. Including caregivers of children hospitalized for psychiatric care in research has proven very difficult. Caregivers may have to travel significant distance to reach the hospital, have employment-related and income-related barriers to participating in research, experience time pressures such as maintaining employment and care for other family members, and may feel stigma or distrust [30,32] and “need to adjust and resolve seemingly insurmountable circumstances with little or no external support” [32] (p. 528). Though research is needed to understand the complexity and heterogeneity of caregivers' experiences and needs, these caregivers are hard-to-reach.

There is a dearth of research in which the burden and experiences of caregivers of children hospitalized for psychiatric illness were reported. The purposes for this report

were to explore the experiences of caregivers of children and adolescents hospitalized for psychiatric care and self-reported caregiver burden and stress. A secondary purpose was to explore the associations of parental perceived stress, youth symptoms and youth school refusal to caregiver burden. This report on caregivers of hospitalized youth is part of a larger study focused on the psychosocial characteristics of youth hospitalized for psychiatric illness (e.g., [25]).

### *Theoretical Framework*

The developmental period of adolescence is characterized by biopsychosocial changes, efforts to gain greater autonomy from caregivers and increased reliance on peers for guidance and support [33]. Moreover, many mental illnesses have an onset before or during the adolescent period [34] which can affect functioning. These changes and challenges may have significant, adverse influences on caregivers. In the theory of stress and coping, Lazarus and Folkman (1984) have reported that appraisal of the situation and of the coping abilities and resources may affect how caregivers view the situation and how stressful the situation may be. These theories can be used to enhance the exploration of caregivers' perspectives.

## **2. Methods**

### *2.1. Ethics*

Institutional approval was obtained from the Tri-Hospital Research Ethics Board (Certificate number 2018-0664) and the University of Guelph's Research Ethics Board (18-08-026) in accordance with the Declaration of Helsinki regarding research on human participants. To maintain privacy consistent with privacy laws in health care, the first point of contact with any study participant must be a hospital member within the patients' circle of care who is only permitted to ask patients and caregivers if they would like to learn of a study from a research assistant; hospital staff may not ask patients or caregivers for consent to participate in this study because it could be perceived as coercive.

### *2.2. Setting*

Patients admitted to the child and adolescent inpatient psychiatry unit often arrive from an emergency department in the same hospital or from a hospital in the surrounding region. The youth were hospitalized in a general psychiatry unit within a community hospital in a medium-sized city in southwestern Ontario, Canada. This unit served a region including urban and rural areas with a combined population of approximately 900,000. The mean length of stay in the unit was approximately seven days. Upon admission, caregivers are contacted by telephone by unit staff for intake purposes. Assessment, stabilization and treatment with a multi-disciplinary team are provided and there is an on-site classroom/school.

### *2.3. Study Design and Participants*

This study was designed as a cross-sectional survey to explore and describe caregiver experiences related to their child with psychiatric illness. In the original study, participants included all patients consecutively admitted to the inpatient unit who provided consent over the course of this study; patients with active psychosis and intellectual disability were excluded. Participants for this report included a convenience sample of caregivers of these patients admitted to a child and adolescent inpatient unit for stabilization and treatment of psychiatric illness for whom consent was obtained. For inpatients less than 14 years of age, on the caregivers' first contact with the hospital, a staff member informed them that a study was in progress and asked if they would like to speak with a research assistant (RA) to learn about this study. For inpatients 14 years old and older, the staff member informed the patient that a study was in progress and asked if they would like to speak with an RA; for those who consented, the RA requested consent to speak with the patients' caregiver. The RA fully described this study to the caregivers, requested their informed consent and

then administered the survey by telephone. Telephone surveys were chosen since it was routine for caregivers to be contacted by phone by hospital staff. Telephone surveys are also considered the least burdensome method [35,36] which is important since, as noted above, caregivers were likely already experiencing considerable difficulties. The RA was a University of Guelph student with extensive training and successfully completed tutorials on (1) confidentiality and privacy in accordance with the Personal Health Information Protection Act, 2004 (<https://www.ontario.ca/laws/statute/04p03>, accessed on 20 June 2023), and (2) ethics in research (<https://tcps2core.ca/welcome>, accessed on 20 June 2023). The RA also engaged in training specific to this project.

#### 2.4. Survey

A questionnaire was created for this survey that included demographic information, questions on a family history of mental illness, open-ended questions on their child's experiences, their own experiences and their thoughts on services, and standardized measures of caregiver burden, stress, youth symptoms and youth school refusal. Thus, caregivers were asked to report on their experiences by answering open-ended questions and rating items on measures.

Caregiver burden was measured with the Burden Assessment Scale (BAS) [37]. It contained 19 items that captured both objective (10 items) and subjective (9 items) consequences of providing continued care to individuals with severe mental illnesses, such as financial problems, limitations on personal activity, household disruption and social interactions. Objective burden refers to the observable behavioral effects of caregiving. Caregivers were asked to respond to questions on a 4-point Likert scale ranging from 1 (Not at all) to 4 (A lot). Responses were summed, and higher scores indicated greater levels of caregiver burden. The measure has been shown to be reliable ( $\alpha = 0.89\text{--}0.91$ ) and valid [37].

Perceived stress was measured with the Perceived Stress Scale, 4-item version [38,39]. The scale included questions about feelings and thoughts that reflected chronic stress. Response options ranged from 0 (never) to 4 (very often), range 0 to 16, with higher scores indicating greater perceived stress. The measure showed internal consistency ( $\alpha = 0.84\text{--}0.86$ ) and test-retest reliability (0.85) [38]. The 4-item scale has shown acceptable reliability ( $\alpha = 0.60$ ) [39]. After these two questions on caregiver burden and stress, caregivers were asked if there was anything else they wanted researchers to know about their own experiences.

Psychiatric symptoms were measured with the parent-report Pediatric Symptom Checklist (PSC) [40]. The PSC is a screening tool that can be used to identify cognitive, emotional, and behavioral problems. It consisted of 35 items with response options that range from 0 (Never) to 2 (Often) [40]. The PSC includes three subscales: attention problems (5 items), internalizing problems (5 items) and externalizing problems (7 items). For children aged 6 years and older a score of 28 or higher indicates psychological impairment. For the three subscales, the cut-off points are seven for attention problems (AP), five for internalizing problems (IP), and seven for externalizing problems (EP). The measure has shown strong internal consistency ( $\alpha = 0.91$ ), test-re-test reliability ( $r = 0.84\text{--}0.91$ ) and validity [39]. Internal consistency on PSC subscales ranged from 0.71–0.82 [41].

Youth school refusal was measured with the parent version of the School Refusal Assessment Scale Revised (SRAS) [42]. The SRAS is used to measure functions of school refusal behavior. It consists of 24-items rated on a Likert-type scale that is scored by deriving the mean item value for each functional condition. Response options ranged from 0 (Never) to 6 (Always). The measure has shown reliability (SRAS-P-R, mean correlations for item sets for each functional condition/subscale were 0.63, 0.67, 0.78, and 0.61) [42]. After these two measures on their child's symptoms and school behaviors, caregivers were asked if there was anything else they wanted researchers to know about their child's school experiences or transition home from hospital.

### 2.5. Data Analysis

Content analysis [43] was used to describe the caregivers' experiences based on responses to the open-ended questions; their responses varied from a few words or point-form bullets to a paragraph. In the preparation phase, caregivers' responses were transcribed verbatim. NVIVO was used to organize the data. The text was read in full to obtain a sense of the overall meaning. In the organizing phase, open coding was performed, and an initial grouping of the codes was produced to generate mutually exclusive categories. Content was sorted into the categories and subcategories emerged. Categories and subcategories were named to represent the content or caregivers' experiences. If there was uncertainty about the placement within a category, the full text was read again to secure reliability of the categorical interpretation. In the reporting phase, a description of the levels of categories was enriched with example quotations. The categories were solely based on caregiver comments and were not based on any hypothesis or theory.

Descriptive statistics were used to present demographic information and scale scores using SPSS Version 26. Data were entered into SPSS by a trained RA, and errors were detected by scanning the values and analyzing frequencies (Statistics, Minimum and Maximum values). Multiple linear regression was used to examine the relationships between caregiver burden, parent stress, youth symptoms and school refusal while controlling for youth age and gender.

### 3. Results

Twenty-four caregivers completed the survey. Their ages ranged from 34 to 69 years ( $M = 46.65$ ,  $SD = 8.45$ ), most caregivers were female ( $n = 22$ ; 91.7%) and 19 were biological mothers (Table 1). The caregivers reported incomes that ranged from CAN 9000 to CAN 150,000 ( $M = \text{CAN } 83,521.74$ ,  $SD = 42,748.59$ ). Regarding their relationship status, 14 caregivers reported being in a couple relationship and 12 (50%) participants reported college as their highest level of education. More than half of the caregivers ( $n = 16$ , 67%) reported a family history of mental illness. The mean burden score for caregivers was 51.71 ( $SD = 14.28$ ), which indicates that caregivers reported a moderate to severe level of burden. The perceived stress mean score was 9.63 ( $SD = 1.86$ ; range 6–12) indicating moderate to high stress.

**Table 1.** Parent characteristics.

Characteristic	
Age, <i>m</i> ( <i>SD</i> )	47.14 (8.32)
Gender, <i>n</i> (%)	( <i>n</i> = 23)
Female	21 (91)
Male	2 (9)
Primary Caregiver, <i>n</i> (%)	( <i>n</i> = 16)
Yes	15 (94)
No	1 (6)
Relationship, <i>n</i> (%)	
Mother	19 (79)
Father	2 (9)
Grandmother	2 (9)
Stepmother	1 (4)
Number of Children, <i>m</i> ( <i>SD</i> )	2.59 (0.91)
Ethnicity, <i>n</i> (%)	( <i>n</i> = 20)
Caucasian	20 (100)
Relationship Status, <i>n</i> (%)	( <i>n</i> = 23)
Coupled	14 (61)
Divorced	4 (18)
Single	3 (13)
Separated	1 (5)
Widow	1 (5)

Table 1. Cont.

Characteristic	
Highest Education, <i>n</i> (%)	( <i>n</i> = 23)
PhD	2 (8.3)
Masters	4 (16.7)
Bachelor	3 (12.5)
College	12 (50.0)
Highschool	3 (12.5)
Income, <i>m</i> ( <i>SD</i> )	CAN \$81,863.64 (CAN \$42,990.91)
Family history of MI, Yes, <i>n</i> (%)	16 (66.7)
Caregiver Burden, <i>m</i> ( <i>SD</i> )	( <i>n</i> = 23)
Total Burden	51.48 (14.56)
Objective Burden	28.70 (7.81)
Subjective Burden	22.78 (7.66)
Perceived Stress, <i>m</i> ( <i>SD</i> )	( <i>n</i> = 22)
Perceived Stress	8.68 (1.43)
Pediatric Symptoms, <i>m</i> ( <i>SD</i> )	( <i>n</i> = 23)
Pediatric Symptoms	68.04 (11.38)
School Refusal, <i>m</i> ( <i>SD</i> )	( <i>n</i> = 21)
Total School Refusal	2.47 (1.19)
Avoidance of Stimuli (Negative Affectivity)	3.25 (1.66)
Pursuit of Tangible Reinforcement	2.28 (1.42) *
Escaping Aversive Situations (Social/Evaluative)	2.17 (1.80)
Pursuit of Attention	2.12 (1.60) *

Note. \* = (*n* = 20).

For the 24 hospitalized youths, the ages ranged from 14 to 17 years ( $M = 15.33$ ,  $SD = 0.92$ ); 17 were female, and half of them ( $n = 12$ ) were in Grade 10 (see Table 2). The mean length of stay was 7.13 days ( $SD = 3.79$ ), and depression was the most common primary diagnosis. The mean score on the PSC was 68.17 ( $SD = 11.15$ ), and 23 (96%) were rated as having moderate to severe psychological impairment. The PSC subscale means indicated that 91.7% ( $n = 22$ ) of youths scored high for attention problems, while 100% ( $N = 24$ ) scored high for internalizing and externalizing problems. The mean school refusal score for youths was 2.50 ( $SD = 1.17$ ). Subscale scores suggested that avoidance of stimuli that provoke negative affectivity was the primary function of school refusal among youths in this study (i.e., the highest mean function was at least 0.25 points higher than the second highest scoring condition, See Table 2).

The caregivers' moderate to high ratings of their burden and stress were reflected in their comments. Analysis of these caregiver perceptions resulted in three categories related to impacts of caregiver burden, challenges and coping facilitators (Table 3). Caregivers reported considerable impacts of burden on their family from mental illness and addictions in the hospitalized child but also themselves and other children. Parents reported instances where their entire families were impacted by their children's psychiatric illnesses, and a number of caregivers reported caring for multiple people with severe and chronic conditions. The parents also expressed challenging parent–youth relationships involving tension, resentment and conflict between the parents and their children with psychiatric illnesses. A number of parents reported rebellion and defiance from their children, as well as ongoing friction in their interactions with their children. Caregivers reported role restrictions and considerable psychological impacts such as feelings of guilt, embarrassment, frustration and hopelessness. Caregivers also reported challenges with the mental health care system such as long wait times for specialized care and challenges with the struggles their children were experiencing. Caregivers also noted resources and supports from the school, family and friends, and having hope as a personal resource.

**Table 2.** Youths’ Characteristics (N = 24).

Characteristic		
Age, <i>m</i> ( <i>SD</i> )		15.33 (0.92)
Gender, <i>n</i> (%)	Female	17 (71)
	Male	7 (29)
Education (Grades) <i>n</i> (%)	12	3 (12.5)
	11	5 (20.8)
	10	12 (50)
	9	2 (8.3)
	Missing	2 (8.3)
Length of Stay in Hospital (days), <i>m</i> ( <i>SD</i> )		7.13 (3.49)
Diagnoses, <i>n</i> (%)	Depression	14 (58)
	Anxiety	5 (21)
	ADHD	4 (17)
	Adjustment Disorder	3 (13)
	Parent–Child Relationship Disorder	3 (13)
	Total Symptoms	68.04 (11.38)
Pediatric Symptoms, <i>m</i> ( <i>SD</i> )	Attention Problems	9.73 (2.40)
	Internalizing Problems	9.77 (2.17)
	Externalizing Problems	11.42 (3.43)
	Total School Refusal	2.47 (1.19)
	Avoidance of Stimuli (Negative Affectivity)	3.25 (1.66)
School Refusal, <i>M</i> ( <i>SD</i> )	Pursuit of Tangible Reinforcement	2.28 (1.42)
	Escaping Aversive Situations (Social/Evaluative)	2.17 (1.80)
	Pursuit of Attention	2.12 (1.60)

**Table 3.** Caregiver Perceptions.

1. Caregiver Burden	
Family Impact	
Family Challenges	“I have a diagnosed mood disorder.” “I have uh, worse problems than [name of youth] though. . . I have a daughter who’s a drug addict on the street who’s probably prostituting herself”
Parent–Youth Relationship	“She blames me.”
Role Restrictions	“I can’t make my child go to school. . .and it frustrates me” “I took off from my job. . .”
Psychological Impacts	“He attempted suicide. . .that’s embarrassing. . . you’re worried of being judged. . . [as] a bad parent because your son. . .struggles with depression.”
2. Challenges	
Mental Health Care System	
Long Wait Times	“She’s currently on a waitlist. . .”
Needing to Advocate	“We felt that we had to fight the system. . .”
Youth Services Needed	“There needs to be a lot more. . .inpatient care. . .”
Caregiver Services Needed	“Caregivers really need. . .a break. . .”
Adverse Situations	
Financial Concerns	“I know there’s financial troubles. . .”
Lack of Control	“I can’t make my. . .child go to counselling.”
Youth Symptoms	
Youth Struggling with Symptoms	“She was so ill that there were days that it was. . .hard for her to get out of bed.”
Disruptive Behavior	“The behavioural problems have gotten increasingly worse.”
Peer-Related Issues	“Bullying was involved.”
Substance Use	“He still takes drugs. . .”

Table 3. Cont.

3. Coping Facilitators Resources	
School Support	"We've got a good support system at the school."
Informal Support	"I go to church and I find that helps. . ."
Family Support	"He talks to me. . .if he has a problem. . ."
Peer Support	"I feel more relieved knowing that I'm not the only person in the world that seems to be going through this."
Personal Resources	Positive Cognitions
Hope	"It's getting better. . ."
Adaptation	"We've had to learn to adapt. . ."

Comments on services and financial situations affecting access to service were particularly important and are elaborated here. Services and supports were identified as: (a) concerns about services and support, (b) satisfaction and positive attitudes towards services, and (c) suggestions for improvement of services and support. Some caregivers ( $n = 5$ ) were concerned that they were not receiving sufficient or adequate support. Others were concerned with the quality of services and support that was provided. These participants mainly focused on issues with referral and communication. Furthermore, they explained that the problem was not resolved, or services were not properly integrated, which was time-consuming and/or frustrating. Comments were as follows:

"I think that it, it's still hard to find follow-up care after. I don't really know that in [youth's name] case, that he gained a lot from it, but I felt like we still had a hard time with doctors and psychiatrists after the fact to help. . .but I understand them not wanting to you know. . .form bonds with the kids because it was a short-term care and it was just giving them the tools. . .but something should still be done after, that makes sense. Yeah, it was still kind of in the dark for the kids. Like you have to be at the family doctor, and unfortunately the psychiatrist was leaving to move, and he referred us to a new one and we still haven't heard anything yet, you know. At the doctor's office we kind of got the run around between the counsellor and the doctor and I had let the counsellor know that. . .I let them know that it wasn't very helpful cause they just kept shifting the answers over to the other [ . . . ] and I said this has to stop. Like, somebody needs to actually take the responsibility and help." (#145)

"I just feel that there was a lot of communication that was, they didn't communicate very well with me. There came a point when she didn't want to visit with me when she was in there and, they weren't keeping me in the loop. I didn't even know she was released. . .so she was back home and I thought she was in there, so that was disappointing." (#80)

"Umm basically CAIP just seemed like a temporary fix. Seemed like a band aid solution and then they just basically assessed her and told us what her needs were, and then sent her on her way. But, really nothing was resolved. . ." (#117)

". . .I don't think the help's gunna get any better. . . I think it's gunna get worse." (#135)

"If a parent goes into hospital 2 or 3 times with their child saying like, she has a diagnosis and she's currently struggling, and she's suicidal, I just don't even get why we would be questioned over and over and over again. If I may just give a little bit of a story here. So, she was completely in crisis, medication was no longer working, her moods and everything was changing by the minute, she had gone to her regular psychiatrist who assessed her and said she needed to go to the hospital and wrote a letter thinking that the letter would help expedite the process and maybe we could jump some hurdles, but as soon as we got to the

hospital, like we were triaged and then had to be seen by like a social worker.” (#160)

Some caregivers ( $n = 4$ ) also expressed satisfaction with services and had a positive attitude towards their experiences. The caregivers focused on benefits such as coping skills, social interaction of the child with others, communication, and their commendation for the unit:

“I think that she received—my daughter received—good help there. I think it was beneficial and I know she’s made friends with some of the other people who are in there, as far as my personal—I feel that they did a good job too” (#80)

He gained some coping skills and what not. . . , so like the CAIP program was good. . .” (#145)

“Uhm, I know everybody does the best they can and obviously the CAIP unit is awesome. They do, they do a great job.” (#49)

“All I can say to them is to keep up the great work!” (#10)

Suggestions for improvement of services were made by caregivers ( $n = 6$ ) who provided comments about services for their child but also for themselves as caregivers. They include

“Okay. What I would, what I would say is that. . .more services for kids with special needs. . .in general, so that would include things like autism. . .it’s still a little bit piecemeal. . .making it easy for parents to get in the system. . .or some type of case worker to help you through it. . .We’re doing a lot of things privately.” (#74)

“I think more help from the doctors.” (#47)

“Uhm. . .I guess caregivers really need like a break or they kind of need like, uh, rest. Or, uhm, they need maybe a service where they could go and get help in terms of somebody coming into the home and dealing with, with the child so that the parent could get a break.” (#97)

“Well, unless the government helps and changes things with the umm, Canadian mental health situation, then.” (#135)

“I think that there needs to be a lot more, inpatient care for kids with her issues” (#117)

“. . .just like you do need help to get through it. You do need a good support system, you do.” (#127)

Financial concerns were expressed by caregivers ( $n = 4$ ) that were related to the child’s condition, the situation at home, and the cost of youths’ treatment:

“I know there’s financial troubles and his mother is sick 90% of the time, so you know, [youth’s name] spends a lot of time helping his older brother look after her.” (#148)

. . .they’re allowed to control their own care (Mhmm), at 16 to 18 that there’s really nothing else there except for private care that costs tens of thousands of dollars (right), that will actually force them to get help. . .because of her age there’s a lot of difficulty trying to get kids that have their own, you know. . .” (#117)

“My circumstances have changed. . .I can’t work outside of the home because I’m a full-time caregiver for my handicapped grandson.” (#125)

“Both my husband and I have very poor health benefits. . . , she does receive a disability tax credit that helps, but because her medications change frequently as well, some months can be more expensive than others. And then, particularly if you’ve just filled a prescription, and then she’s gone to the doctor and it

changes. . .you have got this whole bottle of medicine that you might have spent \$300 on, and suddenly you’re putting money out for something else and probably never going to use the other one.” (#160)

A multiple linear regression was performed to examine the extent to which perceived parent stress scores (stress), youth symptoms (symptoms) and youth school refusal (school refusal) contributed to parents’ total caregiver burden scores (caregiver burden), while controlling for youth age (age) and youth gender (gender). There were statistically significant correlations between caregiver burden, perceived stress, youth symptoms and youth school refusal (Table 4); increased caregiver burden was positively related to increased stress, increased child psychiatric symptoms and school refusal.

**Table 4.** Relationships between Youth Age, Youth Gender, Caregiver Burden, Perceived Parent Stress, Youth Symptoms and Youth School Refusal.

	Age	Gender	Caregiver Burden	Stress	Symptoms	School Refusal
Age	-					
Gender	-0.18					
Caregiver Burden	-0.15	-0.12				
Stress	-0.09	-0.22	0.49 *			
Symptoms	-0.04	-0.07	0.58 **	0.29		
School Refusal	-0.45 *	-0.07	0.70 **	0.62 **	0.64 **	-

Note. \*  $p < 0.05$ ; \*\*  $p < 0.01$ .

The results of the multiple regression indicated that age and gender of youth did not contribute significantly to the variance in caregiver burden scores ( $R^2 = -0.07$ ,  $F(2, 17) = 0.41$ , ns). Parent stress, youth symptoms and youth school refusal contributed 37% of the variance to caregiver burden scores ( $R^2 = 0.37$ ,  $F(5, 14) = 3.22$ ,  $p < 0.05$ ). However, when all the variables were entered into the multiple regression to explore their relative contribution to caregiver burden, all the values were nonsignificant (Table 5).

**Table 5.** Perceived Parent Stress, Youth Symptoms and Youth School Refusal contributing to Total Caregiver Burden, controlling for Youth Age and Youth Gender.

Model		Unstandardized Coefficients		Standardized Coefficients			Collinearity Statistics	
		B	Std. Error	Beta	t	Sig.	Tolerance	VIF
1	(Constant)	89.17	48.86		1.83	0.09		
	Youth Age	-2.27	3.03	-0.18	-0.75	0.46	0.97	1.03
	Youth Gender	-4.59	7.28	-0.15	-0.63	0.54	0.97	1.03
2	(Constant)	-4.75	46.70		-0.10	0.92		
	Youth Age	1.50	3	0.12	0.50	0.63	0.58	1.72
	Youth Gender	-0.73	5.77	-0.02	-0.13	0.90	0.91	1.10
	Parent Stress	0.26	0.87	0.08	0.30	0.77	0.51	1.96
	Youth Symptoms	0.20	0.29	0.19	0.71	0.49	0.47	2.12
	Youth School Refusal	6.19	3.98	0.58	1.56	0.14	0.24	4.22

#### 4. Discussion

Caregivers of youth hospitalized for psychiatric care provided important experiences, both good and bad, related to the services their child received and offered suggestions for improvement mainly on continuity of care for their child and respite for themselves. They also reported considerable burden and stress and several psychosocial and financial impacts on their well-being and the families’ well-being. There was consistency between their subjective ratings on the burden and stress measures and the comments they provided.

Some families were already dealing with difficulty such as scarce financial resources compounding the stress experienced from having a child hospitalized for a severe mental illness. The findings suggest that parents may need services to address multiple concerns related to the management of their situation that include an adolescent with severe psychiatric illness.

These findings are consistent with reports that suggest that caregiver burden is associated with difficulty in the management of psychiatric symptoms [20,44] especially severe symptoms and psychosocial impairments [45]. This burden can be exacerbated by financial challenges and challenges accessing formal services [13,46]. Caregivers deal with the lack of availability and access to resources that could potentially help in decreasing caregiver burden, but instead act as risk factors for heightening it. Risk factors include stigma [47], lack of support in the caregiver role [15], social isolation and financial stress [23,44]. A lack of support for the caregiver role and social isolation resulting from caregiver responsibilities can further increase burden [15,44]. Caregivers may benefit from additional professional support to manage youth psychiatric symptoms, as well as their own circumstances.

Our findings that caregivers reported struggling with intense feelings of worry and guilt, particularly with regard to their children's well-being was consistent with other research on strain reported by caregivers [19,22,48–50]. Parents' feelings of worry typically stem from concern for their children's safety, future and well-being, and guilt tended to be related to parents' perceptions of feeling like they are not doing enough and/or that they have somehow contributed to their children's psychiatric illnesses [22,51].

The reported feelings of embarrassment are common. Parents can be blamed or judged by their children's school faculty or health care providers, as well as family and friends, for their children's mental health issues, which can lead to increased fear of judgement and feelings of guilt [22,51]. Stigma and embarrassment can also impact parents' willingness to seek and accept support for the demands of caregiving, as well as the distressing thoughts and emotions common in individuals raising youth with mental illnesses [47]. Parents who do not access formal and/or informal supports face greater risk for high and unmanaged caregiver burden [15]. Additionally, youth are affected by their own experiences with embarrassment and stigma [7,48,52]; and so, cases where parents' embarrassment of their children's mental illnesses affect their children's well-being and ability to access supports can be particularly harmful to youth [52,53].

Caregivers also reported feelings of frustration, hopelessness and exhaustion related to trying to manage their children's symptoms and behaviors, and concerns about supports available to them. Reported concerns with their children's treatment in the mental health care system, communications from care providers, and the need to advocate in order to receive treatment for their children were consistent with previous research [48,50]. The gaps in available supports and experiences of social isolation were noted by the caregivers have also been reported [50,54]. It is important to note that there are reports on treatments available for adults with mental illness; however, a number of factors tend to inhibit caregivers from receiving care, such as lack of childcare, lack of financial resources, transportation, insurance coverage, stigma and the fear that accessing services will lead to a loss in parental rights [55]. Furthermore, the parents of youth who are struggling with mental illness who are living in poverty and/or belong to marginalized groups are increasingly impacted by these factors [55].

In viewing these findings through Lazarus and Folkman's theory of stress and coping (1984), the caregivers' responses are consistent with primary (e.g., what is at stake or at risk) and secondary (e.g., am I able to cope with this situation) appraisals though the caregivers are not necessarily conducting separate appraisals. The caregivers' responses suggest that the situation of having a child with psychiatric illness severe enough to be admitted to hospital is quite complex and involves many active and interacting aspects including caregivers themselves having a mental illness, their child experiencing bullying and substance use, and financial difficulties. In addition, caregivers related past and current circumstances they deemed relevant to understanding the current situation which is consistent with Lazarus and Folkman's idea that coping (i.e., the behavioral and cognitive

efforts people make to manage the demands of a situation they perceive as stressful) is an on-going process. The caregivers' responses do highlight the transactional nature of perceived stress and coping, and that the situation can include many diverse and dynamic considerations.

Notably, more than half of the caregivers in this study reported a family history of mental illness. A family history of mental illness may exert intergenerational influences. For example, offspring of parents with severe mental illness are at high risk for a range of psychiatric illnesses [56]. While the exact etiology of mental illness is not known, parental mental illness has been correlated with poor family functioning including poor parent-child interactions, adaptability and cohesion which place the child at increased risk for psychological problems [57]. Comorbidity is common; hence, emerging evidence suggests that many mental illnesses share many common environmental and genetic risks [58]. A history of mental illness could potentially impact burden and increase perceived stress for caregivers while they manage their own symptoms as well as that of their children. Thus, attention should be given to help manage burden of caregivers with a reported history of mental illness.

### 5. Implications for Research

An important discovery was the difficulty in recruiting parents of child and adolescent inpatients. In the original study with inpatients [25] of the 161 youth who participated, only 24 of their caregivers participated. There are many influences on parent participation. Many of the youth experienced difficult relationships with their parents, and for this study, youth were asked to provide consent in order for research assistants to contact their parents; many youth did not provide this consent. Moreover, contacting caregivers can be difficult; they may have occupations, other children or family members who require their care or other time pressures. Moreover, visiting hours at the inpatient unit fall outside structured day treatment that includes academic work in the classroom and treatment from a multidisciplinary team. Many caregivers were overwhelmed with their situation and experience emotional and psychological burdens related to admission of their child to psychiatric hospital and other challenges so they may have less availability to participate in research. Furthermore, to protect privacy, the first point of contact for research must be someone within the circle of care of the child; thus, staff may assess whether it is reasonable to ask caregivers about research if the caregivers are experiencing high stress. Staff must also ensure the clinical aspects of care are completed and take precedent over an optional research opportunity. Stigma may also pose as a barrier to participation in research. In the future, researchers may increase inclusion of this hard-to-reach group by offering caregivers supports (e.g., parking) and token thanks (e.g., gift cards), extending the time frame for data collection, and connect with caregiver support group if one exists [59]. However, how to include caregivers for whom the youth has not provided consent to contact would still pose as a barrier.

The age of consent was very well considered for this project from several viewpoints. This study was conducted in a hospital in Ontario, Canada. In this province there is no particular age of consent for medical treatment (College of Physicians and Surgeons of Ontario; CPSO, 2006). Clinicians must consider the child's maturity, not chronological age, to determine if the child is capable of understanding the nature of proposed treatments, their effects and consequences of not receiving the treatment. In routine practice, medical staff must continually assess patients' capacity for decision making (all patients regardless of age) and this practice was extended to this study for patients 14 years and older. It is important to know that these patients were already hospitalized in a secure setting. It should also be noted that parent-child conflict is not uncommon in this population, and it was important to allow patients capable of making decisions the latitude of deciding whether their caregivers participated or not. This procedure is consistent with patient-centred care and efforts for inclusivity (e.g., Patient Voices Network; <https://patientvoicesbc.ca/2021/10/25/nothing-about-me-without-me-the-patients-as-partners-initiative/>, accessed on 20 June 2023).

Telephone surveys were used in an attempt to circumvent some of the challenges caregivers were known to be experiencing. In a feasibility review conducted before ethics review, clinicians indicated that trying to administer an in-person survey if the caregiver visited the hospital was not sensible since it could not be predicted when the caregiver might arrive (any time of day or evening), and caregivers were often upset with the situation. Caregivers were often present at discharge; however, at discharge, caregivers are often overwhelmed with the need for continuing care for their child. Moreover, online surveys have been reported as having very low response rates especially with patients/families with ongoing illness [35]. Telephone emerged as the most viable option.

### 5.1. Implications for Practice

Caregivers, including mothers, fathers, grandparents and step-parents, may benefit from engaging in professional care programs while their child is hospitalized, and after their child is discharged. Providing both hospital-based and community-based options may help reduce barriers to accessing supports for caregivers who are struggling to care for several children, juggling financial constraints, navigating complex mental health care systems (e.g., hospital and community) and managing the serious symptoms of mental illness their child is experiencing. Parents who are involved and offered supports can be beneficial to the well-being of their children, especially in psychiatric treatment settings and contexts of promoting coping and mental health [48,60]. Effective resources for promoting health and self-care targeting parents of youth with psychiatric illnesses could potentially help parents remain instrumental caregivers to their children. Given the high contribution of family and caregiver history of mental illness and family functioning to child mental illness, much consideration should be given to caring for the caregiver. Caregivers may benefit from the provision of professional programming designed to help caregivers support their child with mental illness and simultaneously enhancing the caregivers' well-being. For example, there is some evidence to support offering clinician-led interventions (e.g., [61]) and some may benefit from peer support (e.g., [62–64]) to address caregiver and family challenges, and isolation and its associated risk of burden.

### 5.2. Limitations

It is important to note this study's limitations. While the sample size was adequate to capture caregivers' experiences with open-ended questions, the small sample size only permitted exploratory analysis of the associations with burden. It was important to sample caregivers of youth accessing the highest level of psychiatric care available which necessitated recruitment from hospital but which also posed barriers to accessing and recruiting parents. Youth with mental illness represent a vulnerable, hard to reach group; however, recruiting parents or caregivers of youth hospitalized for psychiatric illness has been reported to be extremely difficult [30]. The structure of the inpatient unit and the availability of parents among other challenges posed as significant barriers to caregiver participation in the present study. Furthermore, many youth hospitalized for psychiatric illness have strained relationships with their caregivers, and for youth 14 years old and older, permission to involve their caregiver in the research was sought. Some youth did not want their caregiver involved in the research which adversely affected the sample size. The reliance on self-reported responses also introduces the possibility of bias such as social desirability and response bias.

## 6. Conclusions

This novel study on a hard-to-reach population makes a significant contribution to the field. Caregivers of children and adolescents hospitalized for psychiatric illness reported considerable burden related to caring for their children with mental illness, as well as other children who were also experiencing challenges, impacts to their psychological well-being, financial strain and a need for supportive resources. Caregivers suggested the importance of hospital staff involving and communicating well with caregivers and helping

them navigate the mental health care system including ensuring their children receive post-discharge care. The caregivers themselves may benefit considerably from specialized parenting interventions to increase their repertoire of skills to manage their child's mental illness, and professional supports for parents to manage their own varied challenges.

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