

Parents' Experience of Caring for an Adolescent with a Mood Disorder

Robert J. Meadus, PhD, RN, CPMHN(C)

Tanya Purchase, RN, CPMHN(C)

Weldon Bonnell, MD, FRCP(C)

Rajive Rajan, MD

Kimberley St. John, MD, FRCP(C)

Hubert White, MD, FRCP(C)

Leslie Wheeler, MD, FRCP(C)

PRESENTER DISCLOSURE

- Presenter: Robert J. Meadus declare no potential conflicts of interest with respect to the research, authorship, and/or presentation/publication of this research study
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MITIGATING POTENTIAL BIAS

- Presenter: Robert J. Meadus
- Mitigation of Conflict

LEARNING OBJECTIVES

- 1) Enhance professional knowledge on the needs of parental caregivers of adolescents with a mood disorder.
- 2) Facilitate dialogue among health professionals of the needs of parents who are caring for a psychiatrically ill adolescent.
- 3) Improve health care professionals understanding of parental caregiving.

OUTLINE

- Background
- Purpose
- Literature Review
- Methodology
- Findings
- Implications
- Conclusion

BACKGROUND

- Mental health disorders are a major concern of Canadian children
- When child/adolescent is admitted to hospital –recognized as crisis for both child/parents
- Challenges associated with caregiving may affect health of the entire family
- Healthcare professionals have been recognized as the least helpful in assisting families (Doornbos,

2002; Ewertzon et al., 2010; Ferriter & Huband, 2003).

PURPOSE

The purpose of the study was to explore the experience of parents whose adolescent is diagnosed with a mood disorder within the mental health program, Eastern Health Authority.



LITERATURE REVIEW

- Most of the literature on caregivers of patients with psychiatric illness has utilized quantitative & qualitative approaches
- Examined the experiences of parents caring for adult children schizophrenia (Johansson et al., 2012; Raymond et al., 2017).
- Examined parents' accounts of caring for young people with psychosis (Darmi et al., 2017; Ferriter & Huband, 2003; Hickman et al., 2016).

LITERATURE REVIEW

- U.S. study-Tuck et al., (1997)
phenomenological study (n=9) explored the phenomenon of caring for an adult child by parents
- U.S. study- Wade (2006) phenomenology
parents (n=10) young children with bipolar disorder
- Cdn study, Milliken (2001) Grounded theory-
parents caring for adult children with schizophrenia

LITERATURE REVIEW

- In summary, parents reported dissatisfaction with care and found health care professionals as uncaring and inattentive to the needs of parents
- Families feel alienated and not included in care partnerships
- No Cdn studies noted that examined the experiences of parents caring for adolescent with mood disorder

ETHICAL CONSIDERATIONS

- Study approved by Human Investigation Committee- Memorial University (HIC).
- Free to withdraw from the study at any time, without having to give a reason, and without affecting the care of their adolescent.

METHODOLOGY

- Design: Phenomenology
- Sampling Plan: Purposeful Sampling
- Procedure: Procurement Poster
- Data Collection – semi-structured interview
 - Data Analysis- Giorgi (1985) series of steps
 - Short demographic form

INTERVIEW QUESTIONS

- ``Tell me your experience of being a parent caring for an adolescent with a mood disorder``
- ``Tell me what you wish mental health professionals to understand about the experience of caring for a son or daughter with a mood disorder``

PARTICIPANT DEMOGRAPHICS

- 12 (3 male, 9 female) parents – two sets of parents
- Martial status – married/divorced
- Number children living at home- 2-3
- Education: College-Trades School-University
- Age- 41-50
- Employment- full time/part-time
- Yearly household income- 60001 and above

THEMES

- **What`s Going On! - Is there a Problem**
- **Decision to Act – Entry to Health Care System**
- **Labour of Caring - Parental Strain**
 - Advocating for child
- **Help Services – Disconnection between health care system, school & community**

QUALITATIVE COMMENTS

- **What`s Going On**
- `` It started probably 13 or 14, she was very moody, not sleeping well, very argumentative, agitated and angry. And we thought (parents) it was because she had a younger brother. And a couple of times she would say, ``I need help.`` I just figured it was hormonal. Oh (name) you`re going to be okay. Its just your age, hormones.`` (Participant, No. 7).

QUALITATIVE COMMENTS

- ``I use to say this is a war zone. We`d call each other at work and say `Are you ready for tonight.` What`s going to be tonight. We didn`t know what to expect. She (daughter) would come out of her bedroom and she`d come out here and let it rip.`` (Participant, No. 6).

QUALITATIVE COMMENTS

- There isn't a diagnosis as such. We're not 100% sure what's going on with him. All his life (son) he has been a very high achiever and all of this changed last August. He was a little bit distant. We put it down to a little bit of embarrassment for him where he didn't go away with his friends. He just kind of spent a bit of time in his bedroom. Just pretty normal, I thought.`` (Participant, No. 1).



QUALITATIVE COMMENTS

- **Decision to Act- Entry to Health Care System**
- “He began cutting himself when he was about 13 years old. At the time it seemed like a lot of kids in the area seemed to be doing that sort of thing, so we weren’t incredibly concerned. It seemed to be more of a phase. But then, he began very deep cutting and that of course concerned us greatly. And, that’s when we sought treatment here [outpatient clinic]. Now we did get in with Dr. [name], we got in very quickly. I have to say it was like maybe three months or so “ (Participant, No. 9).

QUALITATIVE COMMENTS

- “My daughter had sort of a traumatic incident with a very close friend. She really wanted to talk to somebody and really couldn’t talk to me [father] or didn’t feel she could ..so lucky enough my previous employer has an EAP program and we had access to that so we got her assigned to a counsellor, and then she went to provincial outreach. All this time my family doctor was monitoring the situation, The outreach person advised she should probably go see a psychiatrist and which we did, so we hook-up with one, Dr. (name).” (Participant, No. 4).

QUALITATIVE COMMENTS

- “..The phone rang for me. It was [son], wanted me to take him to the hospital. I don't know how I got there [home]. I was expecting the worst when I got there. I thought he was after doing something, you know. Anyway, when I came around the corner, he was out on the lawn. So I was more relieved, He got in the car and he said, 'I've go to go to the Waterford. I said [son] you can't go to the Waterford, you're a child. You have to go to the Janeway. I said, 'What's wrong. 'He said he was having suicidal thoughts.' (Participant, No. 2).

QUALITATIVE COMMENTS

- **Labour of Caring-Parental Strain**
- “It’s just so long, tiring, it’s a journey and when you do anything and everything you can for your kids. But something like this when you’re dealing with a mood disorder there’s just some things you just can’t do, you can’t help them. Sometimes you feel so helpless.” (Participant, No 12).
- “They did take her in as an inpatient. She went in in November and I was, you know, I mean I’m sure you’ve gone through this with parents, but that was one of the toughest days of our lives. Leaving her there that night...she came home for Christmas.” (Participant, No. 8).

QUALITATIVE COMMENTS

- “I think there is a lot of guilt there too. I wish I could take this from her, I can’t but I wish I could. And she always says to me, ‘You and your genes, your genes, and ‘I’d say I know how you feel.’ I wish that I could just take it from her so she could have a normal, happy child’s life.” (Participant, No. 5).
- “You know we kind of blame ourselves. Like maybe it’s because I had her so young. So we felt very alone. And even to this day I deal with it, my husband can’t really associate with it. I take her to the doctor’s appointments and he kind of thinks that she doesn’t need help as such. And that’s been a stress on us as well as a couple.” (Participant, No. 7).

QUALITATIVE COMMENTS

- **Advocating for Child**
- “So I called the Janeway again. I spoke to the same woman again. I said she needs help. So that’s okay. So, she was put on a waiting list. I said, ‘I’m not waiting for no waiting list.’ So we made several trips to the emergency. They came down and talked to her and everything like, it’s okay, well sort of go home and see what happens. Go home and see what happens. Nice, so then okay, ‘I said, you know, what do you do?’”
(Participant, No. 12).

QUALITATIVE COMMENTS

- “You can’t help but learn the ropes and learn what it takes to get access and stuff. And I really think that’s true when it comes to mental health more than when it comes to other, like physical illness and that kind of stuff. I really think that you really do have to be much more proactive. You don’t know that from the beginning.” (Participant, No. 10).
- “The only way to get help is play hard ball. To take your child, nobody should have to do this, ‘To take you child to the hospital and say, ‘I am not bringing him home. You have to help us.’ That’s the roughest part in all of it.” (Participant, No 1).

QUALITATIVE COMMENTS

- **Help Services- Disconnection**

- “The biggest challenge and the biggest problem with the mental health system is access. It’s just getting access and understanding the system and I mean definitely as far as supports for the parents and stuff , I don’t think any exist. I’ve not looked for them. I think it would be a fabulous idea if they’re there and people are made aware of them.”
- (Participant, No. 10).
- “If they could give information to parents on how to help your child cope. Or maybe ask if they have something they could read when leaving”
(Participant, No 8).
- “To get into the system and knowing that in the back of your mind if I got to fight hard ..I can’t even imagine for the kids who are suffering because parents can’t fight. Why is it so hard to get into the system.” (Participant, No. 12).

IMPLICATIONS

- Families need to be included in the mental health treatment of their children
- Mental health resources need to be connected to care providers, school and community agencies
- Foster family care in outpatient and inpatient mental health settings
- Role for advanced practice nurse in ER to screen child, support/listen to parents
- Mental health professionals - assessment of family in home environment

IMPLICATIONS

- Parents' need for information [general/personal] right to privacy- balance
- Improve family functioning- group family therapy
- Health care professionals need to engage therapeutically with parents to understand their personal experiences

CONCLUSION

- The themes and sub-themes illuminate the experience of parents caring for an adolescent with a mood disorder.
- All parents were eager to tell their story in the hopes to help other parents who are living the same situation and increase awareness of the mental health professionals to the needs of parents.
- This study contributes to the literature on the impact of parents whose children are experiencing a mood disorder.

THANK YOU

- **Parents for participating in the research study**

QUESTIONS

