

A TRANSFORMATION PROCESS:

HEALTH TEACHING BY NURSES TO ADULTS WITH INTELLECTUAL/DEVELOPMENTAL DISABILITIES

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LITERATURE REVIEWED

- ↪ Same medical conditions
- ↪ Approaching general population life expectancy
- ↪ Morbidity and Mortality

- ↪ Deinstitutionalization

- ↪ Limited and segregated education of adults with intellectual/developmental disabilities (ID/DD).

- ↪ Registered Nurses (RNs) have had limited education and experience teaching adults with ID/DD

RESEARCH QUESTIONS

- ↪ What are the experiences of RNs who provide health teaching to adults with ID/DD?
- ↪ What health topics do RNs teach adults with ID/DD and how do they select these topics?
- ↪ What teaching strategies do RNs use when teaching adults with ID/DD?

STUDY DESIGN

- ↪ Qualitative and Descriptive (Sandelowski, 2000) using Naturalistic Inquiry (Lincoln & Guba, 1985)
- ↪ Purposive and Snowball sampling
- ↪ $n = 23$

- ↪ Individual interviews ($n = 12$)
- ↪ 2 Focus group interviews ($n = 11$)
- ↪ Non-participant observations ($n = 7$)

SAMPLE PROTECTION

- ↪ IRB approval

- ↪ Director contact
- ↪ Letter of invitation
- ↪ Phone contacts

- ↪ No significant risks
- ↪ Confidentiality
- ↪ Compensation

SAMPLE VARIATION

- ↪ RN Roles - 3 residential agency, 1 working in an agency, 16 from 4 health care quality units, 1 NP, 1 hospital based certified diabetes educator, 1 forensic nurse/family therapist

- ↪ 26 Pennsylvania counties and national/international locations

- ↪ 75 residential/vocational agencies in urban and suburban areas

- ↪ Adults with ID/DD had a wide range of intellectual/functional levels

DATA COLLECTION

- ✧ Began September 2008 and ended November 2008
- ✧ Individual and Focus Group interview guides
- ✧ Non-Participant Observation protocol and guide
- ✧ Individual and Focus Group interviews were audiotaped and transcribed
- ✧ Interviews and observations lasted 45 – 90 minutes
- ✧ Field Notes and Self-reflexive Journaling

DEMOGRAPHIC QUESTIONNAIRE

- ✧ Gender: Women ($n = 21$); Men ($n = 2$)
- ✧ Age range: 25 – 65 (mean – 50.8)
- ✧ Years of RN experience: 4 months – 44 years (mean – 23.4)
- ✧ Years worked in ID/DD nursing: 4 months – 35 years (mean – 10.9)
- ✧ Nursing education: 1 doctorate, 4 masters, 5 baccalaureate, 5 associate, 6 diploma (2 blank)
- ✧ Certifications
- ✧ Nursing experience: home health, medical/surgical, psychiatric/mental health, pediatric

STUDY SETTING

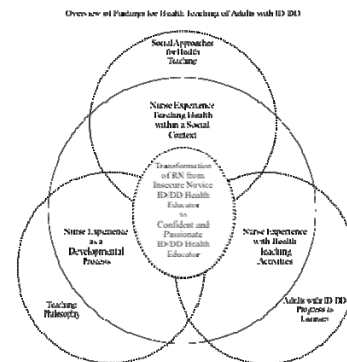
- ✧ Various settings negotiated with participants
 - ✧ Residential & vocational agencies
 - ✧ Health Care Quality Unit offices
 - ✧ Hospital
 - ✧ Coffee shop
 - ✧ Researcher's home
 - ✧ Participant's home
 - ✧ Hotel
 - ✧ Telephone
- ✧ Geographic locations: Bucks, Chester, Delaware, Montgomery, Philadelphia, Schuylkill, Dauphin, and Butler counties. Telephone call to North Carolina.

DATA ANALYSIS

- ✧ Inductive
- ✧ Constant comparative
- ✧ NVivo8©
- ✧ Clusters of data emerged related to the research questions
 - ✧ RN Experiences of ID/DD health teaching
 - ✧ Health Teaching activities
- ✧ Unanticipated clusters of data emerged
 - ✧ Developmental process of the RN
 - ✧ Social context for teaching

SCIENTIFIC RIGOR

- ✧ Credibility
 - ✧ Triangulation of data sources
 - ✧ In-depth interviewing
- ✧ Dependability and Confirmability
 - ✧ Audit trail
 - ✧ Member checking
 - ✧ Peer feedback
- ✧ Transferability
 - ✧ Sample variation
 - ✧ Thick description
- ✧ Trustworthiness
 - ✧ Reflexive journaling



Findings: Experiences as a Developmental Process



Background

- ◇ Life Experiences
- ◇ Nursing Education
- ◇ Practice Experience
- ◇ Continuing Education

“...I heard that I would be dealing with people with mental retardation and I thought they would all have Down Syndrome. That’s what I knew about it” (Betty).

Nurse Characteristics

- ◇ Empathy
- ◇ Enthusiasm
- ◇ Creativity
- ◇ Flexibility
- ◇ Awareness of Personal Limitations

“I admit I had a little bit of a stereotype. I realized there were differences but I never realized every single one of these people are different individuals...their disability doesn’t make who they are” (Donna).

I look forward to my trainings with people with disabilities. They’re my favorite day (Focus Group 2 participant).

“Maybe you’re [the RN] not the one to get the message across. And being able to recognize [who] that person would be...” (Focus Group 1 participant).

Recognizing Variation

- ◇ Communication
- ◇ Comprehension

“Are they [adults with ID/DD] following along? Am I communicating clearly? Are they getting the point?” (Focus Group 2 participant)

“You can’t go in thinking, ‘Oh, well all these people are gonna be this level,’ because pretty much they are all different” (Nancy).

Understanding History of Education

- ◇ Limited Learning Opportunities
- ◇ Underestimating Capacity

In a non-participant observation at a health fair, a vendor asked a caregiver if the man with ID/DD wanted educational materials. The man approximated the sign for “yes” however neither of them saw him do this. The vendor handed the materials to the caregiver.

Teaching Philosophy

- ◇ Unknowing (Munhall, 1993)
- ◇ Recognizing Similarities
- ◇ Accommodating Differences

“Life is about choices and why would somebody with a disability [have] less of an opportunity to make a choice than the rest of us. I use myself as an example. Do I look like someone who hasn’t eaten a bag of chips? Of course I have” (Amanda).

TRANSFORMATION THROUGH TEACHING

- ✧ Feeling Insecure – “When you have to formally plan to do it [teaching], sometimes it is a little intimidating” (Donna).
- ✧ Being Surprised – “I met with them and I was totally blown away by what they wanted to know about” (Betty).
- ✧ Perseverance – “It took a turn that I myself was not totally ready for and had to say ‘Okay, relax here. I can figure this out’ (Marge).

TRANSFORMATION

- ✧ Comfort with Not Knowing – “Even though I was talking with the person and explaining what I was doing, a lot of times there was no response” (Helen).
- ✧ Passion for Teaching – “The joy on their [adults with ID/DD] faces was just phenomenal. That was the best point of my day” (Focus Group 2 participant).

Findings: Experiences of Teaching in a Social Context



SOCIAL CONTEXT

- ✧ Social context influences knowing (Chinn & Kramer, 2008), learning (Boyles et al., 2008), and teaching (Yilmaz, 2008).
- ✧ “Learning processes are socially embedded experiences in practice are expressed within social relations and dynamics” (Chisholm, 2008, p. 140).

SOCIAL CONTEXT DEFINITION

- ✧ The teaching that occurs through the interrelationship of the RNs’ philosophy, social approaches used to access, initiate, and provide health teaching, and the activities used to teach adults with ID/DD about health.

ACCESSING ADULTS WITH ID/DD FOR HEALTH TEACHING

- ✧ Challenges presented by Caregivers (anyone addressing the needs of adults with ID/DD)
 - ✧ Excuses
 - ✧ Scheduling
 - ✧ Turnover
- ✧ Convincing Caregivers
 - ✧ Building trust
 - ✧ Establishing relationships
 - ✧ Engaging caregivers
 - ✧ Expanding knowledge and experience of caregivers
 - ✧ Being responsive

Initiating Health Teaching for Adults with ID/DD

- ✧ Caregivers as Challenges
 - ✧ Scheduling
 - ✧ Inadequate information
 - ✧ Insensitivity
 - ✧ Caregivers as Benefits
 - ✧ Interpreters
 - ✧ Day to day application
- “Sometimes [caregivers] can be down right rude” (Focus Group 1 participant).
- “Sometimes the [adult] is more familiar and comfortable with the [caregivers]...” (Donna).

PROVIDING HEALTH TEACHING IN A SOCIAL CONTEXT

- ✧ Building Trust
- ✧ Establishing Relationships
- ✧ Creating Individual Boundaries
- ✧ Knowing Adults with ID/DD
- ✧ Including Adults with ID/DD in Making /choices
- ✧ Engaging Adults with ID/DD to Participate in Learning
- ✧ Fostering Interactions among Adults with ID/DD
- ✧ Being Responsive
- ✧ Using Encouragement

TRANSFORMATION THROUGH TEACHING

- ✧ Feeling Appreciated – “Once you’re here...all the positives that you get back from people...it would be difficult to give that up” (Sarah).
- ✧ Shared Experience – They [adults with ID/DD] said he [visitor] will be scared, so I acted scared, ‘I want to go home...’ At first they all came [and] swarmed on me. “No I’m afraid...Space, space, space.’ Something then switched and people talked gently and said, ‘Aw, you are safe here.’ I felt so warm because I felt held ...” (James).

Findings: Experiences with Health Teaching Activities



OVERVIEW

- ✧ Group Size
 - ✧ 6 to 15
- ✧ Session Frequency and Length of Sessions
 - ✧ Once to annually
 - ✧ One hour
- ✧ Individualized Teaching
- ✧ Teaching Assistance
 - ✧ Power point
 - ✧ Gender specific topics

Selecting Topics

- ✧ Generated by an Agency
 - ✧ Based on Health Risks
 - ✧ Determined by the RN
 - ✧ Requested by Adults with ID/DD
 - ✧ Spontaneous Requests
- “Somebody [adult with ID/DD] said they wanted to learn about colonoscopies...The doctor told this person they had a polyp, but nobody ever told them [what it was] and they were probably scared to death” (Betty).

TOPICS TAUGHT

- ✧ Health Conditions
- ✧ Health Promotion
- ✧ Mental Health
- ✧ Social Issues

Teaching Preparation

- ✧ Developing Objectives
 - ✧ Finding Resources
 - ✧ Adapting Teaching Materials
- “I’ll download them [internet resource], print them out, and some of it I’ll say, ‘Oh this is too childish,’ but it gets my brain working [in order to adapt materials]” (Marge).

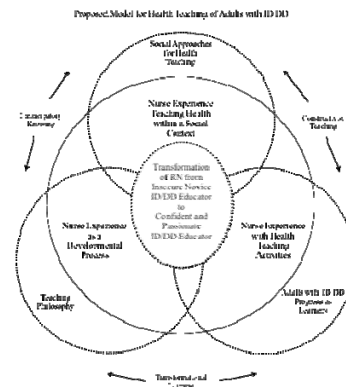
STRATEGIES FOR HEALTH TEACHING

- ✧ Approaches to Facilitate Learning
 - ✧ Easy to Understand
 - ✧ Repetition and Review
 - ✧ Humor
 - ✧ Time
- ✧ Teaching Methods
 - ✧ Questions, Examples, Demonstration, and Discussion
 - ✧ Written Materials, Sharing Experiences, Power Point, and Interactive Approaches
 - ✧ Lectures
 - ✧ Combination of Methods

TRANSFORMATION THROUGH TEACHING

- ✧ Observing Progress – “We use our game show players [after] a social skills training. A few months later, I will follow up with the social skills game and say ‘Okay. Let’s see how much you learned from that’ ... (Nancy).
- ✧ Learning from Adults with ID/DD – “I assume that I know nothing about [the adult with ID/DD] and the more that I unknow, means the more I have any opportunity to learn from them” (Steve).

GRACE SUMMARIZED HER TRANSFORMATION FROM BEING AN INSECURE NOVICE EDUCATOR OF ADULTS WITH ID/DD TO A CONFIDENT AND PASSIONATE EDUCATOR OF THESE ADULTS.



DISCUSSION OF FINDINGS

- ✧ The developmental process shared literature:
 - ✧ Emancipatory knowing and social activism (Chinn & Kramer, 2008).
 - ✧ Unknowing (Munhall, 1993).
 - ✧ Unfolding transformation (Driscoll, 2005).

DISCUSSION OF FINDINGS

- ✧ Transformational learning offered a view of the RNs' change by teaching in a social context through:
 - ✧ Frame of reference and critical reflection (Mezirow, 1997).
 - ✧ Social interaction for learning (Driscoll, 2005; Gredler, 2009).
 - ✧ "Meaningful, genuine relationships" (Cranton, 2006).
 - ✧ Multiple realities (Taylor, 2008).
 - ✧ Paralleled evolution from novice to confident nurse educator (Johnson, 2008; McGranahan, 2008).

DISCUSSION OF FINDINGS

- ✧ Constructivism occurred within the RNs' transformation in the process of health teaching activities through:
 - ✧ Teaching as a medium for making meaning from multiple realities (Brown-Wilson, 2008; Erickson, 2007).
 - ✧ Person centered nursing (McCormack & McCance, 2006).
 - ✧ Cultural historical understanding (Vygotsky in Grendler, 2009).
 - ✧ Use of a social realm to influence knowledge formulation (Yilmaz, 2008).
 - ✧ Critical reflection (Kreber, 2004).

NURSING IMPLICATIONS

- ✧ Nursing Practice
 - ✧ Address stigma
 - ✧ Enhance health teaching activities
 - ✧ Implications for human service disciplines
- ✧ Nursing Education
 - ✧ Teach nursing students about vulnerable populations
 - ✧ Impact professional development through presentations
- ✧ Nursing Science and Research
 - ✧ Proposed model for teaching adults with ID/DD
 - ✧ Extend limited published research

RECOMMENDATIONS FOR FUTURE RESEARCH

Examples:

- ✧ Extend the description of the RNs' experiences beyond Pennsylvania
- ✧ Participatory action research with adults with ID/DD
- ✧ Determine extent of encounters, beliefs, attitudes, educational needs of RNs quantitatively
- ✧ Determine validity of the proposed model from this study

THANK YOU!