Original paper

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Stigma and stigma by association: Findings from a child and adolescent mental health service (CAMHS), Sri Lanka

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Abstract

Background

Young people with mental illness are known to be subjected to prejudice, verbal abuse and to be left out of activities, which leads to social isolation and impairs daily functioning. Parents of children with mental illness also experience an extension of this stigma, which can result in increased caregiving stress and decreased caregiver wellbeing.

Aim

We aimed to assess the extent of stigma against mental illness in children and adolescents and identify associated factors in order to design interventions to minimize stigma against children with mental illness.

Method

A descriptive cross-sectional study was conducted at a CAMHS in Sri Lanka. Perceived stigma was measured using a specifically designed questionnaire with 30-items. The Cronbach's Alpha for the 30-item scale was 0.852, showing good internal consistency. A ROC curve was used to identify the cut off scores of 52.5 for the stigma questionnaire, with a sensitivity of .08 and specificity of 0.78. Chi square was used to analyze the association between categorical variables.

Results

Of the 150 participants, 44% felt that their child had been discriminated in education. More than a quarter (27.3%) have been blamed by others for their child's mental health problems and 23.3% of children have been attacked or physically threatened. Perceived stigma was significantly higher in parents whose children had behavioural problems ($p<0.01$) and those diagnosed as having ADHD ($p<0.05$).

Conclusions

Anti-stigma interventions, specially focused on educational settings, are needed to reduce stigma against children with mental illness.

Keywords: stigma, children and adolescents, mental illness, Sri Lanka

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Introduction

Globally, about 20% of children and adolescents suffer from mental disorders, and half of all lifelong mental health problems start between 11 and 15 years (1). Young people with mental illness are known to be subjected to prejudice, verbally abused and to be left out of activities. Stigma is associated with poor self-esteem, social isolation and impairs daily functioning of young people with mental illness (2).

Parents also experience an extension of this stigma due to their close relationship with their child, which is referred to as "stigma by association" (3). Previous literature has noted parents of children with autism, intellectual disability, attention deficit hyperactivity disorder (ADHD) and schizophrenia to experience such associative stigma (4-6). Parents can internalize this stigma and discrimination, which leads to increased caregiving stress, decreased caregiver wellbeing and less satisfaction with the caring role (7). Stigma is also a primary barrier against help seeking in both youth with mental health difficulties and their parents (2).

The few studies on stigma carried out in Sri Lanka show that the general public did not consider mental illness as an authentic disorder and believed that persons with mental illness were dangerous and violent (8). Discrimination was also shown to be common, with 27%

of the patients reporting discrimination from their employers and 13.6% in educational settings (9).

Studies on stigma in Sri Lanka have not focused on the stigma experienced by children and adolescents with mental health problems. Assessing the extent of stigma against mental illness in children and adolescents and identifying associated factors is vital in designing interventions to minimize stigma against children with mental illness.

Methods

This cross-sectional descriptive study was conducted at the follow-up clinics of the Child and Adolescent Mental Health Service (CAMHS), Colombo South Teaching Hospital (CSTH), Sri Lanka.

A literature review was conducted to identify measures of stigma and stigma by association in children and adolescents with mental illness. A self-administered questionnaire was designed to measure perceived stigma, based on previous literature (4-6, 10-11). The specifically designed questionnaire had 30 close ended questions, with each question having 3 responses. "Agree", "disagree" or "neither agree nor disagree". The questionnaire was checked for face validity by a group of three independent psychiatrists, and pre-tested among five parents of children presenting to the CAMHS, to test for the comprehensibility and the feasibility of the questionnaire. Ethical clearance was obtained from the University of Sri Jayewardenepura. Informed written consent was obtained from all participants. A consecutive sampling method was used, and all parents who were the primary caregivers of their children aged 5-18 years were included in the study.

A stigma score was calculated by allocating 2 marks for the response "agree", 1 mark for "neither agree nor disagree" and 0 marks for disagree for all but questions 1,10,12,14,15,18 and 27. For questions 1, 10, 12, 14, 15, 18 and 27, 2 marks were given for the response "disagree", 1 mark for "neither agree nor disagree" and 0 marks for "agree". SPSS version 22 was used in the analysis. A reliability analysis was done, and the Cronbach's Alpha for the 30-item scale was 0.852, suggesting good internal consistency. A ROC curve (receiver operating characteristic curve) was used to identify the cut off scores of 52.5 for the stigma questionnaire, with a sensitivity of .08 and specificity of 0.78. Chi square was used to analyze the association between categorical variables.

Results

Socio-demographic details

150 parents were included in the study. The socio-demographic details of the participants are displayed in Table 1. The commonest diagnosis was attention deficit hyperactivity disorder (ADHD) (n=56, 37.3%), followed by depression (n=27, 18%) and learning disorders (n=26, 17.3%).

Table 1. Socio-demographic details of the participants

	Number (n)	Percentage %
Age of child		
<12 years	59	39.3
12-18 years	90	60
Missing	1	0.7
Gender of child	83	55.3
Male	67	44.7
Female		
Income		
<25000	45	30
25000 - 50000	62	41.3
50000 - 100000	22	14.7
100000 - 250000	15	10
>250000	1	0.7
Missing	5	3.3

(Continued)

	Number (n)	Percentage %
Parentage		
18-24	2	1.3
25-34	18	12.0
35-44	60	40.0
45-54	65	43.3
>55	4	2.7
Missing	1	0.7
Parent educational level		
No school education	9	6.0
Year 1-5	12	8.0
Year 6-11	41	27.3
Completed OL	29	19.3
Year 12-13	15	10.0
Completed AL	36	24.0
Graduate	8	5.3
Parent occupation		
Employed	101	67.3
Unemployed	45	30
Missing	4	2.7
Parents marital status		
Married	123	82
Separated	15	10
Divorced	5	3.3
Widowed	4	2.7
Single	3	2.0

Perceived stigma

More than half (54.3%) of parents scored high on stigma (score >52.5%). Perceived stigma was significantly higher in parents whose children had behavioural problems (e.g., physical or verbal aggression, truancy, self-harm) ($p<0.01$) and those diagnosed as having ADHD ($p<0.05$).

Close to half of the parents felt that their child had been discriminated in education (44%). More than a quarter (27.3%) have been blamed by others for their child's mental health problems. Nearly a quarter of children (23.3%) have been attacked or physically threatened due to their mental health problems (Table 2).

Parental blaming was significantly higher for parents of younger children (<12 years) ($\chi^2=6.803$, $p<0.01$), parents having lower monthly income ($\chi^2=3.67$, $p<0.05$) and parents whose children had problems behaviours (e.g. verbal/physical aggression, self-harm) ($\chi^2=6.88$, $p<0.01$). Self-blame was significantly higher in younger parents (<45 years) ($\chi^2=6.89$, $p<0.05$) and those having lower monthly income ($\chi^2=6.89$, $p<0.01$). Parents who are not married (either single, separated, divorced or widowed) ($\chi^2=7.42$, $p<0.01$), having lower monthly income and those having younger children ($\chi^2=15.7\%$, $p<0.05$) were significantly more likely to be belittled due to their child's problems. Children with ADHD were significantly more likely to be physically threatened or attacked ($\chi^2=11.65$, $p<0.05$) than children with other diagnoses. Children displaying problematic behaviours were more likely to be avoided ($\chi^2=11.98$, $p<0.01$) and insulted ($\chi^2=11.98$, $p<0.01$). Parents of children with problematic behaviours were also more likely to be insulted ($\chi^2=4.87$, $p<0.05$).

Table 2. Perceived stigma among parents

	Agree	Disagree	Neither agree nor disagree
1. The general public understanding of children with mental health problems	81 (54%)	41 (27.3%)	25 (16.7%)
2. People have made my child feel ashamed of his/ herself because of his/ her mental health problems	49 (32.7%)	79 (52.7%)	22 (14.7%)
3. The way people have treated my child upsets me	5 (33.3%)	72 (48%)	25 (16.7%)
4. My child has been discriminated against in education because of his/ her mental health problems	66 (44%)	68 (45.3%)	15 (10%)
5. Sometimes I feel that my child is being talked down to because of his/ her mental health problems	64 (42.7%)	74 (49.3%)	10 (6.7%)
6. Sometimes I feel that I am being talked down to because of my child's mental health problems	33 (22%)	108 (72%)	8 (5.3%)
7. People have blamed me for my child's mental health problems	41 (27.3%)	91 (60.7%)	17 (11.3%)
8. I feel that I am to blame for my childs' mental health problems	54 (36%)	72 (48%)	21 (14%)
9. I feel ashamed of myself because my child has mental health problems	22 (14.7%)	112 (74.7%)	14 (9.3%)
10. I do not feel bad about my child having mental health problems	55 (36.7%)	76 (50.7%)	15 (10%)
11. People think less of my child because he/ she has mental health problems	47 (31.3%)	78 (52%)	22 (14.7%)
12. I am open to my family about my child's mental health problems	117 (78%)	21 (14%)	9 (6%)
13. I worry about telling people that my child receives treatment for mental health issues	63 (42%)	73 (48.7%)	13 (8.7%)
14. People have never made my child feel embarrassed because of his/ her mental health problems	80 (53.3%)	47 (31.3%)	22 (14.7%)
15. People have been understanding of my child's mental health problems	88 (58.7%)	36 (24%)	24 (16%)
16. My child has been physically threatened or attacked because of his/ her mental health problems	35 (23.3%)	103 (68.7%)	11 (7.3%)
17. I am scared of how other people will react if they find out about my child's mental health problems	62 (41.3%)	63 (42%)	23 (15.3%)

(Continued)

	Agree	Disagree	Neither agree nor disagree
18. I do not mind people in my neighbourhood knowing my child has had mental health problems	57 (38%)	72 (48%)	18 (12%)
19. People's reactions to my child's mental health problems make my child keep to him/ herself	40 (26.7%)	93 (62%)	17 (11.3%)
20. People's reactions to my child's mental health problems have made me keep away from people	24 (16%)	111 (74%)	14 (9.3%)
21. I am angry with the way people have reacted to my child's mental health problems	29 (19.3%)	92 (61.3%)	26 (17.3%)
22. My child has been discriminated against by health professionals because of his/ her mental health problems.	4 (2.7%)	137 (91.3%)	7 (4.7%)
23. People have avoided my child because of his/ her mental health problems.	35 (23.3%)	100 (66.7%)	15 (10%)
24. People have avoided me because of my child's mental health problems	9 (6%)	122 (81.3%)	17 (11.3%)
25. People have insulted my child because of his/ her mental health problems	35 (23.3%)	97 (64.7%)	16 (10.7%)
26. People have insulted me because of my child's mental health problems	13 (8.7%)	118 (78.7%)	18 (12%)
27. I do not feel embarrassed because of my child's mental health problems	7 (52.7%)	53 (35.3%)	16 (10.7%)
28. I avoid telling people about my child's mental health problems	71 (47.3%)	49 (32.7%)	28 (18.7%)
29. I feel the need to hide my child's mental health problems from my friends	49 (32.7%)	80 (53.3%)	19 (12.7%)
30. I find it hard telling people my child has mental health problems	61 (40.7%)	62 (41.3%)	26 (17.3%)

Discussion

Close to half of the parents (44%) in our study reported discrimination at school, which is consistent with previous studies which identify the school as the place where most young people experience stigma (2). However, the rates of discrimination in the current study were much higher than in a previous study in Sri Lanka, which found only 13.6% of patients to be discriminated in educational settings (9). As the great majority of the participants of the previous study were older than 20 years, their recall bias maybe the reason for lower reporting of discrimination.

Our results revealed that parents of children with ADHD experienced higher levels of stigma compared to other disorders. This is in keeping with previous literature which demonstrates ADHD to be more stigmatized than depression (12). Studies from Sri Lanka indicate that the behaviour of children with ADHD is interpreted as purposeful and malicious by teachers, which maybe one reason for children with ADHD to experience higher levels of stigma (13). Furthermore, studies show that primary school teachers in Sri Lanka believe that behaviour displaced by children with ADHD could be controlled by punishment (13). This may explain why children with

ADHD were more likely to be physically threatened or attacked. We found that children who displayed problem behaviours were avoided and insulted more than those without problem behaviours. Children with problem behaviours such as verbal or physical aggression maybe more likely to be perceived as dangerous or violent, which may explain this finding.

We also found that a greater proportion of parents of younger children (<12 years) were blamed compared to parents of adolescents. During adolescence, the behavioural control of children shifts away from parents towards the adolescents, which may explain the parallel shift in the focus of stigma (14,15). Parents having children showing problem behaviours also experienced greater blame, which may be due to public misconception that problem behaviour was due to parents' lack of control or discipline over their children (16). Parents with low income also experienced more parent blaming, possibly due to the public perception that such parents have fewer resources for optimal caregiving than high income parents.

We found that more than a quarter of parents were blamed for their child's mental health problems. Inadequate knowledge on the aetiology of mental illness may be the reason for parent blaming. For example, studies show that majority of the teachers and public health midwives of Sri Lanka believed that ADHD and autism spectrum disorder occurred as a result of poor parental upbringing and parental conflicts during pregnancy and early childhood (13,17), which highlights the extent of parent blaming.

Almost half of the parents in the study avoided telling others about their child's mental illness and almost one third of them tried to hide their child's mental health issues, which is consistent with previous literature (18). Parents who did not disclose about their child's problems are reported to have higher rates of depression and poorer quality of life, which highlights the negative impact of secrecy (19). Moreover, there is also evidence that parents' inclination to conceal their child's mental health difficulties is a prominent determinant of self-stigma among adolescents, through parents' modeling of shame, embarrassment and secrecy (20).

More than half of the parents in our study believed that the general population was not understanding of children with mental health problems. Thus, education about mental illness to combat myths may be a useful intervention to reduce stigma in Sri Lanka. As widespread national anti-stigma campaigns aimed at the general population is less feasible, given the limited financial resources in the country, targeted interventions aimed at people who have high contact with children, such as health professionals, teachers and peers are more practical. Furthermore, as stigma experienced by children and adolescents with ADHD and problem behaviour was found to be significantly higher, an approach that focuses more on specific mental illnesses and the particular issues associated with them may be more useful than a generalist approach focusing on non-specific mental health difficulties.

Limitations

This study was done on a sample of children and adolescents attending CAMHS in a tertiary care hospital, and may not be generalizable to the whole population.

Conclusions

The study shows that approximately half of the children and adolescents with mental health problems experience stigma and that there are high levels of discrimination against children and adolescents with mental illness in schools. Further Nation-wide research is needed to assess the extent of the problem. Anti-stigma interventions should be designed to reduce the stigma against children and adolescents with mental illness.

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