Understanding Family-Centered Care in the Mental Health System:

Perspectives From Family Members Caring for Relatives with Mental Health Problems

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Introduction

• **Family-Centered Care (FCC):**

  Welcoming and respecting family members as partners in caregiving, program planning, and policy-making (Johnson, 2000).
Literature Review

• Various reports (CAMH, 2004; FMHA, 2006; MAG, 2010; MHCC, 2010) recommend:
  – Collaborative partnerships with families
  – Provision of quality mental health information, education, and support
  – Involvement of families in professional training, research, and policy-making

• Many mental health providers implement FCC principles into their practice (Bryan, 2009; Craft et al., 2006; Dixon et al., 2001, 2004; Drapalski et al., 2008; Lefley, 1996; Pickett et al., 2006)

• Some family members respond favourably to FCC efforts (Campbell, 2004, Dixon, 2004; Gerson et al., 2009; Molewyk, 2002, Rethink, 2003)

• Other family members express a significant lack of collaboration, information, and support (Ballon, 2009; Buteau et al., 2008; Drapalski et al., 2008; Friesen, 2006; Worthington & Rooney, 2010)
Definitions:

- **Individual Discrimination:**
  - “Negative or disrespectful actions against [people with mental health issues and their families]” (Everett, 2009, p. 5).

- **Structural Discrimination:**
  - Policies that intentionally or unintentionally restrict the opportunities of people with mental health problems and their families (Corrigan et al., 2004).

- For the purposes of this study, discrimination may occur at both individual and structural levels, and be intentional or unintentional.
Literature Review Cont’d

• Critical mental health literature:
  – Baker, 2007; Bassman, Baker & Packard, 2009; Caras, 1998; Friesen, 2006; Jones, 2002

• Neoliberalism and caregiving:
  – Brown, 1995; Carey, 2009; Furedi, 2006; Henderson, 2005; Teghtsoonian, 2009

• Feminization of caregiving:
  – Canadian Caregiver Coalition, 2008; Canadian Mental Health Association, 2004; Conway et al., 2002; Health Canada, 2004; Pinquart & Sorenson, 2006; Scheyett, 1990
Theoretical Perspective

- Critical Foucauldian analysis (Barker, 1998; Chambon, 1999)
- Knowledge creation through the operation of power
- Mechanisms of power:
  - Dominant discourse
  - Binary identity categories
  - Governmentality
- Biomedical discourses > privilege professional knowledge > create expert/non-expert identity categories
- Psychiatric discourses > describe pathology and dysfunction > create functional/dysfunctional identity categories
- Neoliberal discourses > reinforce individual caregiving responsibilities > create responsible/irresponsible identity categories
Method

• Qualitative, exploratory research method
• 4 female participants, one hour interview per person

• Topic categories include:
  – Principles of FCC:
    • Collaboration
    • Information
    • Support
  – Obstacles to FCC:
    • Client confidentiality
    • Funding limitations
    • Discrimination

• Limitations:
  – small, homogenous, voluntary sample
Findings

FM = Family Member

Collaboration:

FM4: I probably would like to be included more...They don't seem to be interested in the day to day life and...how is that not of any value?...I just don't understand that.

FM2: ... I think they need to involve the families more...you’re a partner but you’re not really a partner. There’s a definite limitation.
Findings

Information:

FM1: I don't even know that [the professional] really spoke to us...two minutes probably...I think that was when he was grabbing a coffee....

FM2: ...there was no communication during any of the hospital stays. I'm telling you right now. There wasn't any.

FM4: They would keep us informed, kind of...The very first time, we had an actual talk with...a social worker...but she was no longer there for the second visit...
Findings

Support:

FM1: I think I’m pretty well connected that we were able to get things moving, but the average person? No, how would they know what to do?

FM4: We know a lot of people in the community...it tends to open more doors...otherwise I...didn't know where to go...

FM1: I think it takes that crisis...we’re talking real crisis, like this is dangerous...to get those supports.

FM2: I was trying to get some help for myself...I felt that I was asking...but nobody was hearing me and... I was desperate...I was in crisis...
Findings

Support Cont’d:

FM4: [Family psychoeducation and support group]...it was amazing...just the talking...the sharing of information...to know you weren’t alone...led me to believe that there was hope...

FM2: I have a friend...but...she’s never...offered to help if I go away...which I feel I can’t do...” and “I work full-time and I’m a single mother...so it’s financially stressful...this economy...it doesn’t help people like us.
Findings

Confidentiality:

FM1: \(\text{...you are not my client...I am not talking to you, you need to get that.}\)

FM4: \(\text{Why are they so afraid to actually talk to the caregivers?}\)

FM3: \(\text{...I guess [the relative] should have that choice...but if a person had cancer...would the family members not be spoken to or not be given the...prognosis at some point?}\)
Findings

Funding Limitations:

FM4: [Mental health providers are] overworked and underfunded and they're probably trying to claw the same doors down that I am... but there's nothing you can do.

FM1: [The mental health provider’s] hands were tied... as far as how much service she could provide.

FM3: I know there's a money issue... I wish there was someone higher up that I could write to...
Findings

Discrimination:

FM1: [The doctor] looked at me like, “you are the worst mother”...[he asked] “why don’t you know where he is living?”...and there was something else he said....like, “you don’t know what [substances] he’s been taking?”

FM3: I don't know...I can't really say that I have... one of the assertive things I did was ...arrange for [my relative] to see this doctor and...[the doctor] was very cool with [my relative]...and I felt it was because he was sort of pushed into the situation...that was the only time I could recall.
Findings

Discrimination Cont’d:

FM2: No, I don't think so... I think it's just such a dark subject... I've seen definite improvement over the years.

FM4: [The community mental health providers] have been very helpful.... but... they’re underfunded and understaffed... I had appointments and I mean it couldn't be helped, but I'd... leave work and the person I was suppose to see was away or out and that was several times.
Findings

Definitions:

- **Governmentality:**
  - process by which people regulate themselves according to certain rules, norms, and values held by the dominant society

- **Neoliberalism:**
  - involves maximizing profit by reducing spending, increasing volunteerism, and emphasizing individual, family, and community responsibility

- **Responsibilization:**
  - the social and moral obligations of citizens to draw on their personal resources so as not to burden the system
Findings

Critical, Foucauldian Analysis

Biomedical Discourse

Expert/Non-Expert Identity Categories:

FM1: I was relieved...I was thankful...we knew it was good...

FM4: ...such a relief, she’s seeing a psychiatrist...

FM4: ...now this is just my opinion, I'm not an expert on it.....you start to feel like you’re not knowledgeable. *They’re* the professionals.
Findings

Psychiatric Discourse

Functional/Dysfunctional Identity Categories:

FM1: We had quite a diagnosis...“dysfunctional family system”...I didn’t feel that we were...dysfunctional...but in hindsight we were...and we still are...

Neoliberal Discourse

Responsible/Irresponsible Identity Categories:

FM2: ...I’m a single parent and...what if something happens to me? What will happen to [my relative]?...I’m hoping that...family members are interested. I’m hoping my daughter will be...and my sister.
Findings

Resistance

Expert/Non-Expert Identity Category:

FM4: I haven't...done the degree...but...I have the expert knowledge of what I'm seeing...

FM4: If I'm dying with cancer, I'm going to get a second opinion. And are we not allowed a second opinion in the mental health field? I can't see why not.
Findings

Resistance

Functional/Dysfunctional Identity Categories:

I ask if there is any way to frame her family situation as something other than dysfunctional.

FM1: crisis?...yeah...we were in a crisis situation...
Findings

Resistance

Responsible/Irresponsible Identity Categories:

FM2: I learned more in the...weeks I went to [the support group] than I have in [several] years...but anyway you learn...and it sometimes takes a crisis to learn... and maybe that's my fault...maybe I wasn’t asking the right questions...I just didn’t know where to go...but...when you don't know...how would you know? There's something just lacking there.

FM3: I do feel a lot of the time that I come on too strong...that I’m too assertive...

FM4: It’s not my nature to be overbearing...but we have kind of been out of comfort zone...pressing...

FM1: I felt kind of like a mothering-pain-in-the-butt but I didn’t care.
Discussion and Implications

Recommendations for Change:

• Many recommendations for improving FCC have already been made

• What is *not* addressed is the unequal distribution of power and resources

• Family members, relatives, and professionals are being constructed to accept failures in the mental health system as natural and inevitable

• Family members in this study:
  – Place maximum value on minimal FCC efforts
  – Exonerate mental health providers
  – Accept funding limitations as inescapable
  – Blame themselves
  – Tend not to recognize and/or label structural discrimination
Discussion and Implications

Transformative work involves:

- Understanding processes that sustain inequality

- Knowing that “since these things have been made, they can be unmade, as long as we know how it was that they were made...” (Foucault, 1983, as cited in Chambon, 1999)

- Recognizing “that the present is not natural and need not be taken as inevitable or absolute” (Chambon, 1999, p. 70)
Discussion and Implications

Recommendations for Change Include:

• Providers can encourage family members and their relatives to:
  – Ask questions
  – Challenge authority
  – Expect equality

• Providers can:
  – Invite family complaints
  – Welcome family anger
  – Facilitate family participation and leadership at all levels
  – Consider our resistance to power sharing
  – Challenge inequitable systems
  – Question our values and beliefs
  – Explore alternatives
Conclusion

- Family members in this study report a need for increased collaboration, information and support, and identify client confidentiality and funding limitations as obstacles to FCC.

- They describe the *effects* of discrimination, but do not label them explicitly as such.

- A critical, Foucauldian analysis is useful in exploring hidden systems of domination and oppression in the mental health system.

- **Ultimate goals:**
  - stimulate critical thinking and discussion
  - disrupt ideological aspects of FCC
  - question role of FCC in reproducing inequality
  - highlight complexities of family involvement
  - illuminate our complicity in the perpetuation of discrimination
  - Facilitate social transformation, equality, and justice
Thank you!

Questions?

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