The Concept of Self-Stigma: A Clinical Investigation

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Disclosure

• Presenters: Linda Carman Copel & Khamis Al-Mamari

• Learner Objectives:
  • Describe the concept of self-stigma as it is experienced by women with disabilities who have extricated themselves from intimate partner violence.
  • Discuss a proposed model to explain the experience of self-stigma and the strategies to decrease its occurrence.

• Conflict of Interest Statement:
  • We have no relationships to disclose.

• Employer: Villanova University

• Sponsorship or Commercial Support:
  • We have no support to disclose.
Background of the Study

- The concept of stigma is recognized as a universal experience which is a major cause of suffering and a deterrent to obtaining health care.

- Vulnerable populations, such as women with disabilities (WWD) who have experienced intimate partner violence (IPV) are at risk for various forms of stigma, especially self-stigma, double stigma and health care provider stigma.

- Stigma has a negative influence on people’s lives by causing high levels of stress and social disadvantages.
Objectives of the Study

- To describe the nature of the phenomenon of self-stigma by women with disabilities (WWD) who had experienced intimate partner violence (IPV) and extricated themselves from their violent situations.

- To identify if additional types of stigma were experienced by WWD and to compare the findings to a proposed stigma model constructed through concept analysis.
Methodology

- Secondary Data Analysis
- Original study: The Lived Experience of Intimate Partner Violence by Women With Disabilities
- Data were collected in 2008 – 2009.
- Research Question: Do women with disabilities who experience intimate partner violence experience stigma?
- Data were from the transcripts of the interviews of women with disabilities who had experienced IPV and extricated themselves from their violent situations.
Methodology

- The sample was a convenience sample of 24 adult females formerly married to abusive male spouses.
- The women were older than 21 years and able to speak, read and write English.
- The study setting was the Mid-Atlantic region of the United States.
- The participants were recruited from a mental health center, and they were receiving individual or group therapy services from the center.
Methodology

- Asked open-ended interview questions:
  - Will you please describe the verbal abuse that you experienced with your spouse?
  - Will you please describe if verbal abuse lead to other types of abuse or violent behavior?
- Completed a demographic data form
- Interviews occurred in the outpatient community mental health center or in the participants’ homes.
- Interviews were audio recorded and from 45 to 95 minutes in length.
Demographic Data

Age: 32-57 years

Race: 14 Caucasian 4 Black

Ethnic Background: 4 Black 4 English
4 Irish 2 German
2 Italian 1 Scotch-Irish
1 Russian
Demographic Data

Religious Affiliation: 2 Baptist
6 Catholic
4 Episcopal
4 Methodist
2 Presbyterian

Education Level: 8 High School
6 College
2 Some Graduate Courses
2 High School/GED
Demographic Data

Employment Status:
- 5 Employed Part Time
- 4 Employed Full Time
- 4 Unemployed
- 3 Volunteer
- 2 Self-employed
Demographic Data

**Occupation:**
- 4 Unemployed
- 3 Volunteers
- 3 Office Work (part time)
- 2 Receptionists
- 2 Teachers
- 2 Self-employed (types/edits)
- 1 Seamstress (self-employed)
- 1 “Librarian” (works in library)
Demographic Data

Identified Disabilities:

4 Orthopedic Injuries
3 Multiple Sclerosis
2 Legally Blind
2 Cardiovascular Accident (stroke)
1 Amputation (leg and fingers)
1 Cardiac (implantable cardioverter defibrillator ICD)
1 Diabetes (with complications)
1 Lupus Erythematosus
1 Paraplegia (post spinal cord injury)
1 Renal Failure (dialysis)
1 Scleroderma
1 Spina Bifida
Demographic Data

Current Problematic Health Problems

Anemia                      Genital Herpes
Arthritis                   Headaches
Breast Cancer               Hearing Difficulties
Depression                  Hypertension
Dry Skin and Skin Irritation Obesity
Gastrointestinal Upset      Vaginal Irritation
Obsessive Thinking          Pain (back, extremities, neck)
Demographic Data

Current Health Problems Related to Identified Disability

Ambulation Problems
Arthritis
Back, Neck, and Arm Pain
Balance and Coordination Problems
Circulation Problems
Depression
Esophageal Reflux and Spasm
Demographic Data

Current Health Problems Related to Identified Disability

- Hearing
- Kidney Problems
- Morning Stiffness
- Muscle Spasms and Pain
- Raynaud’s Phenomenon
- Respiratory Tract Infections
- Urinary Tract Infections
- Visual Difficulties
Demographic Data

- History of abuse prior to marriage:
  - 1 boyfriend (future spouse)
  - 1 father
  - 1 grandfather
  - 1 step-brother

- History of abuse with spouse prior to disability:
  - 4 Abuse history present
  - 20 Abuse history not present

- Onset of disability:
  - 4 Disabled prior to marriage
  - 20 Disabled after marriage
Findings Based on Content Analysis

- 53 statements of self stigma
- 15 statements of double stigma
- 9 statements of health care provider stigma
- 4 empirical referents from the concept analysis
  - Experience of discrimination
  - Feelings of being devalued
  - Negative attitude towards self
  - Struggles with self-care and daily functioning
Findings Based on Content Analysis

- All the women experienced self-stigma.
- Five women experienced double stigma.
- Four experienced health care provider stigma.
- Antecedents of self-stigma from the transcripts:
  - Health problems – disabilities & chronic illness
  - Self-blame for abuse and disability situations
  - Fear of partner
  - Fear of what others thought of them for not preventing, controlling or better handling the abuse
Findings Based on Content Analysis

• The women identified consequences of self-stigma
  • Feeling less than others
  • Isolated from people
  • Experienced multiple types of stressors
  • Unhealthy relationships
  • Uncertain about ability to function
  • Personal barriers to meeting own needs
  • Health care barriers to meeting health needs
Concept Analysis of Stigma

Concept Analysis

• **Antecedents:**
  - Feeling self-conscious
  - Feeling different from others
  - Shame
  - Self-blame
  - Fears

• **Characteristics:**
  - Experience of discrimination
  - Feelings of being devalued
  - Negative attitude towards self
  - Struggles with self-care and daily functioning

• **Consequences:**
  - Feeling less than others
  - Unhealthy relationships
  - Barriers to health care
  - Barriers to social opportunities
  - Barriers to job opportunities
  - Decreased quality of life
  - Assertive discussion of stigma
  - Participation in self-care and health care
  - Participation in health activism
Concept Analysis of Stigma

Research Findings: Concept Analysis

- **Antecedents:**
  - Health problems – disabilities & chronic illness
  - **Self-blame** for abuse and disability situations
  - Fear of partner
  - Fear of what others thought of them for not preventing, controlling or better handling the abuse

- **Characteristics:**
  - Experience of discrimination
  - Feelings of being devalued
  - Negative attitude towards self
  - Struggles with self-care and daily functioning

- **Consequences:**
  - Feeling less than others
  - Isolated from people
  - Experienced multiple types of stressors
  - **Unhealthy relationships**
  - Uncertain about ability to function
  - Personal barriers to meeting own needs
  - Health care barriers to meeting health needs
Self-Stigma in WWD who Experienced IPV

**Antecedents of Self-Stigma**
- Health problems – disabilities & chronic illness
- Self-blame for abuse and disability situations
- Fear of partner
- Fear of what others thought of them for not preventing, controlling or better handling the abuse

**Characteristics of Self-Stigma**
- Discrimination experience
- Feeling devalued
- Negative attitude towards self
- Struggles with self-care and daily functioning

**Consequences of Self-Stigma**
- Feeling less than others
- Isolated from people
- Experienced multiple types of stressors
- Unhealthy relationships
- Uncertain about ability to function
- Personal barriers to meeting own needs
- Health care barriers to meeting health needs

**EDUCATION**
- Client- Family-Community
- Health Care Providers

**EFFECTIVE TREATMENT**
Conclusions

- There is little understanding of the concept of stigma, the various types of stigma, and how stigma negatively influences the well-being of WWD who experienced IPV.
- Self-stigma statements were predominately identified and associated with the negative situations that were connected to the IPV experiences.
- WWD who experienced IPV recognized that stigma negatively influenced the state of their physical and mental health.
Conclusions

- Only a part of the concept analysis of stigma was supported by the experiences of the WWD.
- Although the literature and concept analysis identified the positive consequences of stigma, the WWD who experienced IPV did not speak to any of the positive outcomes related to overcoming stigma.
- Even after being extricated from the IPV, the WWD made statements supporting their experience of stigma, especially self-stigma.
Implications

- Stigma, particularly self-stigma, is a mental health and physical health concern for this population.
- Action and education must be taken to eliminate health care provider stigma for WWD who experienced IPV.
- The model based on the experiences of WWD requires further evaluation based on additional empirical evidence.
- There was a stigma associated with having a disability and experiencing IPV.
Implications

- There is a responsibility for all health care providers to assess and address the antecedents of self-stigma, especially the uncertainty, negativity and fear related to the disability, health issues, and the experience of IPV.
- Issue to consider: How does the experience of disability, abuse and stigma compound the alteration in daily functioning for WWD?
Research Recommendations

- Add to the nursing literature by studying the:
  - Concept of stigma
  - Types of stigma
  - Stigma experienced by WWD
  - Stigma experienced by WWD who encountered IPV
  - Stigma experienced by non-disabled women who encountered IPV

- Investigate and refine the proposed model.