The Association of Caregiver Burden with Perceived Stress and Youth Symptomatology

by

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THE ASSOCIATION OF CAREGIVER BURDEN WITH PERCEIVED STRESS AND YOUTH SYMPTOMATOLOGY

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This exploratory study was focused on caregivers’ burden and stress in families with youths hospitalized for severe psychiatric disorders. The study utilized survey research on caregivers’ perceptions and ratings of burden, stress and youths’ psychiatric symptoms that were gathered in a larger study on school related difficulties reported by youths admitted to a psychiatric unit.

Caregivers (n = 24) reported moderate to severe burden, moderate stress, and psychosocial problems (attention, internalizing, and externalizing problems) among youths. Perceived parental stress and youths’ psychiatric symptoms were not significantly associated with caregivers’ objective and subjective burden. Themes included services and support, financial situation/concerns, and adjustment and coping. The most prominent theme was services and support, which included concerns about the quality of mental health care, satisfaction and positive attitudes towards services and support, and suggestions for improvement of services and support. The limitations, implications and conclusions of the results are discussed.
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Chapter One: Introduction and Literature Review

Mental health problems among children and adolescents (herein, “youth”) represent a major public health concern. Parents caring for youths with psychiatric disorders can experience burden (Angold, Messer, Stangl, Farmer, Costello, & Burns, 1998; Baronet, 1999; Liu, Lambert & Lambert, 2007), where burden is described as the impact of psychiatric related difficulties affecting family members or caregivers (Reinhard, Gubman, Horwitz, & Minsky, 1994). Burden can significantly increase with the severity of youths’ psychiatric symptoms and create additional challenges for families (Angold et al., 1998; Compton et al., 2014).

Additionally, caregivers with youths with problematic symptoms and greater care demands can experience stress (Vaughan, Feinn, Bernard, Brereton, & Kaufman et al., 2013), which is defined as a subjective assessment of an individual’s relationship with the environment, the threats exceeding his or her available resources, and the inability to cope (Lazarus & Folkman, 1984,1987; Lazarus, 1966). Vaughan et al. (2013) found that stress levels were high for parents who had difficulty managing their child’s symptoms or adjusting to the situation. Furthermore, a reciprocal relationship can exist between parental stress and youths’ psychiatric disorders, which can intensify youths’ symptoms and further increase parental stress (Neece, Green, & Baker, 2012).

With regard to youths’ psychiatric hospitalization, families caring for psychiatric patients can experience burden such as negative emotions (Jungbauer, Wittmund, Dietrich, & Angermeyer, 2003; Östman & Hansson, 2000), which may require further family support. Furthermore, investigators (Östman & Hansson, 2000) have recommended that burden research should be focused on different subgroups of family members. In this study, group differences in family history of mental illness and youths’ prior hospitalization on burden were of interest.
Moreover, investigators have found that a family history of mental illness and youths’ psychiatric hospitalization can pose additional challenges for families (Baronet, 1999; Perez Algorta et al., 2017). For example, a parent with a mental illness can increase the likelihood that a child will develop a mental illness (Qin, Agerbo, & Mortensen, 2003; Weissman, Leckman, Merikangas, Gammon, & Prusoff, 1984). Additionally, parents with mental illnesses of their own can be less involved in the patient’s treatment process and more concerned about their situation (Ostman, Hansson, & Andersson, 2000) than parents without mental illness.

With regard to the complexity of family situations, youths’ school refusal behaviour can place youths at risk for further psychiatric problems (Kearney, 2008). Moreover, Egger, Costello, and Angold (2003) found associations between youths with only anxiety-based school refusal behaviour, only truancy-based school refusal, and both types of school refusal with psychiatric disorders such as depression (Anxious school refusers were characterized by anxiety based resistance to school attendance, while truants were characterized by resistance to school attendance which was not associated with anxiety, without the permission of school authorities, and without a reasonable excuse. In addition, almost 90% of youth with both anxiety and truancy based school refusal were diagnosed with at least one psychiatric disorder, and more than 50% of youths had a biological parent with a history of mental illness. Thus, burden may be likely for caregivers who must manage mental health difficulties of their own and school related difficulties associated with their youths’ psychiatric symptoms.

Taken together, the family situation is complex, and researchers (Blizzard, Weiss, Wideman, & Stephan, 2016) have suggested a focus on difficulties of caregivers with hospitalized youths. This focus may highlight the demanding situations that families face and increase specialized interventions for additional support for caregivers and youths (Vaughan et
al., 2013). Furthermore, research incorporating caregivers’ situations may add to the limited knowledge on caregivers’ burden, stress, and experiences in families with youths who were hospitalized.

The purposes of this exploratory study were to: (a) present psychosocial characteristics of participants, (b) explore associations between parental perceived stress and youths’ psychiatric symptoms with caregivers’ burden, (c) investigate group differences between families with youths with and without a history of mental illness and families with youths with prior or no prior hospitalization, regarding subjective and objective caregivers’ burden, parental perceived stress, youths’ psychiatric symptoms and youths’ school refusal behaviour, (d) report caregivers’ views on their experiences caring for youths.

Caregivers’ burden and stress in families with youths with severe psychiatric disorders is layered and complex. According to Lazarus and Folkman (1984), the events in the environment or response to the events in the environment cannot be considered in isolation of individual characteristics. It is important to understand the nature of the relationship that exists between the individual and the environment in order to understand the complexity of responses and adjustment (Lazarus and Folkman, 1984). Therefore, the psychological stress and coping theory (Lazarus and Folkman, 1984) served as a guide for this exploratory study and is reviewed next.

Furthermore, I review the state of psychiatric disorders among youths and caregivers’ burden in families. The youth section will include a review of child and adolescent development, the state of mental health and prevalence of psychiatric disorders, psychiatric hospitalization and treatment, and prior psychiatric admission. In addition, I review research on perceived stress, school refusal and history of family mental illness. Moreover, I consider the importance of exploring caregivers’ burden and outline the purpose and research questions of this exploratory
study. Finally, I report the study methods and data analysis, and present results, discussion, and conclusions.

**The Psychological Stress and Coping Theory**

Lazarus & Folkman (1984) posited that stress is a transactional relationship between a person and his or her environment, which can be appraised as taxing, exceeding resources, as well as threatening to his or her well-being and that of loved ones. Caregivers’ appraisal of their experiences while caring for hospitalized youths can influence the way they perceive stress. This stress and coping theory (Lazarus, 1966; Lazarus & Folkman, 1984; 1987) has been widely adopted and referenced in literature on stress (Krohne, 2002; Meichenbaum, 1977, 1985; Meichenbaum & Jaremko, 1983) and with the examination of parental stress and coping (Lowes & Lyne, 1999).

According to Lazarus and Folkman (1984, the concepts of cognitive appraisal [primary appraisal (How am I affected?), secondary appraisal (If possible what can be done?)] and coping (Lazarus & Folman, 1984; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986) are central to the theory. An appraisal is the cognitive, subjective and continuous process of meaning making and identification of a threat, if any exists (Lazarus and Folkman, 1984). This principle idea presented by Lazarus & Folkman (1984) suggested that an event or stimulus is not inherently stressful. Thus, families may report different experiences while caring for youths, and caregivers may vary in their stress levels, adjustment and coping abilities.

Appraisals exist in two forms (i.e., primary and secondary) (Monat, Lazarus & Reevy, 2007). Primary appraisals and secondary appraisals exist independently and not in any sequential order or form (Lazarus, 1966). Primary appraisals occur when the individual identifies the experience as irrelevant, positive and harmless, or stressful (i.e., if there is a loss or threat).
Secondary appraisal occurs when an individual identifies possible ways to manage a threatening situation, the resources available to take on the task, the possible outcomes for using a resource, and the ability to successfully execute an option and arrive at an expected outcome (Lazarus & Folkman, 1984). Additionally, appraisals are continuous and any new information from the environment and the individual can influence the evaluation process or restart the process.

Clifford & Minnes (2013) found that coping had a critical role to play in family adjustment, while families cared for youth with challenging illnesses. According to Lazarus and Folkman (1984), coping refers to the cognitive and behavioural efforts to deal with internal and external threats that are demanding. Coping is greatly dependent on the resources available to individuals (Taylor & Stanton, 2007) and the extent to which they believe they can access and use these resources (Lazarus & Folkman, 1984). Coping occurs in two forms, which are emotion-focused (i.e., manage emotional response) and problem-focused (i.e., identify and find solutions) (Lazarus, 1993; Lazarus & Folkman, 1984). Emotion-focused coping includes attempts to minimize the distress experienced (e.g., recognizing positive values from negative experiences or selective attention). On the other hand, problem-focused coping involves attempts to problem solve or weight costs and benefits of practical solutions, which may alter the nature of stress.

Furthermore, Lazarus & Folkman (1984) and Folkman, & Lazarus (1980) indicated that individuals may use both forms of coping to manage stress. However, emotion-focused strategies may be used for health-related stressful experiences, when individuals have less control over the situation, and little can be done to alter the experience. On the other hand, problem-focused coping might be used in situations where opportunities for problem solving are presented (e.g., the work environment). According to Lazarus & Folkman (1984) coping resources are
fundamental to the coping process, resources can be inherent in a person or developed over time (e.g., an optimistic attitude, problem solving skills and social skills), and resources can be made available (e.g., money and people such as relative, friends and professionals) to individuals. Optimistic thoughts, good health, social support and material goods are some of the useful resources that individuals may use to cope with stress (Lazarus and Folkman, 1984).

**The Middle Childhood Period**

In middle childhood years (6-12), significant social and emotional changes occur (Harold & Hay, 2005). Furthermore, socio-emotional development is critical for psychosocial adjustment and peer and family interactions become an essential part of social and emotional development (McDowell, Kim, O'Neil, & Parke, 2002). Socio-emotional development includes emotional regulation, social competence and social adjustments, which may influence relationships and vise-versa (Thompson, 1990).

More importantly, the development of social skills, personal characteristics and socio-emotional experiences during childhood can have negative or positive influences on psychosocial adjustment. For instance, Feiring and Lewis (1991) found that the establishment of a healthy relationship was associated with positive experiences and healthy development, while problematic child characteristics (e.g., aggression and fear) and negative social experiences (e.g., peer rejection) were linked to poor psychosocial adjustments (Ladd & Troop-Gordon, 2003). Thus, socio-emotional development during middle childhood involves challenges that can be risk factors for psychiatric disorders (Feng, Shaw, & Silk, 2008).

The presence of a psychiatric disorder during middle childhood has been linked to distress among families and may be compounded by comorbidity (Abram, Teplin, Mcclelland, & Dulcan, 2003; Rockhill, Violette, Stoep, & Grover, 2013) and other contextual issues such as
family history of psychopathology (Angold et al., 1998). Moreover, there can be continuity of psychiatric symptoms during middle childhood, and the occurrence of psychiatric disorders during middle childhood can intensify during adolescence. Additionally, Costello, Mustillo, Erkanli, Keeler, and Angold (2003) reported that one in three of a representative sample of youths aged 9 to 13 years old had one or more psychiatric disorders by 16 years old. Hence, risk factors during middle childhood can be problematic during later years for adolescent development.

**The Adolescent Period**

Adolescence is a period of notable change, which can be perceived by some as stress and storm (Arnett, 1999; Hall, 1904; Steinberg & Morris, 2001). During this period, adolescents become more involved with their peers and social relationships. Additionally, peer acceptance becomes central to peer relationships and socialization, and adolescents hope to be favoured by their peers (Kohlberg, 1984).

Many environmental, social, family and personal influences can place adolescents at risk for psychiatric disorders (Briggs, Maxwell, & Keenan, 2015; Giedd, Keshavan, & Paus, 2008; Paus, Keshavan, & Giedd, 2008) during this period. For instance, conflicted relationships with peers and parents, and challenges at school can lead to negative experiences that can affect psychosocial adjustment (Steinberg & Morris, 2001; Sokol, 2009).

Also, adolescents can engage in risky behaviours found to be associated with psychiatric disorders (Braams, van Duijvenvoorde, Peper, & Crone, 2015; Baams, Dubas, Overbeek, & Van Aken, 2015). For instance, the use of cannabis can place adolescents at risk for some significant psychiatric disorders such as schizophrenia (Chadwick, Miller, & Hurd, 2013). Also, cigarette
smoking was found to be associated with major depressive disorders, drug abuse/dependence, and disruptive behaviours (Brown, Lewinsohn, Seeley, & Wagner, 1996).

Significant adolescent changes can be complex, and researchers continue to explore the significant impact of different contextual factors on adolescent development and psychosocial adjustment (Steinberg & Morris, 2001). For example, family socialization continues to receive attention for its primary role in adolescent development and psychosocial adjustment (Conger, Ge, Elder, Lorenz, & Simons, 1994; Smetana, Campione-Barr, & Metzger, 2006). However, it is important to recognize that a bidirectional relationship exists between youths and caregivers in the family context, and caregivers may also be influenced by adolescent development and psychopathology (Burke, Pardini, & Loeber, 2008). Therefore, the importance of the family context and the possible impact of youths’ psychopathology on caregivers cannot be overlooked. Moreover, it is important to first understand the state of youth mental health before exploring the family context and caregivers.

**The State of Mental Health Disorders among Youth**

Mental health disorders are defined as health conditions with various symptoms that are generally characterized by abnormal thoughts, emotions, behaviours and relationships with others (American Psychiatric Association [APA], 2018. Mental health disorders can affect youth throughout their young adult life (Patel et al., 2007) and predict psychiatric problems in adulthood (Copeland et al., 2009). There is a sustained increase in mental health disorders among youth (Belfer, 2008; Olfson, Blanco, Wang, Laje, & Correll, 2014; Perou et al., 2013), and youth are at risk for the recurrence of psychiatric symptoms even after treatment. Such situations suggest that families with youth with psychiatric problems will need to continually adjust to complex situations to maintain family functioning.
**Prevalence of mental health disorders among youth.** The prevalence estimates of all mental health disorders among youth ranges between 10% and 20% (Offord et al., 1987; Offord, Boyle, Fleming, Blum, & Rae-Grant, 1989; Waddell, Offord, Shepherd, Hua, & McEwan, 2002) with 20% as the most common estimate (Brandenburg, Friedman, & Silver, 1990; Costello et al., 2003; Costello, 1989; Roberts, Attkisson, & Rosenblatt, 1988) and 14% in the clinical range (Waddell, Offord et al., 2002). About 50% of psychiatric disorders have an onset by adolescence, and 75% by 24 years of age (Kessler et al., 2005; Kessler et al., 2007; Kim-Cohen et al., 2003; Waddell, Shepherd, Schwartz, & Barican, 2014). These figures indicate that the onset for a considerable number of psychiatric disorders occurs early in life. Additionally, many youths have more than one mental health disorder; more than 50% of youths have been reported to experience comorbidity (Angold & Costello, 1995; Costello et al., 2003; Garland et al., 2001; Kessler et al., 1994; Waddell et al., 2014). These reports suggest that there is a considerable number of families with youths with complex mental health needs and even these figures may underrepresent families due to factors such as stigma and issues with classification and identification of disorders (Kauffman, 1993).

**Psychiatric Disorders among Youth**

**Etiology.** The cause of psychiatric disorders is unknown. However, some factors, including psychological, biological, social and environmental factors, have been linked to psychiatric disorders. In addition, accompanying cognitive, emotional and/or behavioural symptoms can lead to impairment and distress in various areas of a person’s life (American Psychiatric Association [APA], 2013a; Stein et al., 2010; Waddell et al., 2014). Psychiatric disorders are not merely responses to stressors, but manifestations of a combination of personal
(e.g., biological or genetic), interpersonal (e.g., personality), and external influences (e.g., community) specific to an individual (Stein et al., 2010).

**Disorders.** Some common and prominent psychiatric disorders among the youth population include: anxiety disorders, depression, Attention-deficit/hyperactivity disorder, conduct disorder, oppositional defiant disorder, substance abuse and schizophrenia (Costello, He, Sampson, Kessler, & Merikangas, 2014; Stewart, Kam, & Baiden, 2014; Waddell, Hua, & Shepherd, 2002). Psychiatric disorders can persist throughout life (Carey & Carey, 1999; Kessler et al., 2012). However, treatment can help manage the difficulties associated with the disorder (Weisz, Jensen-Doss, & Hawley, 2006; World Health Organization, 2016a). Youths with psychiatric disorders need attention and support from caregivers to help them manage their symptoms. However, youths with severe symptoms require care in a specialized hospital unit despite the care and support they receive from caregivers.

**Symptoms, Admission, Treatment and Prior or no Prior Admission**

**Symptoms.** Symptoms associated with psychiatric disorders among youths include the following: extreme fears or worries, feelings of guilt, mood changes, withdrawal from friends and activities, sleeping problems, delusions or paranoia, coping problems, and harm to self or others. For example, affective disorders can be characterized by a negative change in mood (with or without associated anxiety), which can be accompanied by a reduction in activity level and symptoms specific to the context of the activity (World Health Organization, 2016b). Depressive disorders can be characterized by symptoms such as sadness and cognitive changes that significantly affect a person’s capacity to function (APA, 2013b). Anxiety disorders such as generalized anxiety disorder can be characterized by excessive fear and anxiety (APA, 2013c).
**Referral and admission.** Psychiatric inpatient hospitalization is indicated when the patient is at imminent risk to self or others or the illness requires stabilization and intensive care (Hanssen-Bauer et al., 2011; Pfeiffer & Strzelecki, 1990). Despite costly treatments and logistical concerns associated with inpatient psychiatric care (Marshall, Crowther, Sledge, Rathbone, & Soares-Weiser, 2011; Torio, Encinosa, Berdahl, Mccormick, & Simpson, 2015), it appears to be an effective option (Barwick & Boydell, 2005; Greenham & Persi, 2014; James et al., 2010).

Youth admitted to an inpatient psychiatric hospital setting can be referred from a primary health care setting or some other psychiatric emergency service (Breslow, Erickson, & Cavanaugh, 2000). For instance, Greenham and Persi (2014) found that almost half of youth patient admissions were based on crises cases and involuntary admissions for psychiatric assessment or treatment. In addition, they reported that more older youth than preadolescent youth were admitted to inpatient psychiatric units. Moreover, most of the patient admissions were not planned, which suggests that patients had to leave school in the middle of the school semester or year to seek treatment, and they had difficulties returning (Preyde, Parekh, Warne, & Heintzman, 2017). Hence, the abrupt change in school attendance and participation can create some difficulty for those affected and their families.

With regard to psychiatric disorders and hospitalization, Gandhi et al. (2016) reported that affective disorders were the most common reasons for psychiatric hospitalizations, while anxiety disorders were the primary reasons for emergency department visits. Psychosis was also commonly reported for inpatient youth admissions in Ontario from 2009 to 2010 (Greenham & Persi, 2014).
**Treatment.** Psychiatric inpatient hospital care can include assessment, stabilization of symptoms (Greenham & Persi, 2014; Sharfstein, 2009), mental health education, treatment, recovery, and overall care of psychiatric disorders (Tharayil, James, Morgan, & Freeman, 2012; Thatte, Makinen, Nguyen, Hill, & Flament, 2013). The average length of stay (LOS) in Ontario has been reported to range from seven days to 22 days (Greenham & Persi, 2014; Preyde et al., 2017; Stewart et al., 2014). However, factors that can lengthen stay include the severity of diagnosis (e.g., severe symptoms associated with schizophrenia, mood disorders, eating disorders, and intellectual disabilities), gender (specifically boys) and an increase in the age of patient (Stewart et al., 2014).

**Prior or no prior admission among youth.** Psychiatric hospital readmission occurs when youths have been treated, discharged, and admitted again to a psychiatric hospital unit for further treatment of severe and persistent disorders (Pottick, Hansell, Miller, & Davis, 1999; Trask, Fawley-King, Garland, & Aarons, 2016). Readmission can be associated with age (i.e., older youth), race, length of index hospitalization, untimely access and use of post discharge services, a short LOS at first admission, higher risk scores and longer LOS owing to severity during the first admission to a psychiatric unit (James et al., 2010; Pavkov, Goerge, & Lee, 1997; Yampolskaya, Mowery, & Dollard, 2013). Cheng at al. (2017) found that 96.1% of children and youths reported psychiatric hospitalization in the 90 days prior to hospitalization. James et al. (2010) also reported that 43% of children and youths experienced psychiatric rehospitalizations over a 30-month follow-up period, and these findings suggest that hospitalized youth require frequent crises stabilization.

Investigators have found that frequent admission of individuals to psychiatric hospitals can be costly for both families and societies (Bodden, Dirksen, & Bögels, 2008). Furthermore,
caregivers of psychiatric patients can be burdened with fear of recurring symptoms, insufficient support from professionals and feeling of loss of relationships with the patient (Jungbauer & Angermeyer, 2002). Presently, it is uncertain whether burden among caregivers differs between families with youth with or without prior admission to psychiatric hospitals. Therefore, an exploration of prior or no prior youth hospitalization on burden among caregivers may provide empirical support for the different resources that families with different situation may need.

**Family Circumstances and Setting**

Caring for youth with psychiatric disorders can be challenging (Saunders, 2003). Such youths require additional attention at home, as well as specialized mental health care (Meltzer, Ford, Goodman, & Vostanis, 2011). The illness and situation can present some difficulty for family relationships, conflict in the home and psychosocial adjustment of caregivers. Furthermore, families with youths with psychiatric disorders can face challenges coping with the situation (Liu et al., 2007).

Family members can influence each other in ways that place them at risk for additional problems. For instance, Ge, Best, Conger, and Simons (1996) found that parent behaviours (e.g., parental warmth, hostility and disciplinary skills) can be associated with youth psychiatric disorders. Youths with no psychiatric problems had parents who were less hostile, showed warmth, and used disciplinary skills, while parents of youth with psychiatric disorders were more hostile and used fewer disciplinary skills. Furthermore, Hale, Engels, and Meeus (2006) found that youths’ perceptions of negative parent behaviours or experiences were associated with psychiatric symptoms. Additionally, youths’ psychiatric symptoms were linked to parent psychiatric illnesses. For example, the presence of youths’ conduct disorder and major depression were linked to increased rates of maternal major depression and paternal antisocial
behavior, and both conduct disorder and major depression in adolescents were associated with high parent–child conflict (Marmorstein & Iacono, 2004). Thus, it is not surprising that burden levels among caregivers can be high for parents with youth with severe symptoms (Angold et al., 1998). Moreover, similar reports were found for burden among parents with youth with psychiatric disorders who were admitted to a psychiatric hospital unit (Liu et al., 2007). Moreover, caregivers of psychiatric patients, have reported relief and emotional distress related to the hospitalization (Jankovic et al., 2011; Jungbauer & Angermeyer, 2002).

Caregiver burden and perceived parent stress can be linked to a sense of loss in normal everyday life (Ivarsson, Sidenvall, & Carlsson, 2004; Knock, Kline, Schiffman, Maynard, & Reeves, 2011), conflicted relationships (Ivarsson et al, 2004), feeling of sadness (Vaughan et al., 2013), worry, anxiety or guilt (Ivarsson et al., 2004; Liu et al., 2007), lowered sense of competence (Weimand, Hedelin, Sallstrom, & Hall-Lord, 2010; Preyde et al., 2015), and costs associated with care and treatment (Knock, et al., 2011; Weimand, et al., 2010). Furthermore, these demands can reduce family functioning and continue to affect family members unless they adjust to meet demands (Liu et al., 2007). Thus, families caring for youth with psychiatric problems can experience greater burden than families with typical youth (Ronan, Dreer, & Gerhart, 2008).

**Caregivers’ burden.** Caregivers’ burden can be described as the aspects of care that can lead to difficulty with emotional well-being, social situations, and quality of life. It has been defined as the perceived negative impact of caregiving on the primary caregiver (Heru, 2000; Ivarsson et al., 2004). Dimensions of caregiver burden can include both objective and subjective forms, and both can be problematic for caregivers (Reinhard et al., 1994; Thompson & Doll, 1982). Objective burden can be described as the easily observable difficulties and
inconveniences associated with the care of a relative with a clinically diagnosed mental illness (e.g., financial strain/disruptions of everyday routine), while subjective burden (e.g., worry, embarrassment/overload) can be described as the negative feelings experienced and associated with the care of a relative with a clinically diagnosed mental illness. Angold et al. (1998) found that 11% of parents with youth with psychiatric illnesses and impairments experienced at least one form of either objective or subjective burden that was associated with their youth’s psychiatric symptoms. In addition, youth with comorbid psychiatric disorders (Maes, Broekman, Došen, & Nauts, 2003; Waddell et al., 2014) can have additional symptoms that can intensify burden (Angold & Costello, 1995; Waddell et al., 2005).

It has been long established that burden is experienced by those providing care to a family member with severe illness (Etters, Goodall & Harrison, 2008; Grunfeld et al., 2004; Smith Fawzi et al., 2010). Moreover, researchers have shown that a strong relationship exists between severity of psychiatric symptoms and impairment, and burden among caregivers (Angold et al., 1998; Baronet, 1999; Saunders, 2003). With regard to care, it is important to recognize that caregivers with hospitalized youth can experience more burden than caregivers with youth accessing outpatient care (Brannan, Athay, & de Andrade, 2012).

There is limited research on caregivers with youth with severe psychiatric disorders who were hospitalized (Ivarsson, Sidenvall, & Carlsson, 2004; Jungbauer et al., 2003). Also, investigators have focused more on burden of caregivers of adults (Biegel, Milligan, Putnam, & Song, 1994; Cook, Lefley, Pickett, & Cohler, 1994; Dyck, Short, & Vitaliano, 1999; Suro & Weisman de Mamani, 2013), the elderly (Andrén & Elmståhl, 2008; Deimling & Bass, 1986; Shakeel, Rana, & Malik, 2015) and family members who have accessed other mental health services including outpatient services (Accurso et al., 2015) and residential services (Brannan et
al., 2006; Schleider et al., 2015) than youths who were admitted to an inpatient psychiatric hospital unit. Moreover, experiences of caregivers with children hospitalized for physical illness or cancer, and PDD (e.g., autism) have been documented but remain limited for severe psychiatric illness (James et al., 2002).

The available literature on caregivers’ perspectives has shown that burden continues to affect parents, and there is need for additional support and services (Blizzard et al., 2016; Patel, Flisher, Hetrick, & McGorry, 2007). Caregivers felt that they were able to manage psychiatric symptoms better if they had more support (e.g., knowledge on behaviour management strategies, improved caregiver and youth relationships, emotional support, and increased access to services for their youths). Given the pivotal role that parents play with the care of developing youths, there is a need to further explore burden among caregivers in Ontario.

**Perceived stress.** Stress can be experienced when individuals perceive a situation as taxing and beyond their adaptive capacity (Cohen, Janicki-Deverts, & Miller, 2007; Cohen, Kessler, & Underwood, 1995). Individuals can attempt to manage stress by coping, which is defined as the person's shifting cognitive and behavioral efforts to manage specific inward and outward demands that are assessed as taxing or exceeding the person's resources (Lazarus & Folkman, 1984).

Investigators have found that youths’ psychiatric disorders can be difficult to manage and caregivers experience stress (Baker and Heller, 1996; Farmer, Burns, Angold, & Costello, 1997; Vaughan et al., 2013). Moreover, extensive research has been documented on parent stress among caregivers with youths with illnesses such as autism spectrum disorder and attention-deficit/hyperactivity disorder (Estes et al., 2013; Hayes & Watson, 2013; Theule, Wiener, Tannock, & Jenkins, 2013; Walsh, Mulder, & Tudor, 2013), and other chronic illnesses (Cousino
& Hazen, 2013) than parent stress among caregivers with hospitalized youths. A recent study on parent stress among caregivers with youth with severe psychiatric disorders (Perez Algorta et al., 2017) focused on caregivers with youth with bipolar spectrum disorders (BPSD). The researchers reported that a higher youth IQ, mania, anxiety, and disruptive behaviours, and caregiver depression predicted increased parenting stress. However, no relationship between parent stress and caregiver burden was examined.

Researchers have shown that reduced parent stress and increased parent support can result in improved youths’ psychiatric symptoms and caregivers’ positive well-being. For instance, a parent empowerment program for hospitalized youths and their caregivers (Melnyk et al., 2004) resulted in fewer youths’ psychosocial problems and maternal stress, and improved parent involvement in care. While these findings support research on parent stress among youths hospitalized for seizures, accident trauma, and other medical conditions, it showed that both parents and youth can benefit from reduced parental stress.

Similarly, Vaughan et al. (2013) found that caregivers with youth with both internalizing and externalizing symptoms reported the highest rates of strain (objective strain, subjective internalized and subjective externalized strain) and parent stress than caregivers with youth reporting symptoms in only one domain and no clinically significant symptoms. Although this study and others have provided insights on parent stress and other significant challenges (Blader, 2004, 2006), it might be helpful to explore the relative contribution of perceived stress to caregiver burden because parent stress and caregiver burden both increase with the severity of youth psychiatric symptoms. This evidence may support more comprehensive investigations on caregivers who may experience both stress and burden.
School-related difficulties. Youth with psychiatric disorders and other comorbid disorders can experience school related-difficulties (Daniel et al., 2006; Trout, Hagaman, Casey, Reid, & Epstein, 2008). Psychiatric symptoms lead to general and school related-difficulties that can worsen psychiatric problems (Hinshaw, 1992; Preyde et al., 2017). For instance, Carroll, Maughan, Goodman, and Meltzer (2005) found that school-related problems can place anxious youth at risk for clinically significant anxiety. Additionally, it has been reported that psychiatric symptoms can be linked to reductions in teacher involvement in academic and school activities (Arnold, 1997). Teachers try to avoid demanding situations with students, and when this happens youth have limited guidance on academic work and school activities. School-related problems can include general academic difficulty with literacy, behaviour problems and social problems in the context of peer relations (Carroll et al., 2005; Lane, Barton-Arwood, Nelson, & Wehby, 2008; Stormshak, Bierman, Bruschi, Dodge, Coie, & the Conduct Problems Prevention Research Group, 1999).

It has been found that the relationship between psychiatric symptoms and academic difficulties can increase with age (Arnold, 1997; Arnold, et al, 2005). Furthermore, extended periods or repeated short-term periods of psychiatric hospital stay can interfere with school work and social adjustments (Blizzard et al., 2016). Specifically, youth admitted to a psychiatric hospital unit can experience additional school related problems and concerns about the transition from the hospital to the community (i.e., home and particularly school) (Preyde et al., 2017). For example, stigma from school staff and peers (Moses, 2010), and youths’ perceptions about their condition and discontinued use of mental health out-patient services can negatively affect the transition back to school. Also, youths can be concerned with the impact of their psychiatric problems on their academic progress and their management of social interactions with peers and
teachers. This situation can be stressful for youths especially when they are returning to school (Preyde et al., 2017; Savina, Simon, & Lester, 2014; Weiss et al., 2015). Taken together, problems associated with youths’ psychiatric symptoms are not limited to the home environment.

**School refusal behaviour among youth.** School refusal can be described as refusal to attend school, intentional avoidance of school or difficulty attending school, and can include truancy, school phobia and anxiety (Heyne, 2011; Kearney & Albano, 2004; Maric, Heyne, MacKinnon, Van Widenfelt, & Westenberg, 2013). It has been reported that function is a better determinant of severity of school refusal than form (Kearney, 2007). The four main functions of school refusal behavior include avoidance of stimuli that provokes negative emotions, escape from challenging or demanding situations, attention seeking, and actions based on tangible reinforcements (Kearney, 2002).

Youths’ school refusal has been linked to some mental health problems, avoidant coping, and school performance (Egger et al., 2003; Kearney, 2007; Knollman, Knoll, Reissner, Metzelaars, & Hebebrand, 2010). School refusal is common among youth with psychiatric disorders (Last & Strauss, 1990; Kearney, 2008; Kearney & Silverman, 1990; Knollman et al., 2010), especially for hospitalized youths (Borchardt, Giesler, & Bernstein, 1994).

Hospitalization has been linked to school related difficulties (Daniel et al., 2006; Kearney & Albano, 2004) and anxiety, which youths must manage when they return to school (Simon & Savina, 2010). For instance, Simon and Savina (2005) found that therapists felt that youths were anxious when they returned to school and were likely to show disruptive behaviour. These difficulties may intensify school refusal behaviour for youth who struggle to cope. Moreover, Clemens, Welfare, and Williams (2010) found that parents felt their children avoided school because they were anxious about returning after a period of hospitalization. Parents were also
concerned about youths’ adjustments and explanations to friends about their condition, and why they were away from school. The evidence outlined here suggests that school related difficulties, specifically school refusal behaviour can lead to worry and anxiety, and intensify pre-existing difficulties for both caregivers and youths.

**Family history of mental illness.** Family history of mental health problems can have considerable implications for youth (Downey & Coyne, 1990; Weissman et al., 1984; Loon, Ven, Doesum, Witteman, & Hosman, 2014). In this study, a family history of mental illness referred to family members with a mental illness who was living in the family home or who had lived in the family home and excluding the focal youth who received psychiatric treatment. There is substantial evidence to show that youth exposed to issues associated with family history of mental illness, such as negative parent behaviours and thoughts and disruptive family situations can be a risk for psychiatric disorders (Murray & Farrington, 2010; Rasic, Hajek, Alda, & Uher, 2014; Stallard, Neorman, Huline-Dickens, Salter, & Cribb, 2004). Investigators have found that a family history of psychiatric symptoms is a greater risk factor for psychiatric symptoms in young people than socioeconomic factors (Agerbo et al., 2002). Additionally, parents with mental illnesses have reported burden and an increase in parental stress by parenthood (i.e., challenges meeting the demands of parenting responsibilities), while youth with parents who have mental illnesses have reported stress (Koelch, Schmid, & Fegert, 2009; Pölkki, Ervast, & Huupponen, 2005; Nicholson, Sweeney, & Geller, 1998). Moreover, it should be noted that parents may misinterpret normal everyday parenting stressors because of the burden of their mental illnesses. These findings suggest that a family history of mental health illness can be a critical factor affecting both the developing youth and the caregiver profoundly. Thus, an exploration of group differences in caregivers’ burden, perceived parental stress, youths’ psychiatric symptoms and
youths’ school refusal behaviour on families with youths with or without mental illness, may provide further information about families. The study may explain caregiving situations better and highlight family differences, if any exist.

**Current Study**

The need to focus attention on caregivers with youths with psychiatric disorders has been recognized (Government of Canada, 2006; Kirby & Keon, 2006; World Health Organization (WHO), 2005). Some challenging family factors (e.g., parent psychopathology) associated with youths’ psychiatric symptoms can negatively impact youths, potentially increase caregivers’ burden and stress, and decrease family functioning. One way to possibly improve families’ situations is to first understand the relationships that exist among some of these factors.

To date, caregivers’ burden and perceived parental stress have been positively associated with severe youths’ psychiatric symptoms (Angold et al., 1998; Vaughan et al., 2013). Specifically, youths’ psychiatric hospitalizations have been associated with burden, stress, family history of mental illness, severe psychiatric symptoms and prior youths’ psychiatric admission (Agerbo et al., 2002; Blader, 2004; Farmer et al., 1997). Additionally, caregivers and professionals have reported challenges with adjustments during the transition of youths from the hospital and returning to their homes and schools (Blizzard et al., 2016; Clemens et al., 2010; Clemens, Welfare, & Williams, 2011; Simon, & Lester, 2014), which may lead to further burden among families.

However, what is unclear is the relative contribution of perceived parental stress and youths’ psychiatric symptoms to caregivers’ burden. In addition, knowledge about group differences in family history of mental health illness and youths’ prior psychiatric hospitalization on caregiver burden, perceived stress, youths’ psychiatric symptoms and school refusal is limited.
for Canadian families. Finally, there is a dearth of knowledge about caregivers’ perspectives on care of youths who were admitted to psychiatric hospitals, which may be addressed with this study.

**Purpose of the Study**

The purpose of this exploratory study was to characterize caregivers’ experiences such as burden and stress when youths were hospitalized for severe psychiatric illness. Also, youths’ psychiatric symptoms and youths’ school refusal, family or no family history of mental health illness, and prior or no prior youths’ psychiatric hospitalization were explored. This study was based on survey research on caregivers’ perceptions that were gathered in a larger study (Preyde et al., 2017) on school-related difficulties among youths who were admitted to an inpatient psychiatric hospital unit for treatment of psychiatric illnesses.

**Research Questions**

1. What are the psychosocial characteristics of caregivers with youths hospitalized for psychiatric care?
2. (a) What are the associations between youths’ psychiatric symptoms and parental perceived stress with caregivers’ objective burden?
   (b) What are the associations between youths’ psychiatric symptoms and parental perceived stress with caregivers’ subjective burden?
3. (a) What differences exist between families with youths with and without a family history of mental illness, regarding subjective and objective caregivers’ burden, perceived stress, youths’ psychiatric symptoms and youths’ school refusal behaviour?
(b) What differences exist between families with youths with and without prior hospitalization, regarding subjective and objective caregivers’ burden, perceived stress, youths’ psychiatric symptoms and youths’ school refusal behaviour?

4. What are caregivers’ perceptions of their experiences caring for youths who were hospitalized for psychiatric illness?

**Chapter Two: Methods**

**Participants**

Participants were 24 primary caregivers with youths with severe psychiatric disorders, who were admitted to a Child and Adolescent In-Patient (CAIP) Unit at a regional hospital, in Ontario Canada. Five of the 24 participants completed an online version of the survey; and the remainder completed telephone interviews. Caregivers were excluded if the youths had an unstable psychiatric condition, intellectual disability or pervasive developmental disability. For youths 14 years old or older, caregivers were also excluded if the youths did not consent for researchers to contact the caregiver.

**Procedures**

Ethics clearance was approved by the Research Ethics Boards of Grand River Hospital and the University of Guelph. From October 2015 to March 2016 all children and adolescents who were admitted to the child and adolescent in-patient psychiatric (CAIP) unit were invited to participate in the larger study while they were in the hospital, and parents were also invited to complete a survey.

For youths less than 14 years of age, on the caregivers’ first visit the Nursing staff informed them that a study on characteristics of youth accessing CAIP was in progress, the caregivers were given an informational sheet, and asked if they would like to speak with a
research assistant (RA) to learn more about the study. For those who agreed, the RA was given information to contact the caregivers about the study. The RA requested informed consent for their child to participate in the study, and obtained child assent. The RA also asked parents if they would like to participate in a survey.

For youths 14 years of age and older, patients with the capacity to consent were informed by Nursing staff about the study and were asked by staff if they could give their first name to an RA to learn more about the study. For youths who agreed to speak with a RA, staff gave the RA the first names and locations of youths. The RA fully described the study, obtained informed consent, and asked consent for the RA to contact their parent, caregiver or guardian to complete a survey on the parents’ characteristics and family environment (this survey was to be completed by a caregiver living or previously living in same household, not a guardian/representative of the Children’s Aid Society). For those who agreed, the RA contacted the caregiver by phone, fully described the study and requested informed consent for their participation. For those who provided informed consent, the RA administered a semi-structured, paper-and-pencil questionnaire over the phone to the caregiver.

Clinical data were provided by the chief psychiatrist working with youths. To maintain confidentiality, two tracking systems were used. The nurses maintained one record of all youths and recorded reasons for exclusion and whether consent to refer to an RA was granted. The RA tracked only youths for whom consent to hear more about the study was obtained. The RA then recorded whether informed consent (or child assent) was granted. The surveys were coded, and the code transcribed onto the clinical form so that the surveys and clinical information could later be linked without any identifying information. The RA temporarily knew the name of the patient
to indicate to the psychiatrist for which patient the form was to be completed and the psychiatrist destroyed the note that included the name and returned the anonymous clinical forms to the RA.

**Setting**

The CAIP is a 13-bed, unit for youths 6 to 18 years of age. Youths in crisis situations are often referred to the unit through emergency services. The 24-hour unit includes a team of nurses, psychiatrists, teachers, social workers, child and youth workers and psychologists for the treatment of patients. During admission, youths also receive support and engage in activities that promote education and communication. Youths admitted to the CAIP Unit have an average LOS of about one week (Preyde et al., 2017). CAIP provides crisis stabilization and treatment to youths who have been admitted to the unit. Primary caregivers often visit CAIP the day after admission to see the patient’s social worker, provide intake information and receive counselling.

**Measures**

Demographic information such as age and ethnicity were gathered, as well as information on family history of mental illness and relationship to the caregiver, and prior admission to a psychiatric hospital. Questions on family mental illness included the following questions: “Does anyone else in your family have a mental health illness?,” “If yes, what is the relation to you (e.g., son, daughter, spouse),” and “What type of illness?” A question on first time admission of youths to a psychiatric hospital included the following question: “Is this the first youth admission to a psychiatric hospital unit?”

Caregivers’ qualitative experiences were gathered with specific questions. Parents were asked to report on their experiences caring for youths who had been admitted to a psychiatric hospital unit. The question on caregivers’ experiences was as follows: “Is there anything you want researchers to know about your own experiences as a caregiver?”
Caregivers’ burden. Caregivers’ burden was measured with the Burden Assessment Scale (BAS) (Reinhard, Gubman, Horwitz, & Minsky, 1994). It contained 19 items that captured both objective and subjective 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 behavioural effects of caregiving. An example of an objective item was “Had financial problems.” Subjective burden refers to the emotions, feelings and attitude about experiences of caregiving. An example of a subjective burden item was, “Guilty for causing illness.” Ten items assessed the extent to which primary caregivers experienced objective burden, and nine items measured subjective burden. Caregivers were asked to respond to questions on a 4-point likert scale. Response options ranged 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 (α = 0.89 - 0.91) and valid (Reinhard et al., 1994). A caregiver advisory group of six family members of long-term mentally ill adults reviewed the burden instrument for clarity and completeness of content.

Perceived stress. Perceived stress was measured with the Perceived Stress Scale, 4-item version (Cohen, Kamarck, & Mermelstein, 1983; Cohen & Williamson, 1988). The 4-item scale included questions about feelings and thoughts that reflected chronic stress. Response options ranged from 0 (never) to 4 (very often), with higher scores indicating greater perceived stress. Items included the following: “In the last month, how often have you felt confident about your ability to handle personal problems?” “In the last month, how often have you felt that things were going your way?” “In the last month, how often have you felt that you were unable to control the important things in your life?” The original measure showed internal consistency (α =
0.84 - 0.86) and test-retest reliability (0.85) (Cohen et al., 1983). The 4-item scale has shown acceptable reliability ($\alpha = 0.60$) (Cohen et al., 1988).

**Psychiatric symptoms of youths.** Psychiatric symptoms were measured with the parent-report Pediatric Symptom Checklist (PSC) (Murphy & Jellinek, 1988; Murphy, et al., 1996). The PSC is a screening tool that can be used to recognize cognitive, emotional, and behavioural problems. It consisted of 35 items with response options that range from 0 (Never) to 2 (Often) (Jellinek, 1999). Items reflect caregivers’ views on the psychosocial dysfunction of children and youths between the ages of 4 - 18 years, with higher clinical cut off scores for children 6 years and up. Scale items included: “Feels hopeless,” “seems to be having less fun,” and “Blames others for his or her troubles.” The measure has shown strong internal consistency ($\alpha = 0.91$), test-re-test reliability ($r = .84 - .91$) and validity (Jellinek et al., 1998; Murphy & Jellinek, 1988; Murphy, et al., 1996). Internal consistency on PSC subscales ranged from 0.71 - 0.82 (Borowsky, Mozayeny & Ireland 2003).

**School refusal behaviour.** School refusal was measured with the parent version of the School Refusal Assessment Scale Revised (SRAS) (Kearney, 2002). The SRAS measures functions of school refusal behaviour. 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). Items included: “How often does your child feel worse at school (e.g., scared, nervous, sad) compared to how he/she feels at home with friends?” and “How often does your child stay away from school because he/she does not have many friends there?” 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) (Kearney, 2002).
**Data Analysis**

**Quantitative analysis.** Quantitative data were analyzed using the Statistical Package for Social Sciences (SPSS) version 24 (International Business Machines, 2016). Participants’ characteristics were presented with descriptive statistics and frequencies. Two hierarchical regressions were conducted to explore associations between perceived stress and psychiatric symptoms with burden, while controlling for youths’ gender and age. One regression was conducted to explore associations with objective burden, while the second was conducted to explore associations with subjective burden. The independent variables were youths’ gender and age, psychiatric symptoms, and perceived stress for both regressions. According to Cohen (1992), a sample size of at least 38 is required for a multiple regression analysis with four independent variables with a large effect size and a statistical power of 0.80 ($p = .05$).

A multivariate analysis of variance (MANOVA) was used to explore differences that existed between families with or without a history of mental illness, and families with youths with or without prior psychiatric hospital admissions on caregivers’ burden, perceived stress, youths’ psychiatric symptoms and youths’ school refusal behaviour. A power analysis was conducted in G*Power 3.1.9.2 (Faul, Erdfelder, Buchner, & Lang, 2009), and the results revealed that the power to detect a statistical significance was below 0.80.

**Qualitative analysis.** Qualitative responses were transcribed verbatim by two trained research assistants, and one interview was transcribed by a graduate candidate (AO). NVIVO 11® Pro qualitative analysis software (QSR International, 2015) was used to organize themes. A conventional content analysis (Hsieh & Shannon, 2005) was conducted to explore caregivers’ experiences while caring for youths who were admitted to an inpatient psychiatric hospital unit. The aim of the conventional approach was to describe the phenomenon under study.
After transcripts were uploaded into NVIVO, in keeping with the conventional form of content analysis, the researchers coded directly from the text without any preconceived information from literature or theory (Hsieh & Shannon, 2005). Intercoder agreement was above 70%. However, discussions led to 100% agreement. Researchers independently read the full transcripts to get a sense of the whole. They then read the texts to derive codes by highlighting exact words and sentences that appeared to capture key concepts or thoughts. The next step was to identify labels for codes that emerged and reflected more than one key concept or thought to gain an initial coding scheme. Codes were sorted into categories and emergent categories were used to organize and group codes into meaningful clusters. Themes emerged immediately and were labeled based on broad ideas for that category. No predetermined categories were used to guide the analysis. Inductive open coding (Creswell, 2007) was used to categorize the texts. After open coding of all responses, themes were examined and modified to merge themes if needed, identify subthemes and delete redundant coding. Notes gathered during the reading of the whole text and open coding process assisted in modifying the final themes and subthemes. As an example, the researchers reviewed the key thoughts or words that reflected the themes and how themes differed from each another. To ensure clarity, the text was re-read several times to establish appropriateness of labels for categories. Consistent with the conventional approach, references to theory and past research were reserved for the Discussion chapter, while explicit examples were provided within the Results chapter.

A rich and thick description, peer debriefing, reflexivity, and triangulation were used to verify findings (Creswell, 1998). In this study, detailed accounts of the analytical process, examples of themes and a rich description of the phenomenon under study were provided. Debriefing occurred with an experienced researcher, a professor in the field of mental health who
did not conduct interviews, transcribe interviews or analyze data. The process led to the identification of hidden biases, uncovered other perspectives and made the researcher aware of the overall attitude towards data and the research study. Additionally, the comparison of independent analysis by two researchers strengthened the identification of key themes and overall description of the phenomenon under study. Discrepancies were reconciled, and labels were modified accordingly. Reflexivity was an essential element of rigour in this study.

Reflexivity is a systematic approach to the context of knowledge construction, which may clarify researcher bias if any. For example, notes were written concerning the nature of the sample and study context, the choice of analysis for both the quantitative and qualitative section, and the analytical process. Thus, references were made to the written notes throughout the study process.

In the discussion, a similar approach was used when prior research and theory were discussed (i.e., notes served as a guide for comparison of results). Reflexivity encouraged dialogue, which provided further guidance for researchers about the phenomenon under study. Additionally, it led to clarity of subjective opinions about participants and possible influences researches might have on the study. Finally, triangulation served as a form of trustworthiness by prompting reliance on multiple investigative approaches and analyst triangulation used in qualitative section of this study. In this exploratory study, triangulation was used to shed light on caregivers’ burden and offer a deeper understanding of burden among caregivers.

Study participants formed part of a convenience sample of caregivers with youths with severe psychiatric disorders who were hospitalized. Caregivers can be a hard to reach population and the area of study has been shown to be sensitive. Although the sample size in this study may limit generalization, it was the best suitable option for a study of this nature. Saturation of themes
was reached when no additional information (i.e., no new theme) was gathered from the data and when themes appeared to be redundant (Walker, 2012).

Chapter Three: Results

Characteristics of Caregivers

The study consisted of 24 caregivers and ages ranged from 34 to 69 years ($M = 46.65$, $SD = 8.45$) (see Table 1). The majority of the caregivers were females ($n = 22$; 91.7%) and 19 were biological mothers. Twenty-one (87.50%) of the caregivers reported that they were Caucasian. The caregivers reported incomes that ranged from $9,000 to $150,000 ($M = $83,521.74, $SD = 42,748.59$). Regarding their relationship status, 14 caregivers reported being in a couple relationship, nine caregivers reported not being in a couple relationship, and one caregiver did not report his/her relationship status. For 12 (50%) participants, college education was reported as their highest level of education. Focusing on mental health, more than 50% of caregivers 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. Also, the small standard deviation associated with the mean burden score suggested that individual mean scores were close to the mean burden score. The mean for objective burden in this sample was 28.79 ($SD = 7.65$), while subjective burden was 22.92 ($SD = 7.52$). The perceived stress mean score was 9.63 ($SD = 1.86$) and scores ranged from six to 12. The perceived stress measure is not a diagnostic instrument, so there was no cut-off score to consider and greater numbers indicated greater perceived stress.

Characteristics of youths. For the 24 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 LOS in CAIP was 7.13 days ($SD = 3.79$ days), and major depressive disorder (MDD) was
the most common primary diagnosis. Also, the youths’ mean scores were considerably high on the 35-item PSC measure ($M = 68.17$, $SD = 11.15$), clustered around the mean, and above the reported cut off score of 28. (28 or above was an indication of impairment, and 27 or below indicated that youths were not impaired). Frequency distributions revealed that 87.5% ($n = 23$) scored positive on the PSC measure. Furthermore, PSC subscale means suggested that youths in this study rated high on psychosocial impairment (see Table 2). The majority of youths’ mean scores were above the cut-off points of seven, five, and seven for attention problems (AP), internalizing problems (IP), and externalizing problems (EP). Additionally, 91.7% ($n = 22$) of youths scored positive for AP, while 100% ($N = 24$) scored positive for IP and EP. Fifty percent of the caregivers reported considerable subjective improvements in their youths’ psychiatric condition. 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).

**Objective Burden**

A hierarchical multiple regression analysis was computed on objective caregivers’ burden with two independent variables, youths’ psychiatric symptoms and perceived stress, while controlling for youths’ gender and age. Assumptions were tested and met. There was no multicollinearity as none of the predictor variables highly correlated above 0.80 (Field, 2013). The variance inflation factor (VIF) values were below 10 and tolerance values above .2, which both fall within acceptable ranges (Field, 2013). Thus, the assumption of multicollinearity was met (Youths’ Age: Tolerance = 0.70, VIF = 1.42; Youths’ Gender: Tolerance = 0.97, VIF = 1.03; PSC score: Tolerance = 0.99, VIF =1.01; PSS score: Tolerance = 0.71, VIF = 1.41. The Shapiro-
Wilk’s test confirmed normality of distribution for the dependent variable (objective caregiver burden, $p = .91$). Also, a histogram and a P-P plot of standardized residuals indicated that the data met the assumption of normally distributed errors. The Durbin-Watson test indicated that the assumption of independent errors was met with a value of 2.311. Additionally, a scatter plot of standardized residuals indicated that the data met the assumptions of homogeneity of variance and linearity. The acceptable ranges for minimum and maximum values for standard residuals were met (Minimum = -2.23, Maximum = 2.44).

In order to control for age and sex, these variables were entered into the model in the first stage. Perceived stress score (PSS) and youths’ psychiatric symptoms score (PSC) were entered in the second stage. The correlation matrix of caregivers’ objective burden and stress and psychiatric symptoms appears in Table 3. The results of this analysis revealed that 5.7% of the variance was explained by age and sex ($R^2 = .057, F(2,21) = 0.640, p = .537$). With the addition of youths’ psychiatric symptoms and perceived stress in the model, there was an increase of 14.4%; thus 20.1% of variance was explained ($R^2 = .201, F(4,19) = 1.198, p = .34$). The standardized beta-coefficients revealed that age, gender, psychiatric symptoms, and perceived stress were not significantly associated with objective burden (see Table 4).

**Subjective Burden**

A second hierarchical multiple regression was conducted to explore relationships between psychiatric symptoms and perceived stress with subjective caregiver burden, while controlling for youths’ gender and age. Assumptions were tested and met. Specifically, the Shapiro-Wilk’s test confirmed normal distribution of the dependent variable (Subjective caregivers’ burden, $p = .32$). VIF values were below 10 and tolerance values above 0.1, which met the assumption of multicollinearity (Youths’ age: Tolerance = 0.70, VIF = 1.42; youths’
gender: Tolerance = 0.97, VIF = 1.03; youths’ psychiatric symptoms: Tolerance = 0.99, VIF = 1.01; perceived stress, Tolerance = 0.71, VIF = 1.41 (Field, 2013). Perceived stress was moderately correlated with youths’ age ($r = 0.54$). Additionally, all predictors had low correlations with the outcome variable, and youths’ age was inversely correlated with the dependent variable. For the assumption of independent errors, the Durbin-Watson test indicated that this was met with a value of 1.965. Also, a histogram and a P-P plot of standardized residuals indicated that the data met the assumption of normally distributed errors. Additionally, a scatterplot of standardized residuals indicated that the data met the assumptions of homogeneity of variance and linearity, and the minimum and maximum values for standard residuals were acceptable (minimum = -1.62; maximum = 2.61). The correlation matrix of caregivers’ subjective burden and stress and psychiatric symptoms appears in Table 5. The results revealed that 7.9% of the variance was explained by youths’ age and gender ($R^2 = .079$, $F(2,21) = .903$, $p = .420$). With the addition of youths’ psychiatric symptoms and perceived stress, there was an increase of 3.3%; thus 11.2% of the variance in subjective burden was explained ($R^2 = .112$, $F(4,19) = .597$, $p = .67$). Beta-coefficients appear in Table 6, indicating non-significant results.

**Family History of Mental Illness**

An exploration of the assumptions for the multivariate analysis of variance (MANOVA) revealed that univariate normality was met. Univariate normality was assessed as a necessary condition for multivariate normality. The Shapiro-Wilk’s test confirmed normality ($p > .05$) for the dependent variables objective and subjective burden, and youths’ psychiatric symptoms (see Table 8). Small departures from normality were observed for school refusal ($p = .05$) and perceived stress ($p = .04$). However, some multivariate tests (e.g., Pillia’s trace) are quite robust
to and not significantly influenced by the assumption of normality, and in cases where group sizes are unequal, results are interpreted with caution. There was no multicollinearity as none of the predictor variables were highly correlated above .80 (Field, 2013). Also, all correlations were low, excluding the moderate correlation of perceived stress with youths’ age ($r = .54$). Results for the Levene’s test of equality of variances was met for the Manova’s (objective caregivers’ burden: $F(1, 22) = 1.036, p = 0.32$; subjective caregivers’ burden: $F(1, 22) = .008, p = 0.93$; youths’ psychiatric symptoms: $F(1, 22) = 1.18, p = 0.29$; perceived stress: $F(1, 22) = .000, p = 1.00$ and youths’ school refusal: $F(1, 22) = 1.41, p = 0.25$). The assumption of independence of observations was met, and residuals were statistically independent. Based on the assumptions met, the MANOVA was deemed suitable for the analysis. Of the 24 caregivers, 16 (66.7%) reported a family history of mental illness and 8 (33.3%) reported no family history of mental illness. There were no statistically significant differences between the two groups on caregiver burden, perceived stress, youths’ psychiatric symptoms or school refusal (Table 7).

Prior Admission to a Psychiatric Hospital Unit

An exploration of the assumptions for the MANOVA revealed that univariate normality was met, as part of a condition for multivariate normality. The Shapiro-Wilk test (Table 8) confirmed normality for objective burden, subjective burden and psychiatric symptoms, and the assumption of homogeneity of variance was satisfied ($p > .05$). Results for the Levene’s test of equality of variances was met for the Manova’s (objective caregivers’ burden: $F(1, 22) = 2.958, p = .10$; subjective caregivers’ burden: $F(1, 22) = 3.014, p = .10$; youths’ school refusal: $F(1, 22) = 298, p = .59$; youths’ psychiatric symptoms: $F(1, 22) = 3.619, p = .07$ and perceived stress: $F(1,22) = .191, p = .67$). The Box’s M results revealed that the assumption was violated for the first test ($p = .019$). However, Box’s M results for the second test was non-significant ($p = .169$),
which confirmed homogeneity of covariance matrices of the dependent variables across the levels of prior admission to a psychiatric hospital. Of the 24 caregivers 19 (79.2%) reported a prior admission of their child to a psychiatric hospital unit and 5 (20.8%) reported no prior admission. There were no statistically significant differences between families with youths with or without prior admission to a psychiatric hospital unit on objective and subjective caregivers’ burden, youths’ psychiatric symptoms and school refusal, and perceived stress (Table 9).

Themes: Caregivers’ Experiences

There were 24 caregivers in this study, and 14 of these caregivers shared their experiences in response to the question “Is there anything that you want researchers to know about your own experiences as a caregiver?” Three key themes were identified in the conventional content analysis: (1) services and support, (2) financial concerns, and (3) adjustment and coping.

Theme 1: Services and support. The most prominent theme included views on services and support for caregivers and youths. Descriptions included comments on services that were utilized and the quality of these services. Subthemes for services and support 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 = 2) expressed both satisfaction and concern about their use of services.

Concerns about 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 made the process 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)

Satisfaction and positive attitudes towards services. 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:

“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 and support. The third subtheme included comments from caregivers (n = 6) with suggestions for improvement of services and support:
“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)

**Theme 2: Financial situation/concerns (n = 4).** Caregivers described financial concerns, which 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)

**Theme 3: Adjustment and coping (n = 3).** One caregiver described a frustrated situation with signs of uncertainty, but it was not clear whether the concerned situation was related to the family’s situation, caregiving, or the youth’s condition. Another caregiver expressed concern for a different child whom she described as problematic (i.e., family member) and who was not doing well in comparison to the focal child. The caregiver was more concerned about the other sibling for whom data were not collected than the primary youth. Also, the caregiver described a personal experience, which suggested that she may have had some mental health problems of her own though the specific illness was not stated. However, the caregiver was hopeful her child was in a better position than she was in her adolescent years. Lastly, one caregiver showed frustration with the situation and a perceived lack of control over her child’s treatment choices and commitment. It appeared that efforts to encourage the child to seek professional help had been futile:

“I’m being told that I’m doing above and beyond (yeah), and I still don’t feel like I’m (okay), uh I feel like I’m missing something.” (#125)
“Uhh, but see 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. Like that’s worse than what [name of youth] has ever done… [name of youth] honestly doesn’t really give me the problems, that I get from [name of youth’s sister], like not even half the problems. I mean I went through a teenage depression too (Mhmm). You know, a lot worse than what [name of youth] did…one thing to note was that [name of youth] probably did better than what I did. I always wore black, I had a hard time leaving my room, not that I ever tried to kill myself or anything like that…or did drugs. I just couldn’t leave my room and I wouldn’t wear anything but black and didn’t understand anything that was going on.” (#127)

“… kids getting into the drugs early. I mean when we tried to stop it and everything, you know, I think that affects, you know, their thinking ability, right? …I would do something, I would do, but, uhm, I can’t make my, I can’t make my, my child go to counselling. I can’t make my child go to school. I can’t make my child do things that, and it frustrates me when, you know, you talk to the doctors and they’re like ‘Well, you have to have…and it’s like ‘He’s 16! He’s not making any other good choices…How do you think he’s going to make them now?’” (#47)

**Chapter Four: Discussion**

The aim of the current study was to explore burden among caregivers with youths hospitalized for psychiatric care. Both quantitative and qualitative results suggested that caregivers experienced burden and stress with their situations. However, none of the quantitative analysis were statistically significant. Caregivers were particularly concerned about the quality of mental health services, professional support for their families, and youths’ access to treatment.
Characteristics of Caregivers and Youths

The present results are consistent with past research reporting that the majority of caregivers with hospitalized youths were biological parents, primarily female and Caucasian (Biegel et al., 1994; Blader, 2007; Blizzard et al., 2016; Bryson & Akin, 2015), and that more females than male youths experience the illnesses for which referral to inpatient psychiatry is needed (Kessler et al., 2012; WHO, 2002). Internalizing disorders, specifically mood disorders were the most frequently reported diagnosis for hospitalized youths, similar to prior reports on youths outside (Blader, 2004; Cheng, et al., 2017) and in Ontario (Stewart et al., 2014).

The identification of psychosocial impairments on all three subscales (i.e., attention problems, internalizing problems and externalizing problems) for the majority of hospitalized youths in this study alluded to the burden and difficulties caregivers experience while managing youths’ symptoms (Blizzard et al., 2016; Rockhill et al., 2013). While there was no statistically significant difference in burden scores ($t = 1.03, p = 0.30$; Murdoch, Rahman, Barsky, Maunula, & Cawthorpe, 2014) with an adult sample, the caregivers in the present study reported significantly higher stress than a normative sample of adults ($t = 8.4889, p = 0.0001$; Cohen & Williamson, 1988). Thus, caregivers’ perceived stress in this study is consistent with prior reports that suggest that certain groups of individuals with greater care demands might lack effective coping strategies and/or sufficient resources to cope with situations (Liu et al., 2007; Thompson & Doll, 1982).

Association of Burden, Family History of Mental Illness and Prior Admission of Youths

No clear relationship was established between youths’ psychiatric symptoms and perceived stress with caregivers’ burden (i.e., objective and subjective burden) through quantitative analyses. There were no differences between families with youths with and without
a family history of mental illness, or families with youth with or without prior psychiatric hospitalization on the characteristics of interest in this study.

**Themes: Caregivers’ Experiences**

Overall, caregivers’ comments emphasized the importance of mental health care and professional support for families. The most prominent theme was related to services and support, including concerns about the quality of mental health services, positive attitudes towards service provision and hospital staff, and suggestions for improvements to mental health care.

Consistent with prior reports (Owens et al., 2002; Weiss et al., 2015), caregivers in this study reported concerns about difficulties navigating the mental health system and identified a specific need for aftercare and transitional services. Caregivers’ views reflect barriers that exist within the primary health care and mental health care systems (Dolan, Fein, & Committee on Pediatric Emergency Medicine, 2011; Greenham & Persi, 2014), which may pose additional structural challenges and intensify family burden.

Caregivers in this study were also concerned about the short term psychiatric treatment youths received. However, CAIP and similar psychiatric units are intended for short stays and crisis management of severe symptoms (Grand River Hospital, 2017; Sharfstein, 2009), and youths should be followed in less intense settings such as outpatient units and aftercare settings to manage symptoms and reduce readmission after discharge.

Caregivers’ reports on the perceived lack of communication with professionals, limited interactions, and lack of clarity about treatment pathways were consistent with prior reports from caregivers of young adults with serious and persistent mental illnesses (Doornbos, 2002). Caregivers also reported feeling left out in the overall treatment process. It can be difficult for
parents to digest all the information that they may be given, and this finding suggests care
providers could improve their communication with caregivers.

Researchers have shown that privacy and confidentiality (Ford, English, & Sigman, 2004) may limit caregivers access to patient information, and conflicted relationships between caregivers and youths (Preyde et al., 2014) can lessen caregivers’ involvement in youths’ treatment and research. For instance, hospital staff must rely on pediatric patients’ maturity and comprehension of treatment and consequences, and exercise discretion even with minors to determine when to involve caregivers (College of Physicians and Surgeons of Ontario; CPSO, 2006). They are only legally required to share personal information with a substitute decision-maker (e.g., when there is risk of harm). Additionally, youths might not consent to researchers and treatment providers contacting their parents (Preyde et al., 2014).

Owen et al. (2002) found that parents’ perceptions of negative experiences with professionals and lack of confidence in support or recommendations contributed to barriers (e.g., poor help seeking behaviours) to mental health care. It should be noted that parents who were overwhelmed by the needs of their children perceived issues that were nonexistent or had the tendency to exaggerate issues (Owen et al., 2002). Therefore, caregivers relying heavily on interactions with professionals, their recommendations and referrals (Shanley, Reid, & Evans, 2008) may have reported additional burden.

It is important to recognize that even if professionals work hard to communicate well (i.e., provide support and assistance) with caregivers, they may experience significant burden that can interfere with how they process or receive information. Moreover, eligibility criteria and proximity of services may prevent caregivers from accessing resources. Caregivers’ views were consistent with findings that indicated that support from mental health professionals can be just
as important as social support from family and friends (Saunders & Byrne, 2002). However, negative perceptions of social support (i.e., lacking from family or professionals) can be associated with emotional and behaviour problems among youths and higher levels of caregivers’ burden (Biegel et al., 1994; Garnefski & Diekstra, 1996). According to Cobb (1976), social support includes information leading individuals to believe that they are cared for and loved, esteemed and valued, and belong to a network of communication and mutual obligation. Moreover, such forms of support, intentional or not, can serve as protective factors in stressful situations by reducing perceived threats (Cohen & Wills, 1985), which suggests that caregivers may benefit greatly from professional and peer support. Furthermore, it has been found that individuals with negative support systems or weak support systems may experience greater consequences associated with their health and wellbeing. Thus, there should be professional consideration for families’ and caregivers’ support networks, with particular attention to weak support systems that might intensify burden and stress.

Irrespective of the available mental health support (The Canadian Standing Senate Committee on Social Affairs, Science and Technology, 2006), caregivers may continue to struggle with access to resources owing to the fragmentation and piecemeal services that underlie mental health care (Davidson, 2011; Mental Health and Addictions Scorecard and Evaluation Framework (MHASEF) Research Team, 2015). Additionally, there is strain on mental health service provision found among the different sectors and disciplines that provide services to families and insufficient number of trained mental health professionals the meet the demands of families (Davidson, 2011; Kutcher & Davidson, 2007).

Amidst the reported concerns, there were consistent reports with prior findings on satisfaction and positive attitudes towards service utilization and professionals (Saunders &
Byrne, 2002). Moreover, Byalin (1993) and Godley, Fiedler, and Funk (1998) found that satisfaction with mental health services was associated with severity of youths’ psychiatric symptoms, and parents who perceived symptoms as severe were less satisfied. In this current study, some caregivers were satisfied and concerned with their experiences with the mental health system. Some positive attitudes were related to the youths’ psychosocial adjustment and others were related to services or professional support. Investigators have shown that caregivers can report concerns as well as satisfaction in different areas of service use and support (Ambikile & Outwater, 2012; Blizzard et al., 2016).

Caregivers in this study shared suggestions for improved services and further support from professionals (e.g., aftercare and transitional support), which were consistent with prior caregivers’ reports (Blizzard et al., 2016). Of particular note was a suggested need for more support specifically from doctors and breaks for caregivers. Reinhard (1994) found that caregivers who received professional support (practical advice) about managing behaviours of patients with severe mentally illness and other caregiving matters reported significantly less objective burden and higher levels of personal control. Caregivers in this study expressed helplessness and frustrations about their situations, which may be managed by imparting a sense of control that is influenced by practical advice from professionals.

Caregivers with youths with serious impairments (Chan, & Sigafoos, 2000) have reported a need for a break. Moreover, a break from care can provide caregivers with time to engage in other personal and daily activities, which can reduce their emotional strain. The focus on support mainly for youths may not necessarily reflect overall caregivers’ needs. In the present study, caregivers were asked to report on experiences on caregiving and not specifically for selected domains (e.g., parenting skills, relationships with youths or emotional support, social support or
respite care). Moreover, one caregiver may have indicated a need for a break; however, it is possible that some caregivers in this study may have felt the need for additional respite support, but did not emphasize such needs.

The second theme identified was related to financial concerns or situations. This finding was consistent with prior reports that indicated that caregivers experienced financial burden and reported limited resources (Kuo, Cohen, Agrawal, Berry, & Casey, 2011). One caregiver indicated that she stayed home to take care of the youth, which may provide additional support to the child but limit financial resources. Moreover, researchers have found an association between youths’ psychiatric symptom severity and caregivers’ participation in paid labour force (Brennan & Brannan, 2005). Youths’ severe psychiatric symptoms were associated with regular school absences, less access to child care, burden related to caregivers missed work and neglect of duties, and fewer work hours. Furthermore, the addition of work–family fit, work flexibility, child care difficulty, and satisfaction with child care for children with emotional and behaviour problems can be related to parental stress (Brennan & Brannan, 2005; Rosenzweig, Brennan, Huffstutter, & Bradley, 2008). It appears that youths’ psychiatric symptoms may place additional burden on caregivers with existing financial problems and work commitments, and families with less child care support may experience additional family disruptions in everyday life. Furthermore, caregivers may be forced to accept less income and less work responsibilities to attain flexibility for child care responsibilities, and this flexibility may also affect family income.

The third theme was related to adjustment and coping. In the present study, caregivers’ views suggested that they had difficulties coping with stressful experiences, which was similar to previous findings on caregivers who reported needing emotional support to address treatment related issues and distress, and caregivers who lacked helpful coping patterns to maintain
functional family life (Blizzard et al., 2016; Liu et al., 2007). Individuals who experience stress can identify threats and assess strategies, which they believe can aid in their ability to cope (Folkman et al., 1986; Lazarus, 1993; Lazarus & Fokman, 1984). However, parents with youths with mental illness have many challenges that can affect adjustment and emotional coping. With regard to caregivers’ coping and social support, investigators have shown that parent support groups in which parents support one another, receive validation, and share mutual experiences can improve parent psychosocial health including stress and certain mental illnesses (Barlow, Smailagic, Huband, Roloff, & Bennett, 2014; Kutash, Duchnowski, Green, & Ferron, 2011). Moreover, providing social support (e.g., emotional support) to other caregivers might be more beneficial to caregivers’ than receiving social support (Brown, Nesse, Vinokur, & Smith, 2003). Given the importance of coping during challenging periods, the addition of professional-led parent support groups may foster caregivers’ provision of support and improvement of coping strategies used in the family context.

The final theme was related to adjustment and coping. In this study, caregivers’ views suggested that they had difficulties coping with stressful experiences, which was similar to findings on (a) caregivers who reported needing emotional support to address treatment related issues and distress and (b) caregivers who lacked helpful coping patterns to maintain functional family life (Blizzard et al., 2016; Liu et al., 2007). Individuals who experience stress can identify threats and assess strategies, which they believe can aid in their ability to cope (Folkman et al., 1986; Lazarus, 1993; Lazarus & Fokman, 1984). However, parents with youths with mental illness have many challenges that may affect the cognitive processes required to target distress. If this situation occurs, caregivers may experience difficulties with adjustment and emotional coping, and may also adopt harmful coping strategies. For example, self-deception may result
from an attempt to maintain hope and remain positive (Lazarus & Folkman, 1984). However, it may lead to denial and distortion of reality, which can be disadvantageous to people.

With regard to caregivers’ coping skills, investigators have shown that some forms of social support, specifically parent support groups in which parents support one another, receive validation, and share mutual experiences can improve parent psychosocial health including stress and certain mental illnesses (Barlow, Smailagic, Huband, Roloff, & Bennett, 2014; Kutash, Duchnowski, Green, & Ferron, 2011). In this case, social support may act as a buffer for stress and reduce the perceived consequences of threats, and/or enhance coping skills. Moreover, providing social support (e.g., emotional support) specifically to other caregivers might be more beneficial to caregivers’ than receiving social support (Brown, Nesse, Vinokur, & Smith, 2003). It should be noted that caregivers should also believe or feel that when needed, they will receive support, and this idea may have implications for coping outcomes (Lazarus & Folkman, 1984). Given the importance of caregivers’ coping during challenging periods and in everyday life, the addition of professional-led parent support groups may foster caregivers’ provision and receipt of support and potentially improve the use of coping strategies in the broader family context.

Surprisingly, only one caregiver, explicitly mentioned concerns about the youth’s psychiatric symptoms and behaviour (i.e., drugs and the impact of drugs on the youth). The caregiver expressed frustration with motivating her child to seek help and was concerned that nothing more could be done. Also, it appeared that age was a problem for two caregivers who indicated that their children were older and so had more control over their care. They suggested that youths made poor decisions and did not follow through with care or support. Rickwood, Deane, and Wilson (2007) found that older youths were often reluctant to seek help for mental health services. Moreover, they were likely to find help if they felt emotionally capable or if they
had established trustworthy relationships with those who could help. This finding supports the notion that care for older youth can be more complex and indicates that caregivers with older youths may require additional assistance with caregiving.

**Implications for Practice**

Overall, the key findings for this study suggest that caregivers can experience burden and stress related to the access of mental health care, professional support and unique families’ circumstances. These findings emphasize the need for additional services including aftercare and transitional support (specifically professional interaction and communication, and respite care) for families. There should be an investment in tailored services for caregivers with youths who were hospitalized and particularly for families with challenging circumstances that may interfere with their access and use of suitable services. Moreover, caregivers may benefit from information about some of the challenges and barriers to expect when youths are hospitalized so they might be better prepared for such demanding situations. Parent support groups facilitated by an allied health or medical staff person or parent-to-parent support may help caregivers to cope with some of these demanding situations (Pickett, Heller, & Cook, 1998; Preyde & Ardal, 2003; Smith, Gabard, Dale, & Drucker, 1994).

More importantly, it should be recognized that crisis stabilization and short-term psychiatric admissions provide temporary ways of managing psychiatric symptoms that require immediate attention and treatment options that are intended to de-escalate the mental health crisis, so youths can then be referred to less restrictive and intense services after discharge from hospital. Thus, caregivers need to be informed about professional roles and responsibilities while navigating the mental health system, so they may seek additional support beyond the psychiatric in-patient hospital setting. Furthermore, caregivers’ enlightenment on the nature of the mental health
health care system in Ontario (e.g. policies and criteria) might be useful to families in need of frequent service use. A continuum of services and support for caregivers may assist families with youths who require constant attention for their symptoms and even after hospitalization.

Although many treatment approaches have been found to reduce youths’ psychiatric symptoms (Burns, Hoagwood, & Mrazek, 1999; Das et al., 2016; Schoenwald, Ward, Henggeler, & Rowland, 2000) symptoms can recur, and caregivers may continue to experience burden. Thus, respite care and therapeutic support for caregivers should be considered in the continuum of youth and family care. In this study, a caregiver suggested a need for a break and this speaks to the amount of pressure caregivers in such situations can experience. It has been found that caregivers need relief and a break from their caregiving activities, and caregivers have also requested for such support (Exel, Graaf, & Brouwer, 2007). If more respite and therapeutic programs are made available to families, caregivers may have the opportunity to recover from the pressures of caregiving (Jeon, Brodaty, & Chesterson, 2005).

Professionals might have time constraints and additional commitments that may limit their interactions with caregivers (Kaas, Lee, & Peitzman, 2003). Caregivers might benefit from additional support from professionals if policy makers accommodate supplementary caregivers’ needs (i.e., time spent communicating effectively and interacting with caregivers). Professionals may benefit from training focused on sensitivity to caregivers needs and improvement in communication and interaction, as well as directing caregivers to the additional sources of support.

**Implications for Research and Future directions**

Investigators should consider exploring caregivers’ views on how best they cope with hospital situations. This knowledge may help professionals to assist families with complex
situations and conflicted parent-child relationships. For example, Liu et al., (2007) found that specific coping strategies (e.g., maintenance of family integrity, positive attitudes and social support) helped caregivers manage subjective burden. It also appeared that coping with objective burden was more difficult than subjective burden because contributing factors were beyond the caregivers control (e.g., financial problems). Furthermore, the perspectives of caregivers with diverse family structures may provide additional evidence regarding burden in the family context. Investigators should consider exploration of professional and youth views on burden, in addition to that of caregivers. This exploration may highlight common views, confirm or clarify caregivers’ views, and identify issues that might be hidden from caregivers.

With regard to mental health care provision, efforts to reduce caregivers’ challenges (Ontario Ministry of Children and Youth Services (OMCYS), 2016) have been provided and documented (e.g., funded programs for respite care for children with special needs under 18 years). However, a comprehensive nationwide investigation may help to identify the conditions that may interfere with the families’ ability to meet criteria for access and use of quality services (e.g., insured health care services through the Canada Health Transfer; Butler & Phillips, 2012). Furthermore, such investigations may highlight when and why the available services and support is not sufficient for families with challenging situations and care demands.

**Limitations**

The sample was small and convenient, predominantly female, and limited in ethnic and regional representation. Caregivers with youths with psychiatric disorders were hard to reach, so the small sample size limited statistical analyses but permitted a descriptive analysis of caregivers’ perceptions. Due to privacy protocols, the first point of contact for the study were medical and allied health staff who often had psychiatric priorities and did not always have the
time or thought the time was right to ask parents for permission to give their contact information to an RA. Staff may have been concerned with overwhelming caregivers with additional research opportunities during the challenging period of inpatient treatment, especially when caregivers’ attention was required during the treatment process. Some caregivers are also employed and have other children at home making participation in research difficult. These situations can pose challenges for the research recruitment of caregivers and youths for whom caregivers’ consent is needed. Caregivers were recruited through one psychiatric inpatient unit, so reports (e.g., nature of burden and concerns about services) may have been specific to that hospital and the accompanying resources available to caregivers.

It is important to recognize that a focus on caregivers’ reports alone may have limited findings on burden and stress in this context. Both professional and youths’ reports and perspectives on psychiatric symptoms and caregivers’ burden and stress, might be valuable in future studies. It is possible that caregivers who participated differed from those who did not participate in this study, and caregivers who agreed to participate in this study may not have adequately represented the sample. Caregivers with greater demands and complex situations may have had less time or opportunities to participate in this study, and therefore their perspectives on their experiences were not captured in this study. Moreover, caregivers’ income ranges, completed education level, and even relationship to youth between may have had implications for caregivers reports on psychiatric symptoms, burden and stress, and views on their experiences. While some of these caregivers’ characteristics may have been controlled during the quantitative analyses, the sample size did not permit further statistical analysis.

With regard to investigations on sensitive research topics, social desirability should be considered. Caregivers may have reported socially acceptable responses by underreporting or
overreporting responses, which may have had undesirable consequences for the findings on burden and caregivers’ experiences. Additionally, the use of telephone interviews and online surveys may have had its advantages in this study (e.g., cost effective), and telephone interviews have been shown to yield responses comparable to that of face-to-face interviews (Sturges, & Hanrahan, 2004). However, these data collection methods might have limited the interaction and rapport between the interviewer and interviewee, which may have been advantageous for the richness of the data (De Leeuw, 1992). Moreover, there may have been some possible loss of non-verbal data (e.g., body language) or distortion of data during the data collection process. Finally, the limited statistical power associated with the sample size of 24 in this study may have played a role in the non-significant findings detected. Therefore, these findings are not conclusive and cannot be generalized.

**Conclusions**

Caregivers reported challenges; they indicated that they needed additional support and resources, particularly related to improvements in access to service and professional support. Furthermore, caregivers’ views suggested that they might have had challenges coping with burden and stress. It is possible that without improved communication and interactions with professionals and better knowledge about mental health care systems and community resources, caregivers may continue to experience burden and stress. Therefore, a comprehensive continuum of services for caregivers should be a priority for service providers.

With regard to family functioning, caregivers should be considered key stakeholders during the development of mental health care frameworks and organizational structuring of mental health care settings. Furthermore, family interventions should not be a secondary service option for families. Rather, interventions (e.g., parent support groups) should be a core
component of youths’ treatment pathways and even after hospitalization. It is important for caregivers to maintain positive mental health during challenging periods, so they might be in the better position to support youths. Thus, coping should be a focus for professionals working with families. Moreover, additional funds may be needed to support research that aligns with the best evidence based approaches concerning caregivers caring for hospitalized youths.

In summary, these findings extend the knowledge base on caregivers with hospitalized youths with severe psychiatric symptoms, and foster an understanding of burden and stress in the family context. There were multiple sources of burden among families with hospitalized youths, and there was an apparent need for additional support in all areas of life. The findings indicate a need for further research with larger samples, which may further facilitate the understanding of burden among caregivers in a general population. Moreover, additional research may draw attention to the need for improvements in the quality of mental health services and practice, and identify ways to increase services, professional support, and specialized programs for caregivers. Overall, the findings add to the knowledge on caregivers’ burden and stress and provide further support for research and practice in the field of mental health.
References


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Appendix A: Ethics Approval

RESEARCH ETHICS BOARDS
Certification of Ethical Acceptability of Research
Involving Human Participants

APPROVAL PERIOD: September 29, 2015
EXPIRY DATE: September 29, 2016
REB: G
REB NUMBER: 15AU014
TYPE OF REVIEW: Full Board
PRINCIPAL INVESTIGATOR: Preyde, Michelle (mpreyde@uoguelph.ca)
DEPARTMENT: Family Relations & Applied Nutrition
SPONSOR(S): N/A
TITLE OF PROJECT: Youth Accessing In-patient Psychiatry: Academic/School Difficulties and Concerns about Reintegration to Community Schools

The members of the University of Guelph Research Ethics Board have examined the protocol which describes the participation of the human participants in the above-named research project and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement, 2nd Edition.

The REB requires that researchers:
- Adhere to the protocol as last reviewed and approved by the REB.
- Receive approval from the REB for any modifications before they can be implemented.
- Report unexpected events or incidental findings to the REB as soon as possible with an indication of how these events affect, in the view of the Principal Investigator, the safety of the participants, and the continuation of the protocol.
- Are responsible for ascertaining and complying with all applicable legal and regulatory requirements with respect to consent and the protection of privacy of participants in the jurisdiction of the research project.

The Principal Investigator must:
- Ensure that the ethical guidelines and approvals of facilities or institutions involved in the research are obtained and filed with the REB prior to the initiation of any research protocols.
- Submit a Status Report to the REB upon completion of the project. If the research is a multi-year project, a status report must be submitted annually prior to the expiry date. Failure to submit an annual status report will lead to your study being suspended and potentially terminated.

The approval for this protocol terminates on the EXPIRY DATE, or the term of your appointment or employment at the University of Guelph whichever comes first.

Signature: Date: September 29, 2015

L. Kuczynski
Chair, Research Ethics Board-General
Appendix B: Consent form

CONSENT TO PARTICIPATE IN RESEARCH

School and Personal Experiences of Youth receiving In-patient Services: Parent Survey

You are being invited to participate in this study. Your participation is completely voluntary, and choosing to take part will not affect the care your child receives. You are asked to participate in a research study conducted by Dr. Parekh at Grand River Hospital and Professor Preyde, Department of Family Relations and Applied Nutrition, University of Guelph. This research project is not intended as therapy.

If you have any questions or concerns about the research, please feel free to contact Dr. Parekh at 519-749-4300 Ext 3862 or Professor Preyde at 1-519-824-4120 Ext 58599 (mpreyde@uoguelph.ca).

PURPOSE OF THE STUDY
The purpose of the study is to explore school issues and the characteristics of youth who access in-patient mental health services.

PROCEDURES
If you volunteer to participate in this study, we would ask you to do the following things:

Complete a survey in which you rate your child’s school and personal experiences, your experiences with your child’s school and your personal well-being. The survey will take approximately 20 to 30 minutes to complete. Using a code (child’s birth month, last 3 digits of postal code and last two digits of your phone number), we will link your survey to your child’s, then we will destroy this code.

Please contact the principal investigator (Professor Preyde) if you would like a summary of the results.

POTENTIAL RISKS AND DISCOMFORTS
There may be a risk of psychological upset with participation in this study because parents are being asked about their personal well-being and their child’s well-being. If this occurs, the research assistant will promptly request Social Work or Nursing support for the parent.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY
There are no known potential benefits associated with participation in this study. By learning more about parent’s perceptions of their child’s and their own experiences, we hope to learn how to improve the planning and care for patients.

PAYMENT FOR PARTICIPATION
While we greatly appreciate your participation in the study, there will not be any payment for your participation in this study.
CONFIDENTIALITY

Your privacy and confidentiality will be respected. No identifying information will be collected in this survey. The information collected will be kept in a confidential locked cabinet at the University of Guelph for 7 years and then shredded. The University of Guelph research assistant who will be talking with you at the hospital will not record your full name on the survey, and you will not be required to record your full name on the survey. There will be no videotapes made. No identifying information will appear in any publications.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. Once the survey is submitted it cannot be withdrawn because the researchers cannot identify which survey is yours. You may also refuse to answer any questions you don’t want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise that warrant doing so.

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. This study has been reviewed and received ethics clearance through Grand River Hospital and the University of Guelph Research Ethics Boards. If you have questions regarding your rights as a research participant, contact:

Dr. Michael Coughlin, Chair  
Tri-Hospital Research Ethics Board  
Grand River Hospital  
Telephone (519) 749-4300, Ext. 5367  
FAX (519) 749-4250  
Email: coughlin.michael@gmail.com

Sandra Auld, Director, Research Ethics  
University of Guelph  
437 University Centre  
Guelph, ON N1G 2W1  
Telephone: (519) 824-4120, ext. 56606  
E-mail: sauld@uoguelph.ca  
Fax: (519) 821-5236
Table 1

*Caregivers’ Characteristics (N = 24)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Category</th>
<th>N</th>
<th>%</th>
<th>Mean (SD)</th>
</tr>
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<tbody>
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<td>Age</td>
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<td>24</td>
<td></td>
<td>46.65 (8.456)</td>
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<tr>
<td>Gender</td>
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<tr>
<td></td>
<td>Males</td>
<td>2</td>
<td>8.3</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
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<td>87.5</td>
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<td></td>
<td>Missing</td>
<td>3</td>
<td></td>
<td></td>
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<td>13</td>
<td>54.2</td>
<td></td>
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<tr>
<td></td>
<td>Divorced</td>
<td>4</td>
<td>16.7</td>
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</tr>
<tr>
<td></td>
<td>Single</td>
<td>3</td>
<td>12.5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Common law</td>
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<td>4.2</td>
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<tr>
<td></td>
<td>Widow</td>
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<td>4.2</td>
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<tr>
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<td>Separated</td>
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<td>4.2</td>
<td></td>
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<td></td>
<td>Missing</td>
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<td>4.2</td>
<td></td>
</tr>
<tr>
<td>Relationship to youths</td>
<td>Mother</td>
<td>19</td>
<td>79.2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>2</td>
<td>8.3</td>
<td></td>
</tr>
<tr>
<td>Category</td>
<td>Count</td>
<td>Percentage</td>
<td></td>
<td></td>
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<tr>
<td>----------------------------------</td>
<td>-------</td>
<td>------------</td>
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<td></td>
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<td>Grandmother</td>
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<td></td>
</tr>
<tr>
<td>Step-mother</td>
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<td>4.2</td>
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<th>Number of Children in the home</th>
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<td>4.2</td>
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<tr>
<td>4</td>
<td>3</td>
<td>12.5</td>
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<td>3</td>
<td>7</td>
<td>29.2</td>
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<td>45.8</td>
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<td>Masters</td>
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<td>16.7</td>
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<tr>
<td>Bachelor</td>
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<td>12.5</td>
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<td>25.0</td>
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<tr>
<td>$50,001 - $100,000</td>
<td>11</td>
<td>45.8</td>
</tr>
<tr>
<td>$10,001 - $50,000</td>
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<td>20.8</td>
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<tr>
<td>&lt;$10,000</td>
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<td>8.3</td>
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<td>66.7</td>
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<tr>
<td>No</td>
<td>8</td>
<td>33.3</td>
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<tr>
<td>------</td>
<td>-----</td>
<td>------</td>
</tr>
<tr>
<td>Caregivers (BAS)</td>
<td>Objective burden</td>
<td>28.79 (7.65)</td>
</tr>
<tr>
<td></td>
<td>Subjective burden</td>
<td>22.92 (7.523)</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>51.71 (14.29)</td>
</tr>
<tr>
<td>Perceived stress (PSS)</td>
<td></td>
<td>9.63 (1.86)</td>
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*Note. *MD = mental disorders
<table>
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<th>Variable</th>
<th>Category</th>
<th>N</th>
<th>%</th>
<th>M (SD)</th>
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<tr>
<td>Age</td>
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<td></td>
<td></td>
<td>15.33 (0.92)</td>
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<tr>
<td>Gender</td>
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<td></td>
<td>Male</td>
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<td>29.2</td>
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<td>Education (Grades)</td>
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<tr>
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<td>20.8</td>
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<td></td>
<td>10</td>
<td>12</td>
<td>50.0</td>
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<tr>
<td></td>
<td>9</td>
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<td>8.3</td>
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<td></td>
<td>Missing</td>
<td>2</td>
<td>8.3</td>
<td></td>
</tr>
<tr>
<td>Length of stay in hospital (days)</td>
<td></td>
<td></td>
<td></td>
<td>7.13 (3.49)</td>
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<tr>
<td>Prior hospitalization</td>
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<tr>
<td></td>
<td>Yes</td>
<td>5</td>
<td>20.8</td>
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<td>Primary diagnosis</td>
<td>Depressive disorders</td>
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<td></td>
<td>Major depressive disorder</td>
<td>10</td>
<td>41.7</td>
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<td></td>
<td>Bipolar disorders</td>
<td>1</td>
<td>4.2</td>
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<td></td>
<td>Attention deficit</td>
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<td>12.5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>hyperactivity disorder</td>
<td></td>
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<td>Anxiety disorders</td>
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</tr>
<tr>
<td></td>
<td>Generalized anxiety</td>
<td>2</td>
<td>8.3</td>
<td></td>
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</table>
### Improvements in youths’ conditions

- **Very much improved**: 2 (8.3%)
- **Much improved**: 12 (50.0%)
- **Minimally improved**: 8 (33.3%)
- **Not assessed**: 2 (8.3%)

### Youths’ psychiatric symptoms

**Youths’ psychiatric symptoms (PSC)**

- **Attention problems**: 9.73 (2.40)
- **Internalizing problems**: 11.77 (2.17)
- **Externalizing problems**: 11.42 (3.43)
- **School refusal behaviour**: 2.50 (1.17)

**Seasonal affective disorder**

- Social anxiety phobia: 1 (4.2)
- Obsessive-compulsive disorder: 1 (4.2)
- Parent-child relationship conflict: 1 (4.2)

**Adjustment disorder:**

- 3 (12.5)

**Seasonal affective disorder**

- 1 (4.2)

**Substance abuse**

- 1 (4.2)
Avoidance of stimuli that provoke negative affectivity

Escape from aversive social and/or evaluative situations

Pursuit of attention

Pursuit of tangible reinforcement

Note. MDD = major depressive disorder; ADHD = attention deficit hyperactivity disorder; OCD = obsessive-compulsive disorder; PCRC = parent child relationship conflict.
Table 3

*Correlations (outcome and predictor variables, N = 24)*

<table>
<thead>
<tr>
<th></th>
<th>OB burden</th>
<th>Youth age</th>
<th>Youth gender</th>
<th>Psychiatric Symptoms</th>
<th>Perceived stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>OB burden</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Youth age</td>
<td>-0.228</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Youth gender</td>
<td>0.103</td>
<td>-0.136</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychiatric Symptoms</td>
<td>0.358</td>
<td>0.011</td>
<td>-0.094</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived stress</td>
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<td>0.535</td>
<td>-0.069</td>
<td>-0.045</td>
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</tr>
</tbody>
</table>

*Note.* OB = Objective burden score
Table 4

*Associations between PCS and PSS with objective caregivers’ burden*

<table>
<thead>
<tr>
<th></th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
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</thead>
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<tr>
<td></td>
<td>B</td>
<td>SE</td>
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<tr>
<td><strong>Step 1</strong></td>
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<tr>
<td>Constant</td>
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<td>27.58</td>
</tr>
<tr>
<td>Youths’ age</td>
<td>-1.82</td>
<td>1.79</td>
</tr>
<tr>
<td>Youths’ gender</td>
<td>1.22</td>
<td>3.53</td>
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<tr>
<td><strong>Step 2</strong></td>
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<td></td>
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<td>Constant</td>
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<td>Youths’ age</td>
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<td>Youths’ gender</td>
<td>1.79</td>
<td>3.43</td>
</tr>
<tr>
<td>Youths’ psychiatric symptoms</td>
<td>0.26</td>
<td>0.14</td>
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<tr>
<td>Perceived parental stress</td>
<td>0.44</td>
<td>1</td>
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</tbody>
</table>

*Note. Dependent variable: Objective burden score*
Table 5

*Correlations (outcome and predictor variables, N = 24)*

<table>
<thead>
<tr>
<th>SB burden</th>
<th>Youth age</th>
<th>Youth gender</th>
<th>Psychiatric Symptoms</th>
<th>Perceived stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Youth age</td>
<td>-0.053</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Youth gender</td>
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<td>-0.136</td>
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<td>Psychiatric Symptoms</td>
<td>0.12</td>
<td>0.011</td>
<td>-0.094</td>
<td></td>
</tr>
<tr>
<td>Perceived stress</td>
<td>0.054</td>
<td>0.535</td>
<td>-0.069</td>
<td>-0.045</td>
</tr>
</tbody>
</table>

*Note.* SB = Subjective burden score
Table 6

Associations between PCS and PSS with subjective caregivers’ burden

<table>
<thead>
<tr>
<th></th>
<th>Unstandardized Coefficients</th>
<th>Standardized Coefficients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td>SE</td>
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<tr>
<td>Step 1</td>
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<td>Youths’ age</td>
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<tr>
<td>Youths’ gender</td>
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<tr>
<td>Step 2</td>
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</tr>
<tr>
<td>Youths’ gender</td>
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<td>Youths’ psychiatric symptoms</td>
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<td>.15</td>
</tr>
<tr>
<td>Perceived parental stress</td>
<td>.50</td>
<td>11.04</td>
</tr>
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</table>

Note. Dependent variable: Subjective burden score
Table 7

*Differences - Family History of Mental Illness (Mean, SD)*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Yes $n = 16$</th>
<th>No $n = 8$</th>
<th>Total mean</th>
<th>$F$</th>
<th>$p$ value</th>
</tr>
</thead>
<tbody>
<tr>
<td>OB burden</td>
<td>30.13 (7.02)</td>
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<td>28.79 (7.65)</td>
<td>1.49</td>
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</tr>
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<td>SB burden</td>
<td>24.25 (7.77)</td>
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<td>22.92 (7.52)</td>
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<tr>
<td>PSC</td>
<td>68.16 (9.75)</td>
<td>68.19 (14.30)</td>
<td>68.17 (11.15)</td>
<td>0.00</td>
<td>0.99</td>
</tr>
<tr>
<td>PSS</td>
<td>9.50 (1.826)</td>
<td>9.88 (2.03)</td>
<td>9.63 (1.86)</td>
<td>0.21</td>
<td>0.65</td>
</tr>
<tr>
<td>SRAS</td>
<td>2.75 (1.209)</td>
<td>2.01 (0.97)</td>
<td>2.50 (1.17)</td>
<td>2.26</td>
<td>0.15</td>
</tr>
</tbody>
</table>

*Note.* OB = objective burden; SB = subjective burden; PSC = Pediatric symptom checklist; PSS = perceived stress; SRAS = School Refusal Assessment Scale
Table 8

Tests of Normality

<table>
<thead>
<tr>
<th></th>
<th>Kolmogorov-Smirnov&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Shapiro-Wilk</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Statistic df p value</td>
<td>Statistic df p value</td>
</tr>
<tr>
<td>Objective caregiver burden</td>
<td>.10 24 .20*</td>
<td>.98 24 .91</td>
</tr>
<tr>
<td>Subjective caregiver burden</td>
<td>.12 24 .20*</td>
<td>.94 24 .20</td>
</tr>
<tr>
<td>Perceived parental stress</td>
<td>.15 24 .18</td>
<td>.92 24 .04</td>
</tr>
<tr>
<td>Youths’ psychiatric symptom</td>
<td>.16 24 .13</td>
<td>.97 24 .63</td>
</tr>
<tr>
<td>School refusal</td>
<td>.14 24 .20*</td>
<td>.92 24 .06</td>
</tr>
</tbody>
</table>

*This is a lower bound of the true significance. a. Lilliefors Significance Correction.
Table 9

*Differences - Youths’ Prior Admission to a Psychiatric Hospital (Mean, SD)*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No (n = 19)</th>
<th>Yes (n = 5)</th>
<th>Total mean</th>
<th>(F)</th>
<th>(p) value</th>
</tr>
</thead>
<tbody>
<tr>
<td>OB burden</td>
<td>29.89 (8.12)</td>
<td>24.60 (3.58)</td>
<td>28.79 (7.65)</td>
<td>1.97</td>
<td>0.17</td>
</tr>
<tr>
<td>SB burden</td>
<td>23.68 (8.27)</td>
<td>20.00 (2.12)</td>
<td>22.92 (7.52)</td>
<td>0.95</td>
<td>0.34</td>
</tr>
<tr>
<td>PSC</td>
<td>69.21 (12.27)</td>
<td>64.20 (3.42)</td>
<td>68.17 (11.15)</td>
<td>0.79</td>
<td>0.38</td>
</tr>
<tr>
<td>PSS</td>
<td>9.68 (1.95)</td>
<td>9.40 (1.67)</td>
<td>9.63 (1.86)</td>
<td>0.09</td>
<td>0.77</td>
</tr>
<tr>
<td>SRAS</td>
<td>2.66 (1.17)</td>
<td>1.90 (1.05)</td>
<td>2.50 (1.17)</td>
<td>1.70</td>
<td>0.21</td>
</tr>
</tbody>
</table>

*Note.* OB = objective burden; SB = subjective burden; PSC = Pediatric symptom checklist; PSS = perceived stress; SRAS = School Refusal Assessment Scale