A Global perspective of caring for the mentally ill: Empowering individuals who live with schizophrenia

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Background

- Schizophrenia has a lifetime prevalence of 1% wordwide (McGorry, 2004)

- Schizophrenia is disproportionally higher in males and disadvantaged communities (McGrath, et al. 2004; Aleman, 2003)

- Suicide is a serious outcome of schizophrenia (Kim et al.,2003; Lewis, 2004; Pompili et al.,(2004); with a lifetime prevalence of 4.9% (Palmer et al.,2005)

Background

- Stigma affects how individuals with schizophrenia self-identify & underscores feelings of worthlessness, depression and loss of self empowerment (Walker & Read,2002)
- Despite advances in neuroleptics, a sizable percentage of psychotic individuals are unresponsive to meds, and likely to relapse (Bustillo, et al, 2001; Heinsen, Lieberman & Kapelowicz, 2000)

Statement of the Problem

- Yet, worldwide, potential for improved outcomes and quality of life has not been translated into reality (McGorry, 2004)

Schizophrenia

- Schizophrenia:

  DSM IV criteria require six months of continuous symptoms including an active phase of at least one week

  Symptoms include disturbances in thought, language, perception, affect and self identity

Purpose

This qualitative study had two specific aims: to generate understanding regarding the experience of the schizophrenia and the relationship between self and the symptoms of schizophrenia

Method

A Heideggerian-hermeneutic approach investigates the meaning of self and phenomena using narratives as the epistemological tool

- Purposive sample of 12
- Inclusion criteria: articulate adults with schizophrenia
- Recruited from 2 out-patient settings in Southeastern Virginia
- IRB approval
- Provided informed consent and could terminate interview without penalty
- Opportunity for supportive counseling and follow-up
- Created own pseudonym
- 30-45 minute confidential interviews audio taped and transcribed verbatim
- Unstructured interview questions
- Use of probes and exploring questions
- Field notes written immediately after interview
- Qualitative analysis using Diekleman, Allen & Tanner's (1989) method

Qualitative analysis using Diekleman, Allen & Tanner's (1989) method:

Audio recorded interviews and notes were read by researcher and team (three adv. practice clinicians and three Heideggerian researchers)

- Implicit and explicit meanings were extracted
- Hermeneutic stories were developed by team
- Themes were developed using software (Martin, 1995)
- Themes that went against the pattern were identified and compared with the team
- Constitutive patterns were justified

Demographic Profile

- 6 African American & 6 Caucasian:

  Mean age 50 years
- At the time of the interviews all of the participants were on psychiatric meds.
- 7 w/HS diplomas, one participant had a reading disorder and 3 w/some college.

Study Conclusions

1. With two exceptions, all described a litany of negative consequences

2. All but one was able to recall this experience as something positive

3. Living a life of loss, losing connections w/family and links w/the community were unexpected results

4. Most related lending a different kind of meaning to this experience as integral to surviving mental illness.

5. All developed a sense of overcoming and surviving in their own way.

6. Almost all agreed schizophrenia and its symptoms were not expressive of who they were.

Theme 1: Are they who they are?

- **Conscious of a negative**
  - 1st awareness of a negative-I am not all right
- **Merging with reality**
  - The voices, shapes, persons appeared so real they at once became part of the person's reality
- **Lending meaning**
  - Hallucinations and delusions provided some kind of meaning
  - Voices and visions expressed their duality

Theme 2: A not so certain life

- Participants related a sense of ambiguity about treatment that resembled the uncertain course of chronic illness

- Compellingness of symptoms

  - Coercive feature of hallucinations

"I hear voices-they tell me what to do, what not to do-tell me to hate myself when I'm really down. They gave me sorrow." (Mary)

  - Feeling powerless; feeling vulnerable: The need to obey

"I know better,…and I knowed everything I was doing, but I just couldn't help it." (Katrina)

Theme 3: Finding strength in the broken places

- Depression was heightened by losses
- Participants described a succession of missed opportunities
- Cultural definitions of success were missing

Theme 3: Finding strength in the broken places (cont.)

- Loss occurred in a larger sense as their role in the community subsided
- Participants related feeling as “if I haven’t done anything with my life”
- Loss resembles disenfranchised loss as outlined by Doka (1989)

Theme 3: Finding strength in the broken places (cont.)

- Regaining balance
  - Schizophrenia provided opportunities for growth
  - Suffering gave a heightened sensibility to the suffering of others
    - "Makes you more giving" (Mary)
- Finding strength
  - Surviving with a different reality
    - "It gave me courage" (Mack)
  - Medication management
    - "Honey I need my medication, I do" (Louise)
    - "Clozaril was a lifesaver" (Jimmy)
    - "The medications give me hallucinations" (PFC)

Theme 4: I am still me

- Damaged self-esteem
  - Most revealed that their 1st awareness of symptoms were hallucinations were images or voices that attacked them; however, a few felt their self-esteem attacked.
- Getting in touch with me
  - As damaging as the disease symptoms were to the psyche, there still was the core, the being, of the remembered person. "I am still me" (Akim)

Constitutive pattern: Akim's Story

- Akim's story highlighted the participants discovery that despite numerous attacks on self-esteem they would remain in touch with who they were.

Global Implications for Research

- Explore disenfranchised grief, preservation of self, and issues of re-hospitalization
- Investigate the process of coming to terms with mental illness
- Finding balance in providing care: individualizing care
- Language/expectations that fit this population
- How do we educate our nurses? If nurses do not know what the experience of schizophrenia is like for the individual, how can meaningful nursing interventions be chosen?

Global Implications for Education

Etiology:

- Genetic vulnerability-variable combination of multiple genes
- “First hit” and “second hit” model

Global Implications for Education

- Insight and depression-while insight creates a path for understanding one's situation, research indicates that insight may deepen depressive symptoms and increase the risk for suicide (Sharaf, Osman, & Lachine, 2012)

Implications for Practice

- Diagnosis is complicated in cross cultural settings
- Social disadvantages impede access and early treatment
- Engaging and treating the individual in the prodromal stage:

"A greater capacity to engage and treat young people in this phase needs to be developed" McGorry, 2004, p. 16

Final thoughts

- Nurturing the sense of self
  - Corin & Lauzon (1992) – Nurturing the sense of self
- Our goals are not necessarily the client's goals
  - Sells, Stayner & Davidson (2004)

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