

The role of families in first-episode psychosis

Srividya N. Iyer, Ph.D.

Program Coordinator, PEPP-Montreal
Assistant Professor, Department of Psychiatry

Families play an important role

- Service engagement (Conus et al., 2010; Schimmelman et al., 2006; Abadi et al., in preparation)
- Medication adherence (Rabinovitch et al., 2013; Coldham et al, 2002)
- Help-seeking (Addington et al., 2002; O'Callaghan et al., 2010; Morgan et al., 2002)
- Clinical and functional outcomes (Norman et al., 2005, 2007;)

Families/relationships matter

- Social support and family relations are an integral part of subjective perceptions of recovery among individuals with first-episode psychosis (Windell et al., 2012 *a,b*).
- One major category of treatment goals for persons with first-episode psychosis may relate to relationships with family (e.g., “care for my child”; “live happily with my husband”) (Iyer et al., 2010)

Family factors in Chennai and Montreal

- Very little is known about what factors contribute to differences in outcomes between 'developed' and 'developing' countries
- Family factors seem to be a good candidate

Family factors in Chennai and Montreal

- Little is known about the role of the family in terms of what they do, how they are involved, what they do that helps etc.
- Even less is known about how this role played by families is seen by persons with psychosis and their families themselves
- Our focus group study with service users and family members in Chennai, India and Montreal, Canada

Findings

- Some Common themes
 - Being there

Findings

- Being there
 - Physical presence of the family in the practice of caregiving
 - Wide range of support extended by them.
- Being there was considered by both family members and patients as the most relevant component of the family's role.

Being there for the ill relative

- *We must let the patient know that we are there for him or her.*
- *So I believe that being the mother, and my daughter, she's the last one so you know, I just feel that as long as I'm there for her, that's how I feel, as long as I'm there for her and I can do the best I can do....*

“Being there” at many levels

- The role of the family in
 - Help seeking
 - Involvement in treatment (attending appointments, creating liaison with treatment providers and promoting medication adherence)
 - Facilitating social reintegration and recovery
 - Emotional/psychological support

Being there is appreciated

- *I just expect somebody to be there that I can be able to talk to so that way I don't feel like I'm all by myself.*
- *They [family members] can take care of the patient with love and affection.*
- *My father told me, "If you don't have anywhere to go, if you don't find a place to sleep, you can come to my house."*
- *Especially support that they gave me but also financially, because it also entails a cost when one is sick. You need support, and they're there.*

“Being there” can entail loss

- *Patient: I cried. I didn't like that at all. Especially when I arrived here at the [inpatient unit] and when my mom brought my clothes and my clothes, yes, I really found that hard.*

Moderator: Yes?

Patient: Yes.

Moderator: What about that was difficult?

Patient: Well, it was as if I was losing my autonomy.

“Being there” is seen differently

- *It's ok that I'm in my room and that I'm listening to music, that's not worrisome. What's worrisome is if I start being anxious about problems that are preoccupying me, then that's worrisome. But they mix the two up a bit, they have some difficulty discerning the difference.*

“Being there” is seen differently

- *Only we know what we go through.*
- *If I talk about my voices, then they tell me not to keep thinking about it all the time.*

Being there - Involvement in treatment

- He drives me here to my appointments; he comes and picks me back up. He always asks me what the doctor said and stuff like that, he's very helpful.

Findings

- Different moral languages
 - Montreal - Stressed terms such as will, autonomy, personal responsibility, and independence. Intertwined with this moral language was a legalistic language of rights (“court order”, “consent”, “right to confidentiality”).
 - Chennai - stressed terms such as obedience, respect, and conformity on the one hand and love and affection on the other.

Relevant quotes

- All subjects are open but I'd like it if they talked to me about it before. *If they have a problem with certain things that I've done or haven't done, I'd like it if they'd talk to me about it first and from there, we could decide together if we should talk about it with the family or not.*
- *Because I don't want my family knowing too many things about me. There is a lot of stuff I haven't told them.*

Findings

- Differences in notions of self and personhood, the morality of caring, and political economies of health care could underlie these different moral languages.

“Being there” : Duty or choice?

- *Someone should take 100% care and responsibility for them and look after their needs.*
- *We should never view a patient as a sick person. If there is a 2 year old child in our house and if he or she commits mistakes we take it lightly. In the same way, we should stop viewing a patient as a patient and treat them like a child.... If we treat patients like children and attend to their needs it will help a lot.*
- *We should be affectionate towards them.*

“Being there”: Duty or choice?

- *Well, there's only so much I feel like doing. He's not my son, he's my brother and I've sacrificed a lot for him....Because at some point it has to come from him, he has to work it out*
- *It is time that he takes decision for himself, you know*

Concluding thoughts

- How do persons with psychosis, families and treatment providers define families?
 - the concept of families is being constantly reconstructed in societies.

Concluding thoughts

- Need for more research
 - Investigating the engagement of families in specialized early intervention and their uptake of family interventions and factors influencing these
 - Engaging families as co-investigators
 - Examining definitions, roles, and perspectives of family members

Family member perspectives

- Understanding family member perspectives has important implications

Early Intervention in Psychiatry 2011; 5: 163–167

Brief Report

Concerns reported by family members of individuals with first-episode psychosis

Srividya N. Iyer,¹ Heleen Loohuis,¹ Nicole Pawliuk,¹ Ridha Joobar^{1,2} and Ashok K. Malla^{1,2}

doi:10.1111/j.1751-7893.2011.00265.x

Family member perspectives

- In order of frequency of endorsement, concerns listed by families were
 - self-esteem and identity (19.67%),
 - social behaviour (16.39%),
 - substance abuse (14.34%),
 - medications (13.11%),
 - stressful situations, early warning signs, resources and support, stigma, and sexuality and intimacy.

Acknowledgements

- PEPP (Montreal)
 - Alessandra Miklavcic, Ph.D.
 - Elsje van Der ven
 - Heleen Loohuis
 - Nicole Pawliuk
 - Megan Pope
 - Ridha Joober, M.D., Ph.D.
 - Ashok Malla, M.D.
- SCARF (India)
 - Mangala Ramamurti, M.D.
 - Sushma Rameshkumar
 - Thara Rangaswamy, M.D., Ph.D.