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Risk Factors for Complex Special Needs Among Male Children Seeking Mental Health Services

Authors

Alshaba S. Billawala,[1]
Chloe A. Hamza,[2]
Shannon L. Stewart[1]

[1] Faculty of Education, Western University, London ON

[2] Ontario Institute for Studies in Education, University of Toronto, Toronto ON

Correspondence

chloe.hamza@utoronto.ca

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Abstract

Children and youth with complex special needs (CSN) present with mental health issues and experience diverse developmental and physical health challenges, often requiring care from several service sectors throughout their lifespan. Despite the chronic service needs of children with CSN, little is known about the factors that contribute to the need for additional financial support to care for these children. To address this gap in the literature, the present study sought to identify risk factors present amongst children and youth seeking mental health services whose families were referred for complex special needs funding in the province of Ontario, Canada. Using data collected from 1,020 male children in Southwestern Ontario using the interRAI Child and Youth Mental Health assessments, the present study examined whether children referred for CSN funding differed from children in clinical care who were not referred for CSN funding. Binary logistic regression analyses revealed that impairments in family functioning (OR = 6.206, CI: 1.827-20.551) were most strongly associated with CSN funding referral. Child challenges in completing activities of daily living were also associated with CSN referral, but this effect was small (OR = 1.063, CI: 1.020-1.100). Implications for decisions around funding allocation with respect to CSN funding in Ontario are discussed.

Many children and youth (hereafter referred to as children) seeking mental health services in Ontario require specific time-limited interventions to improve or resolve their symptoms (Clark, O'Malley, Woodham, Barrett, & Byford, 2005). A small percentage, however, (approximately 10% of those referred for mental health services) present with increased complexity (Epstein, Kutash, & Duchnowski, 2004; Reid et al., 2011). The expense for caring for these children accounts for a disproportionate portion of health care costs, as these children require "episodic, chronic, and ongoing care" from multiple service sectors (Reid et al., 2014; Stewart & Hirdes, 2015). Although the term complex special needs (CSN) has been used to describe these children in Ontario, a variety of terms have been used in the literature, including: multiple disadvantaged, technology dependent, and medically complex (Cohen et al., 2011; Davidson, Bunting & Web, 2012; Day, Davis & Bidmead, 2002; McArthur & Faragher, 2014; Rosengard, Laing, Ridley, & Hunter, 2007).

Of particular interest is the subset of children with complex special needs (CSN), due to mental health problems, who are referred for specialized funding due to the extensive resource needs of the child (Day et al., 2002; Robinson, Jackson, & Townsley, 2001; Tahhan, St. Pierre, Stewart, Leschied, & Cook, 2010; Teare, 2008). According to the Ministry of Children and Youth Services (n.d.) in Ontario, children with CSN who may be eligible for CSN funding are children who: (1) are under the age of 18 and are in need of long term and/or continuous specialized supports, (2) have two or more different special needs and require integration of services across different sectors (e.g., mental health, disability services, education), and (3) have needs based on a variety of comorbid conditions, including: mental health diagnoses, intellectual, physical and developmental disabilities, and chronic, terminal and severe physical health illnesses. Although families may be eligible to apply for funding, provincial governments cannot provide funding to every family and policy makers have struggled to identify which families are most in need of this envelop of specialized funding (Burnside, 2012; Robinson et al., 2001; Spratt, 2010). These difficulties in funding allocation underscore the need for a system that is able to better distinguish families most in need of additional funds. One way to identify families with the greatest need for CSN funding is through an examination of the risk factors present among children who have been referred for CSN funding.

Risk Factors for CSN Funding

Identifying risk factors that contribute to a high needs presentation (and need for additional financial assistance to meet service needs) can serve to inform provincial-level decisions around service allocation. Although research on which families are referred for CSN in Ontario is non-existent, several potential risk factors may be associated with increased need for funding. For example, the presence of mental health concerns and/or physical, intellectual or developmental disabilities (e.g., autism, Down syndrome, spina bifida; Burnside, 2012; Carnaby, 2007; Coller et al., 2016; Kennedy et al., 2007; Tean, 2014; Vig, Chinitz, & Shulman, 2005) may be associated with increased resource need, and thus the demand for more extensive financial support. Moreover, children with more severe disabilities may also experience challenges with daily activities (e.g., bathing, toileting, mobilizing), and be more dependent upon caretakers and equipment, making these children extremely high need (Department of Health, 2004; Goddard, Davidson, Daly, & MacKey, 2008; Pastor, Reuben, & Loeb, 2009; Roberts & Lawton, 2001; Rosengard et al., 2007). In addition, family dysfunction (e.g., presence of parental illness/disability, poor parent-child interactions, and lack of supports) has been known to be predictive of poor outcomes for children, such as psychiatric illnesses and developmental delays (Hewitt-Taylor, 2005; Landy & Tam, 1998; McArthur & Faragher, 2014). Moreover, these families often report lacking the support they need to cope with increased responsibility, emotional exhaustion, heightened distress, and reduced quality of life (Brown, Geider, Primrose, & Jokinen, 2011; Carnevale, Alexander, Davis, Rennick, & Troini, 2006; McArthur & Faragher, 2014; Robinson et al., 2001; Webb, Bunting, & Shannon, 2014), placing these children at greater risk for foster or residential care, treatment-based facilities and other institutions (Burnside, 2012; Stewart, Hassani, Poss & Hirdes, 2017; Tahhan et al., 2010).

The Current Study

Despite increased research on children with CSN, there is a paucity of research on understanding which families of children with CSN are referred for additional funding in Ontario. Moreover, current studies are limited by individual surveys that focus on particular areas of risk (Davidson et al., 2012). Although studies like these elucidate the impact of particular risk factors, researchers have recommended the need for comprehensive assessment tools that can objectively identify “multiplicity of problems” (Carnaby, 2007; Clark et al., 2005; Spratt, 2010; Stewart et al., 2017). To address these gaps in the literature, we examined which risk factors (i.e., activities of daily living [ADL], mental illness comorbidity, physical/medical illness, and impairments in family functioning) may assist in predicting CSN funding referrals by comparing children seeking mental health services who were referred for CSN funding to children seeking mental health services not referred for specialized CSN funding. Although the present study was largely exploratory, it was hypothesized that children referred for CSN funding would present with reduced capacity for completing ADL, increased physical/medical illness and mental illness comorbidity, and more impairments in family functioning relative to children who were not referred for this specialized funding.

Method

Participants

The present sample consisted of 1,020 male children between 4–18 years (*M*age = 10.96, *SD* = 3.43) who completed the interRAI Child and Youth Mental Health or Child (ChYMH) or Child and Youth Mental Health - Developmental Disability (ChYMH-DD) assessment in Southwestern Ontario between October 2012 and August 2015. Of the 1,020 participants, 44 were specifically referred to the Ministry of Children and Youth Services of Ontario by agencies across Southwestern Ontario for CSN funding. Of those youth referred for CSN funding, 30% had a provisional diagnosis of autism at time of treatment intake, and 27% had a provisional diagnosis of a learning or communication disorder. Females were excluded from the present study (N = 10), due to ethical concerns around reporting on the characteristics of small samples (in order to protect participant confidentiality). All participants completed the assessments on a voluntary basis and their quality of care was not impacted if they choose not to participate.

Measures

The two instruments that were utilized were the ChYMH or the ChYMH-DD, which were created by interRAI, a not-for-profit collective of researchers and clinicians from over thirty countries. The ChYMH (Stewart, Hirdes et al., 2015) and ChYMH-DD (Stewart, LaRose et al., 2015) are comprehensive instruments that incorporate information that would typically require multiple assessment tools (e.g., Stewart, Currie, Arbeau, Leschied, & Kerry, 2015; Stewart & Hirdes, 2015). The ChYMH-DD is an adapted version of the ChYMH, specifically for children with intellectual and/or developmental disabilities. At time of intake, assessors completed the ChYMH for children with an IQ above 70, and children with an IQ of 70 or below completed the ChYMH-DD (i.e., all youth had one of the two assessments completed). Trained assessors completed the assessments; these assessors had a diploma or degree in the mental health field, at least two years of clinical experience with children and youth, and had completed a 2.5-day training program for administration of the interRAI ChYMH and ChYMH-DD. The interRAI suite of instruments have strong validity and reliability for children and adults (Phillips et al., 2011; Phillips et al., 2012; Stewart & Hirdes, 2015). The scales used on the ChYMH and ChYMH-DD have been shown to have good internal consistency, as well as well as criterion validity (Stewart & Hamza, 2017; Lau, Stewart, Saklofske, Tremblay, & Hirdes, 2017). In the present study, risk factors for CSN funding assessed using the ChYMH and ChYMH-DD included: activities of daily living, mental health comorbidity, presence of a physical/medical condition, and family functioning.

Activities of Daily Living (ADL) scale. The ADL scale assessed the child's ability to engage in a variety of different daily living tasks (e.g., dressing, bathing, locomotion) on a 6-point scale (0 = *independent* to 6 = *total dependence*). Participants are scored from "0–48" with higher scores indicating greater dependency on others to perform ADL.

Mental illness comorbidity. For the purposes of this study, a mental illness comorbidity variable was created using items measuring different provisional DSM-IV diagnoses (e.g., mood disorder, anxiety disorder, etc.) as indicated by a psychiatrist or physician. This data was then used to create a variable which was coded as: 0 = *no mental illness comorbidity* (if 0 or 1 DSM diagnosis) or 1 = *presence of mental illness comorbidity* (if 2 or more DSM diagnoses).

Physical/medical illnesses. For the purposes of this study, a physical/medical illness variable was created using items on the instruments that inquired about previous medical diagnoses (e.g., asthma, diabetes, epilepsy). This data were then used to create a variable that was coded as 0 = *no physical/medical illness* or 1 = *presence of physical/medical illness.*

Family Functioning Scale (FFS). The FFS evaluates family cohesion, conflict and hostility. It also measures whether or not family members feel overwhelmed by the child's current condition or feel unable or are unwilling to continue caring for the child. Additionally, information regarding the mental health status of the parents, siblings and other close family members is also measured. This scale was treated dichotomously with scores of "0" indicating no difficulties in family functioning and scores greater than 0 indicating the presence of difficulties in family functioning.

Procedure

Clinicians completed the ChYMH or ChYMH-DD instruments using all available sources of information, including direct contact with the family and child, and other service providers and records (e.g., educators and health care clinicians) at time of clinical referral. A majority of the participants completed the instrument when seeking mental health services at one of twenty mental health facilities as typical standard of care (*N* = 976). The children and families who were referred to the Ministry of Children and Youth Services of Ontario for CSN funding (*N* = 44), completed the assessments with a trained assessor after a specialized team had reviewed the referrals. The data collected was approved by the Western University Ethics Review Board (REB: 106415).

Analysis

To examine whether a set of risk factors could be used to predict CSN funding referral, binary logistic regression analyses were used. First, it was examined whether the set of risk factors predicted CSN funding referral using the entire sample. Second, given that the sample size of the CSN group was disproportionately smaller than the non CSN group, we then ran the analysis using an age-and instrument-type matched (ChYMH or ChYMH-DD) sample of non CSN cases (*N* = 44).

Results

Preliminary Analyses

Of the 1,020 male children included in the present study, 178 children completed the ChYMH-DD, and 842 children completed the ChYMH. Children who completed the ChYMH-DD were more likely to be referred for CSN funding than children who completed the ChYMH, χ^2 (1) = 55.35, $p < .001$. Specifically, 18 out of 178 children who completed the ChYMH-DD were referred for CSN funding, compared to 26 out of 842 children who completed the ChYMH (see Table 1). Additionally, children who completed the ChYMH-DD were more likely to have physical/medical illnesses $\chi 2$ (1) = 12.999, $p < .001$, and experienced greater difficulties in activities of daily living than children who completed the ChYMH, $t(1017) = -19.980$, $p < .001$. It is also important to note that children who were assessed using the ChYMH-DD were less likely to have mental illness co-morbidity than children who completed the ChYMH $\chi 2$ (1) = 9.323 $p < .01$, although both groups did not differ with respect to challenges in family functioning.

In total, 44 children and youth (4.31%) were referred by community agencies across Southwestern Ontario to be considered for CSN funding, whereas 976 (95.69%) were not referred for CSN funding. Of the 976 participants not referred for funding, 798 (82%) presented with no physical/medical health illnesses and 177 (18%) presented with 1 or more illness; in contrast, 32 (73%) of the CSN group presented with no physical/medical health illnesses and 12 (27%) presented with 1 or more. With respect to mental illness comorbidity, 451 (46%) of the non CSN group presented with 0 or 1 mental health illnesses and 525 (54%) presented with 2 or more. In addition, 22 (50%) of the CSN group presented with 0 or 1 mental health illnesses and 22 (50%) presented with 2 or more.

Primary Analyses

Results indicated that the full model provided a significantly better fit relative to the constant only model ($\chi^2 = 28.931$, $p < .01$, $df = 4$; See Table 2) suggesting that the predictors (i.e., risk factors) reliability distinguished participants referred for CSN funding to those not referred for funding. Results indicated that of the 4 predictors, impairments in family functioning and challenges with ADL significantly predicted CSN funding referral.[1] These results were consistent with the matched sample ($\chi^2 = 26.632$, $p < .01$, $df = 4$; See Table 3). See Tables 2 and 3 for regression coefficients, Wald statistics, odds ratios and 95% confidence intervals for the reported odds ratios. The predictor that most increased risk for complex special need funding referral was impairment in family functioning.

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[1] The pattern of results for the binary logistic regression analysis was consistent, regardless of whether ADL was treated as a continuous variable, or a categorical variable (e.g., mean split).

Table 1. Demographics of CSN Funding and Non CSN Funding Group

	N (%)		*ChYMH Instrument (%)*		*ChYMH-DD Instrument (%)*		*Age in Years Mean (±S.D.)*	
Non CSN	976	(95.69%)	824	(84.4)	152	(15.6)	10.88	(3.43)
Referred CSN	44	(4.31%)	18	(40.9)	26	(59.1)	12.86	(2.82)
Matched non CSN sample	44	(4.31%)	18	(40.9)	26	(59.1)	12.84	(2.78)
Total	1,020	(100%)	842	(82.5)	178	(17.5)	10.97	(3.43)

Table 2. Logistic Regression Results for Complex Special Needs Funding and Risk Factors (full sample)

Predictor	*B*	*Wald*	p *Value*	*Odds Ratio (ExpB)*	*95% Confidence Interval*
Challenges with activities of daily living	0.061	12.509	.000	1.063	[1.028–1.100]
Presence of physical/medical illness	0.308	0.713	.398	1.360	[0.666–2.777]
Comorbid mental illness	-0.339	1.110	.292	0.713	[0.380–1.338]
Impairments in family functioning	1.825	8.927	.003	6.206	[1.827–20.551]

Note: B = coefficient estimate of predictor; Wald = Wald Coefficient, indicates whether the B coefficient significantly differs from zero; p *Value = significance value, scores less than 0.05 are significant; Odds Ratio (Exponent B [ExpB]) = provides an estimate of the change in odds of being referred for complex special needs funding depending on change in the risk factor. Scores greater than 1 indicate that the predictor is associated with increased odds of being referred for complex special needs funding. Confidence interval = 95% confidence interval around the Odds Ratio.*

Table 3. Logistic Regression Results for Complex Special Needs Funding and Risk Factors (matched sample)

Predictor	*B*	*Wald*	p *Value*	*Odds Ratio (ExpB)*	*95% Confidence Interval*
Challenges with activities of daily living	0.106	5.471	.019	1.112	[1.017–1.215]
Presence of physical/medical illness	0.400	0.410	.522	1.491	[0.439–5.068]
Comorbid mental illness	-0.582	1.257	.262	0.559	[0.202–1.546]
Impairments in family functioning	2.416	11.118	.001	11.203	[2.707–46.359]

Note: See note under Table 2 describing table headings.

Discussion

Although children with CSN have significant clinical care costs (Stewart et al., 2017; Stewart & Hirdes, 2015), research to understand which children are referred for additional financial supports in the province of Ontario is lacking. The purpose of this study was to identify the combination of risk factors that could distinguish families referred for complex special needs funding from those who were not referred for CSN funding from mental health agencies in Southwestern Ontario. It was found that children identified as at risk for having a developmental disability, were more likely to be referred for CSN funding as compared to children who were not identified as at risk for a developmental disability. These findings are consistent with previous research, which suggests that children who present with intellectual and developmental delays, may have greater service needs than children without such delays (Coller et al., 2015). When we examined the specific risk factors assessed that could best differentiate children, as predicted, it was found that difficulties in completing activities of daily living and impairments in family functioning predicted funding referral; however, contrary to expectations, the presence of a physical/medical condition and mental illness comorbidity were not predictive of CSN funding referral in the present sample. These findings underscore both the role of impairments in ADL and family functioning as significant risk factors related to CSN funding referrals, and can serve to inform policy decisions around resource allocation.

Families seeking CSN funding in Southwestern Ontario were more likely to have impairments in family relationships (e.g., exhibit hostility toward the child, express feelings of being overwhelmed by the child's condition), and to a lesser extent, were more likely to have children who had challenges completing ADL independently. It is possible that deficits in adaptive functioning amongst children with CSN may lead to family members experiencing increased pressure to be available for their child on a daily basis (Contact a Family, 2011; Kilic, Gencdogan, Bag, & Arıcan, 2013; Teare, 2008). Indeed, the demands placed on the family of a child with CSN may result in high levels of physical and psychological stress, as well as financial burden. On the other hand, if parents present with health conditions (e.g., mental health, disabilities, and substance use issues), they may be less likely to be available to address their child's needs, feel competent in caring for their child, familiarize themselves with resources that may be of assistance to the child, participate in their child's treatment and may experience greater degrees of perceived burden (Angold et al., 1998; Head & Abbeduto, 2007; Preyde, Cameron, Frensch, & Adams, 2011; Stewart et al., 2017). This can further limit the opportunities the child is provided with to develop skills that may help him/her become more independent with respect to daily living.

Contradictory to previous research which has suggested that the multiplicity of physical and mental health issues is the main characteristic that distinguishes CSN children (Burnside, 2012; Hewitt-Taylor, 2005), the present study found that physical/medical illness and mental health comorbidity were not significantly predictive of CSN funding referral. The lack of significant differences may have several explanations. First, studies examining children with complex needs have found that although these children are at a much higher risk for comorbid psychopathology, diagnoses of psychopathology prove challenging due to a variety of reasons (e.g., differential presentation of symptomology; dependence on parental report for symptoms, and diagnostic overshadowing; Cooper, Melville, & Einfeld, 2003; Costello & Bouras, 2006; Matson & Matson, 2015; Meltzer, Gatword, Goodman, & Ford, 2000). Alternatively, it is possible that mental health comorbidity was not a distinguishing factor of the CSN group because the current sample was a highly clinical one (i.e., both groups seeking mental health services), with high rates of mental health comorbidity in both groups. Another interpretation is that the predictors used were not specific enough to ascertain degree of medical and psychological severity. For example, some physical illness diagnoses may be more severe than others; due to the limited sample size, however, we could not explore variability in diagnosis (e.g., perhaps only severe health impairments differentiate CSN youth from non-CSN youth in clinically referred samples). Future research involving larger samples of youth referred for CSN could address this limitation. Importantly, given our use of a multivariate model in the present study, utilizing more precise measures of psychiatric disorder comorbidity and medical/physical illnesses, could also impact the relative strength of other predictors in the model (i.e., activities of daily living and family functioning).

Limitations

The findings of this study need to be taken into account within the context of its limitations. First, it is important to note that due to the cross-sectional nature of the study, the study does not provide information with respect to the direction of the relationship between impairments in family functioning and challenges in completing ADL and how these impact families need for funding. The findings do, however, indicate the combination of risk factors (i.e., impairments in family functioning and challenges in completing ADL) that profile children who are at the greatest risk for additional financial support. Second, we were only able to examine risk factors among males referred for CSN funding; future research should also examine whether males and females applying for CSN funding present with different risk factors. Third, as previously stated, the sample consisted of a sample of children seeking mental health services in Southwestern Ontario, which limits the generalizability of the study, as this sample may not be representative of the broader population of children with CSN who may seek funding at different agencies across Ontario and elsewhere (e.g., children's hospitals or treatment centres). Finally, the small sample size of children referred for CSN funding limited the number of risk factors that could be examined in the present study. For example, research suggests that aggression to self and others may be important markers of service referral among clinical samples (Pompili et al., 2012; Tremmery et al., 2014). Nevertheless, our findings provide the first empirical investigation of factors related to CSN funding referral in Southwestern Ontario, and future large-scale studies could examine additional factors that may be associated with funding referral (e.g., socio-demographic status, location of family in relation to location of services needed).

Conclusions and Implications

By examining children referred for funding for CSN, a combination of risk factors that distinguished families seeking CSN funding from other clinically referred children were identified. Findings suggest that although many clinically referred children present with physical/medical and mental health problems, children and their families applying for complex special needs funding experience greater difficulties in family functioning, and to a lesser extent, greater activities of daily living. These findings suggest that clinicians need to move away from assessments and treatment plans that only examine the child, and examine factors that extend beyond just the child's presentation (also see Bailey, Raspa, & Fox, 2012; Preyde et al., 2015). Additionally, assessments evaluating the impact that the child's adaptive functioning has on the family (or vise versa), should also be considered. The results of the present study underscore the need for utilizing comprehensive assessments (e.g., ChYMH and ChYMH-DD) that take into account the families functioning and ability to attend to their child's needs, when making decisions around funding allocation for children with CSN.

Key Messages From This Article

Professionals. To promote best outcomes for children with complex special needs, it is important to conduct a thorough assessment and create treatment plans that consider the family. Special attention needs to be paid to family functioning and impairments the child has with completing daily living tasks (e.g., eating, dressing, personal hygiene), as these factors have known to be present among families requiring extensive resources.

Policymakers. In order to make informed decisions about funding allocation for children with complex special needs, it is essential to conduct thorough assessments to get a comprehensive understanding of each child and family.

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