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Parenting with mental illness among patients presenting to a teaching hospital in Sri Lanka: Challenges and perceived care needs

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ABSTRACT

Parenting with mental illness is associated with family conflicts, parenting difficulties, low parental confidence and increased mental health and behavioural problems in children. Family focused interventions improve child outcomes by about 40 %. However, such services are not available in Sri Lanka.A cross sectional descriptive study was carried out in the general adult psychiatry follow-up clinics in a Teaching Hospital in Colombo, Sri Lanka to assess the needs of parents with mental illness. A specifically designed interviewer administered questionnaire was used to collect sociodemographic details, difficulties with parenting and perceived care needs. A specifically designed data extraction form was used to gather information from the clinic records, about the parents' illness.Our study revealed that 45.1 % of children knew that their parent had a psychiatric disorder. A total of 67.3 % of parents believed that their mental illness had an impact on their parenting of which, 26.8 % thought that this impact was marked. 67.8 % of parents believed that their illness was having an impact on their children. A total of 36.4 % of parents reported having concerns about their children's behaviour, emotions or relationships but only 16.4 % of them said that they would discuss these with their treating doctor. Our study showed that mental illness in parents had a substantial impact on parenting and their children. However, those who sought professionals help in this regard were few and far between. Services aimed at the specific needs of these parents should be developed.

1. Introduction

Women and men suffering from psychiatric disorders are as likely to be parents as those who do not (Nicholson et al., 2001). Recent studies estimate that 20–30 % of the adults with mental illness have dependent children (Howe et al., 2012) and that 23 % of children live with parents who have a mental illness (Maybery et al., 2009)

Having parents with mental illness (PMI) can have many implications for families including socio-economic disadvantage, family conflict, parenting difficulties, low parental confidence and disruption to care and everyday life (Bartsch et al., 2015). Furthermore, higher rates of mental health problems, behavioural difficulties, suicidal ideation and interpersonal difficulties have been reported in children of PMI (Wickramaratne and Weissman, 1998). In addition, PMI are more likely to be involved with child welfare system or to have children in out-of-home care (Park et al., 2006).

PMI are described to be less emotionally available, less reciprocative, less positive and lax in their parenting styles when compared to healthy controls. They were also found to lack warmth in mother-child interactions, have less supervision of their children and were more likely to use denial as a means of dealing with child-care concerns (Oyserman et al., 2004; Shenoy et al., 2019).

Children of PMI often have inadequate, incomplete or inaccurate information about the causes and symptoms of their parents' mental illnesses (Gladstone et al., 2011), as their hunger for information is often dismissed as "too young to understand" (Garley et al., 1997; Handley et al., 2001; Stallard et al., 2004). However, it has been demonstrated that accurate information about the parents' illness helps them to cope with their circumstances and to avoid unnecessary emotion al turmoil (Mordoch, 2010).

Previous studies have revealed that 28–45 % of the children of PMI needed referral to child protection services (Howe et al., 2012; Ruud et al., 2019), 35 % needed referral to education-psychological services and 7% needed referral to family counseling (Ruud et al., 2019).

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Furthermore, 39 % of the children of PMI required referral to the Child and Adolescent Mental Health Services (CAMHS), to receive treatment for their own mental health issues (Ruud et al., 2019). Higher rates of referrals among children were found where the parent was female, single, had low educational level, did not have stable housing, did not have paid work and where social support was lacking (Maybery et al., 2009; Ruud et al., 2019). These studies provided a strong rationale to include parental status and parenting roles into the assessment and treatment plan (Ruud et al., 2019). However, it has been found that patient files do not accurately record parental status and 38–71 % of patients have not been asked about their parental status during assessment (Jessop and De Bondt, 2012; Ruud et al., 2019).

Although, the difficulties of PMI have been studied widely in the western world, such studies from developing countries are limited. The impact of mental illness on parenting has not been studied in Sri Lanka. As the family structure, parenting expectations and practices vary widely among cultures, the findings from Western cultures may not be generalizable to the Sri Lankan population.

It has been recommended that children require services to minimize the ill effects of PMI, maximize family strengths and maintain safety (Mordoch, 2010). Providing family focused interventions for PMI has been shown to improve child outcomes and reduce the risk of them developing mental health issues by up to 40 % (Siegenthaler et al., 2012). However, no such services exist in Sri Lanka. This study aimed at assessing the needs of the PMI in Sri Lanka as the first step towards developing such services for this specialized population.

2. Methodology

This was a cross sectional descriptive study done at the general adult follow-up clinics of Colombo South Teaching Hospital, Sri Lanka. The study sample consisted of male and female patients attending the follow-up clinics, who were in remission and having children less than 18 years of age. Patients who were not the primary caregivers of their children, those who were in a relapse or recurrence and patients whose children were intellectually disabled or had a neurodevelopmental disorder were excluded.

A sample size of 385 was calculated, using a 95 % confidence interval and the percentage of the population as 50 %. All consenting patients fulfilling the inclusion and exclusion criteria were included in the study.

A specifically designed interviewer administered questionnaire was used to collect socio-demographic details, childs' awareness of the parents mental illness; parents perception of the impact of their mental illness on their parenting and the impact of their mental illness on their children; their concerns about their children; parents perception of what the mental health services can provide to support their parenting and any barriers to discuss the problems regarding their children with mental health services. The questionnaire was based on the previous studies by Stallard et al., 2004, Wahl et al. 2016 and the Royal College of Psychiatrists report 2011 (Psychiatrists, 2011; Stallard et al., 2004; Wahl et al., 2017). The questions and content were modified to make it culturally acceptable. The questionnaire was pretested among 10 patients to check for feasibility. Ethical clearance was obtained from the University of Sri Jayewardenepura.

Chi square test was used to analyze categorical data. SPSS version 22 was used in the analysis.

3. Results

3.1. Sociodemographic details

Of the 385 patients studied, 57.1 % (N = 220) were females. Majority (79 %, N = 304) were married, 55.8 % (N = 215) were employed and 40 % (n = 154) were living with extended families. More than half (54 %, N = 208) had only one child and 29.9 % (N = 115) had one or more children under 5 years (Table 1).

Table 1
Socio-demographic details.

	Number (n)	Percentage (%)
Age of parent:		
18–24 years	26	6.8%
25–34 years	65	16.9%
35–44 years	132	34.3 %
45–54 years	102	26.5%
55–64 years	48	12.5%
> 65 years	12	3.1%
Gender:		
Male	165	42.9%
Female	220	57.1 %
Educational level:		
No school education	13	3.4%
From year 1–5	11	2.9%
From year 6–11	81	21%
Passed O/L*	148	38.4%
From year 12–13	72	18.7%
Passed A/L**	47	12.2%
Graduate	13	3.4%
Occupation:		
Employed	215	55.8 %
Not employed/ Home makers	170	44.2%
Marital status:		
Married	304	79 %
Separated	15	3.9%
Divorced	35	9.1%
Widowed	31	8%
Single	9	2.3%
Living circumstances:		
Nuclear family	231	60%
Extended family	154	40 %
Number of children:		
1	208	54 %
2	124	32.2%
3	46	11.9%
4	8	2.1 %
Age of youngest child:		
< 5	115	29.9 %
5–12	165	42.9%
13–18	105	27.3%
Number of children < 5 yr		
0	271	70.4%
1	99	25.7%
2	15	3.9%

* O/L – Ordinary level examination, held at the end of year 11.
** A/L – Advanced level examination, held at the end of year 13.

3.2. Characteristics of the parents' illness

Schizophrenia was the commonest diagnosis (19.7 %, N = 76) followed by bipolar affective disorder 17.9 %, (N = 69) major depressive disorder 16.1 %, (N = 62) and alcohol dependence 9.3 %, (N = 36).

Of the sample, 34 %, (N = 131) have had the illness for 1–5 years. Majority, (84.7 %, N = 326) had previous hospital admissions and 39.7 % (N = 153) had previous attempts of self-harm.

3.3. Childs' knowledge on parental mental illness

Our study showed that 45.1 %, (N = 174) of children knew that their parent had a mental illness. Out of these children, 35.6 % (N = 62) were told by the parents themselves, but 31 %, (N = 54) of children have figured it out on their own. Out of the parents whose children were not informed of their parents' illness, 68.2 % (N = 144) believed that the children were too young to understand (68.2 %, N = 144). Fear of upsetting the children (42.1 %, N = 89), the belief that telling the children will not change anything (35.5 %, n = 75) and not knowing what/how to tell children (23.6 %, N = 50) were other reasons for not

Table 2
Factors associated with children's awareness about PMI.

	Percentage of children aware of the parents illness
Age of the parent (in years)	
18–24	0.0
25–34	6.1
35–44	30.3
45–54	70.5
55–64	87.5
> 65	100.0
Gender	
Mother	48.8
Father	37.5
Marital status	
Single	88.8
Widowed	72.7
Divorced	42.8
Married	41.7
Separated	26.6
Living circumstances	
Nuclear family	51.5
Extended family	33.1

telling the children. 20.8 %, (N = 44) have been advised by the relatives or friends not to inform the children about their illness.

The children's knowledge about parental mental illness differed significantly with the parent's age (X^2 = 149, p < 0.01), gender (X^2 = 6.12, p < 0.05), marital status (X^2 = 17.16, p < 0.01) and living circumstances (X^2 = 12.68, p < 0.01) (Table 2).

3.4. Impact on parenting

A total of 67.3 % (N = 259) of parents believed that their mental illness had an impact on their parenting, with 26.8 % (N = 103) believing that this impact was marked. The perceived effects of the mental illness on their parenting are displayed in Table 3 (Table 3). Some patients reported having more than one effect.

The perceived impact of mental illness on parenting was significantly associated with the age of the parent (X^2 = 34.9, p < 0.01), age of the youngest child (X^2 = 34.2, p < 0.01), number of children under 5 years (X^2 = 19.062, p < 0.01) and the support from friends/family (X^2 = 15.02, p < 0.01).The impact on parenting was not associated with gender, marital status, educational level, occupation, number of children, diagnosis, duration of illness or previous hospital admissions (Table 4).

3.5. Impact of mental illness on the child

Nearly two thirds of the parents (67.8 %, N = 261) thought that their illness was having an impact on their children, with 29.6 % (N = 114) believing that the impact on their children was marked (Table 5).

The impact of the parental illness on children was significantly

Table 3
Perceived impact of mental illness on parenting.

Impact on parenting	Number	Percentage
Difficulty in organizing day to day activities	99	25.7
Worry that children will be stigmatized because of their illness	98	25.5
Do not feel confident about their parenting skills	83	21.6
Worry that their child will develop a mental illness	79	20.5
Not motivated to play or spend time with children	69	17.9
Difficulty in making decisions regarding children	66	17.1
Worry that children will be ashamed of them	51	13.2
Often get angry / Often irritable	50	13.0
Side effects of medication makes it difficult to attend to daily activities	46	11.9

Table 4
Factors associated with perceived impact on parenting.

	Percentage having an impact on parenting
Age of the parent (in years)	
18–24	96.1
25–34	84.6
35–44	69.6
45–54	57.8
55–64	47.9
> 65	41.6
Age of the youngest child	
< 5 years	83.4
5–12 years	69.0
> 12 years	46.6
Number of children under 5 years	
0	60.5
1	82.8
2	86.6
Support from family or friends	
Yes	56.6
No	75.3

Table 5
Impact of parental mental illness on children.

Impact on children	Number	Percentage
Children have more responsibilities at home compared to same aged peers	94	24.4
Children miss out on extra-curricular activities	92	23.9
Children are unable to have friends over at their house	64	16.6
Children have limited contact with people outside the family	64	16.6
Children often get late to school	62	16.1
Children often miss school	47	12.2

Table 6
Factors associated with perceived impact on children.

	Percentage of patients whose illness has an impact on their children
Age of the youngest child	
< 5 years	89.7
5–12 years	74.5
> 12 years	57.1
Support from family and friends	
Yes	48.7
No	82.1
Previous acts of self-harm in parent	
Yes	74.5
No	63.3

associated with the age of the youngest child (X^2 = 8.9, p < 0.05), support from family and friends (X^2 = 48.23, p < 0.01) and history of deliberate self-harm in the parent (X^2 = 5.24, p < 0.05) (Table 6).

In the event where one of the parents has received treatment as an inpatient, 49.5 % (N = 167) have been cared for solely by the other parent, 37.9 % (N = 128) by the extended family and 12.4 % (N = 42) by friends. During parental hospital admissions 53.4 % (N = 179) children have not engaged in their routine day-to-day activities such as schooling and other extracurricular activities.

3.6. Current concerns about the child's mental health

A total of 36.4 % (N = 140) parents reported having concerns about their children's behaviour, emotions or relationships, with 2.1 % (N = 8) of them expressing major concerns.

The parental concerns were significantly associated with the number of children in the family (X^2 = 12.8, p < 0.01), age of the

Table 7
Factors associated with parental concerns about their children.

	Percentage of parents concerned about their children
Number of children in the family	
1	28.6
2	48.0
3	39.0
4	37.5
Age of the youngest child	
< 5 years	13.9
5–12 years	43.6
> 12 years	49.5
Number of children under 5 years	
0	45.1
1	15.1
2	6.6
Age of parent (in years)	
18–24	0.0
25–34	24.6
35–44	32.5
45–54	49.0
55–64	56.2
> 65	33.3
Parents employment status	
Employed	42.0
Not employed/home makers	29.0
Duration of illness	
< 6 months	18.8
6months – 1 year	27.2
1–5 years	33.5
5–10 years	42.1
> 10 years	57.1

parent ($X^2 = 34.86$, $p < 0.01$), parent's occupational status ($X^2 = 6.5$, $p < 0.05$), age of the youngest child ($X^2 = 36.6$, $p < 0.01$), number of children under 5 years ($X^2 = 35.2$, $p < 0.01$) and duration of parental illness ($X^2 = 22.3$, $p < 0.05$) (Table 7).

Alarmingly, only 16.4 % (N = 23) of parents who had concerns about their children said they would discuss this with their treating doctor. The main reason being that the treating doctor never asked them about their children (57.8 %, N = 66). In addition, 40.3 % (N = 46) said that the doctor seemed too busy and another 21.9 % (N = 25) reported that they thought that the doctor was only there to treat their illness and not to discuss about their children.

3.7. Perceived care needs

Out of all the parents, only 39.7 % (N = 153) said that they wanted extra support from the mental health services. Of those, 51.6 %, (N = 79) said that they wanted to be educated on how to communicate their illness to the children, 45 % (N = 69) wanted advice on whether or not to tell their children about their illness, 41.8 % (N = 64) wanted to be educated on the possible effects of parental mental illness on children and 37.2 % (N = 57) said they would like to receive advise on how to improve their parenting. Further 26.7 % (N = 41) said that they want the doctors to help them talk to their children about their illness and 11.1 % (N = 17) wanted to discuss how to manage difficult behaviour in their children. Finally, 18.3 % (N = 28) wanted practical help such as financial assistance, help with day care, educational support, flexible clinic dates and arrangements for special attention for their children at school.

4. Discussion

4.1. Children's awareness of parental mental illness

Only 45.1 % of children in our study were aware about their parents' illness. The main reason for parents to conceal their illness was the belief that the children were too young to understand. This is in keeping with the previous literature that describes that childrens' hunger for information is often dismissed as "too young to understand" (Garley et al., 1997; Handley et al., 2001; Stallard et al., 2004). However, previous studies have shown that children of all ages were aware that something was wrong, even when their parents tried to hide their illness (Gladstone et al., 2011). Another reason for parents to conceal their illness was the fear of upsetting the children. However, according to earlier studies, children's worries about their parent's safety and well-being and self-blaming for their illness was worsened by the lack of understanding about parents' illness (Somers, 2006), as they experienced undue worries by imagining parental outcomes based on incomplete information (Mordoch, 2010). Therefore, parents should be educated that, providing age-appropriate information regarding their illness to the children does not add to their worries, but rather help to mitigate their fears, anxieties and self-blaming.

None of the children of parents between 18–24 years in our study were aware about the parents' illness; whereas all the children of parents aged > 65 years knew about their parents' illness. Children of younger parents are likely to be young and are less likely to attribute parents' behavioural changes to mental illness unlike older children. Furthermore, parents are more likely to disclose about their illness if they feel that the children are old enough to understand.

Our study found that more children were aware about their mothers' illness than their fathers' illness. The mother is usually the primary caregiver of children and is likely to spend more time with children, which may contribute to this difference.

Children of parents who were widowed or single were more aware of their parents' illness compared to those who were married, divorced or separated. Similarly, children who lived in nuclear families were more aware of the parent's illness, compared to children who lived with their extended families. Having the other parent or extended family for support probably made the behavioural changes or functional deterioration of the ill parent less obvious, making the children to be less aware of the parents' illness.

4.2. Impact on parenting

A total of 67.3 % parents believed that their mental illness impacted their parenting. Difficulty in organizing daily activities, worrying about their children and lack of confidence in their parenting were the major difficulties encountered by parents in our study. Worrying about the well-being of the children was also identified as a major concern in PMI, in a review by Wahl et al. (Wahl et al., 2017). Greater parenting confidence has been shown to be associated with better mother-child interactions (Gelkopf and Jabotaro, 2013; Oyserman et al., 2004). Therefore, improving parenting confidence is an important step in reducing the impact of parental mental illness on children.

The perceived impact of mental illness on parenting was higher when the mother was younger, the children were younger and where there was no social support. As the younger parents are relatively immature and have inadequate coping skills, they may find it increasingly difficult to cope with the demands of parenting when having a mental illness. In addition, younger parents are more likely to have younger children who are more dependent on their parents, which make parenting of young children especially hard in the presence of mental illness.

4.3. Impact of parental mental illness on the child

A significant number (67.8 %) of parents believed that their illness had an impact on their children. The main impact on children was having to undertake more responsibilities at home compared to same aged peers. Children of PMI may be entrusted with multiple responsibilities including management of the parents' medication, looking after other family members and seeking help for the parent involved that can

restrict their opportunity for leisure activities, social networking and peer relationships (Psychiatrists, 2011). In keeping with the previous literature, in our study 23.9 % of the children missed out on extra-curricular activities, 16.6 % of the children were unable to have friends over and another 16.6 % had limited contacts outside the family. These findings are concerning as social isolation has been identified as a risk factor for development of psychological problems in children (Foster, O'Brien, & Korhonen, 2012). Outdoor activities, interaction with peers and relationships with other safe adults in the child's life are recommended to minimize the impact of parental mental illness (Foster et al., 2012).

Previous studies have shown higher rates of referrals among children among parents who were female, single, had low educational level, did not have stable housing, did not have paid work and where social support was lacking (Ruud et al., 2019). Our study also found that lack of social support was associated with higher perceived impact on children. However, we did not find impact on the parent to be significantly associated with the parents' gender, educational status, marital status or occupational status.

Despite having concerns about their children, only 16.4 % were willing to seek help from the treating mental health team. Fear of being seen as bad parents, fear of stigmatization and fear of losing custody have been described as reasons for parents not to seek help for their children (Diaz-Caneja and Johnson, 2004). In contrast, only a small percentage (7% and 4.3 %) reported that they did not seek help due to the fear of being considered as bad parents or fear of being judged as not being fit to care for their children. The main reasons in our study were because the doctor never asked them about their children (57.8 %) and the doctor being too busy (40.3 %). The lack of mental health professionals makes relatively less time available for the treating doctors to spend with their patients in the Sri Lankan setting. This may cause the doctors to focus mainly on the patients and ignore the needs of their children.

4.4. Perceived care needs of parent

Although 67.3 % of parents believed that their illness had an impact on parenting, only 39.7 % wanted extra support from the mental health services. Parents being too preoccupied with their own needs and poor awareness about the possible adverse effects of parental mental illness on children may be possible reasons for parents not to seek professional help (Stallard et al., 2004). In addition, fear of stigmatization may be another possible reason for not wanting help from mental health services.

4.5. Implications for service development

As the findings of this study shows that impact of parenting is higher when the mother is younger, the children are younger and when there is poor social support; extra parenting support is especially needed for younger parents, parents with children less than 5 years and those with poor social support.

Likewise, as the study shows that parental concerns about children are higher when the children are older and the parents have had the illness for a longer duration, extra support should be provided to the children when they are older and the longer the duration of parental illness.

Our study showed no significant difference between the parents' diagnosis and the perceived impact on parenting, the perceived impact on children, concerns with regard to the children emotions and behaviour or the perceived need for help from mental health services. Hence, parenting status and the need for support should be assessed in all patients caring for children, regardless of their diagnosis.

In addition, our results showed that more than half of the children have not engaged in their routine activities when a parent received inpatient treatment. Goodyear et al. has recommended that crisis care planning, (i.e. planning for the care of the children when the severity of the parental mental illness limits their capacity for caregiving) should be an integral part of developing services to PMI (Goodyear et al., 2015). Having a crisis plan would help to minimize the effects of parental hospitalization on children and needs to be developed in Sri Lanka.

According to the findings of our study, 57.8 % of patients did not discuss the concerns about their children as the doctor never asked them about their children. The lack of awareness of adult mental health workers on the difficulties encountered by PMI and the impact on their children maybe one of the reasons for adult mental health staff to not pay attention to the parental status of their patients. Stallard et al. have described that clinicians' lack of skills and anxiety about exploring family issues and the clinician trying to protect their client by avoiding discussing potentially distressing child issues as other barriers to implement family focused interventions within the adult mental health services (Stallard et al., 2004). Therefore, raising awareness among adult mental health workers about the effects of parental mental illness on children and the effective interventions would also be an important step in developing services to this population.

PMI are described to be less emotionally available, less reciprocative, less positive, lax in their parenting styles and lack warmth in mother-child interactions (Oyserman et al., 2004; Shenoy et al., 2019). Positive parenting attitude and behaviours have been shown to reduce undesirable behaviours in offspring (Sekaran et al., 2020). Therefore, assessing parental behaviour and parent-child interactions would help in deciding the degree of support and the level of supervision the parent needs and will be useful in designing interventions to improve parenting skills (Ganjekar et al., 2020; Sekaran et al., 2020). Though there are existing tools such as the Postpartum Bonding Questionnaire (PBQ) (Brockington et al., 2006), the Bethlem Mother–Infant Interaction Scale (BMIS) (Kumar and Hipwell, 1996) and the NIMHANS Maternal Behaviour Scale (NIMBUS) (Ganjekar et al., 2020) to assess the quality of mother-child interactions, none have been culturally validated for the use in Sri Lanka Therefore, developing culturally sensitive tools to assess mother-child interactions may be an useful in planning services for these parents.

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Declaration of Competing Interest

None.

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