

Developing a cultural model for long-term female urinary incontinence

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Abstract

The purpose of this study is to examine the subjective experience of long-term urinary incontinence and to show how a cultural model helps define that experience. Using a narrative approach within a cultural models framework, the specific aims are to describe and analyze: (1) what urinary incontinence means; and (2) how that meaning is constructed and negotiated by women living with urinary incontinence. 17 community-dwelling women (from Philadelphia, USA, and its immediate suburbs) participated in semi-structured interviews. Plot types and shared themes were compared with themes that emerged from media representations of female incontinence, and a cultural model was developed. Findings suggest: (1) the meaning of long-term female urinary incontinence is constructed and negotiated as a result of individual and shared experiences; (2) the cultural model constructed by women differs significantly from the professional, primarily biomedical model; and (3) women's narratives provide a method for accommodating similarities and differences between lay and professional models.

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Introduction

Ms. T: I'm sure if you're in it [urinary incontinence (UI)]; it's not as funny. (Laughs)...And I guess there's just not.... what's that thing you get....Cultural literacy? It's sort of cultural knowledge about them, like menopause. I haven't been through menopause but I have a general idea of what menopause is like but I don't have a general idea of what incontinence is and I have it. (Laughs) So there's not an everyday language being spoken that relates to

incontinence. Whereas, there is about many other things like menopause or ...Viagra[®]. Oh hell, we're *all* talking about that. But...with incontinence you're not really—there's not an education that you get just from living. You don't get an education from watching TV or reading the newspapers because they never mention it...Like menopause you sort of have a middle-aged woman. And...Viagra[®]—I don't know what you have but it's definitely a guy. (Laughs)...But incontinence...I don't even know still...

Ms. T's comments serve as an example of one woman's description of the meaning of UI. As she sees it, there is no cultural model for UI in our society. She is looking for (and not finding) a way to

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fit UI into her identity as a woman, but there are no cultural cues or shared ideas upon which to draw.

The purpose of this study was to examine the subjective experience of women who suffer from long-term UI and to show how a cultural model helps define that experience. Specific aims were to describe and analyze: (1) what UI means; and (2) how that meaning is constructed and negotiated by women with long-term UI.

Background and theoretical framework

Narrative inquiry

This study employed a narrative approach within a cultural models framework. Narrative can be defined as [an] “organizational scheme expressed in story form” (Polkinghorne, 1988, p. 13). This definition implies that the terms “story” and “narrative” are used interchangeably, and encompasses the process of making a story, the cognitive scheme of the story, and the result of the process (Polkinghorne, 1988). In this study, a narrative approach was used as a method for understanding how cultural resources are used to construct the stories that inform people’s lives (Dressler, Bindon, & Neggers, 1998; Silverman, 2000).

Approaches to narrative analysis differ across disciplines and according to the theoretical orientation of the researcher. Linguists, for example, have developed analytic methods that emphasize story structure. For many researchers in the social and health-care sciences, the structure of stories is less important than how they fit into a larger life story, and what they mean for the teller. In this case, analytic strategies center on finding themes and plots that help in understanding the story (Bradway & Huss-Ashmore, 2006). McAdams and Bowman (2001) analyzed life-stories of successful and unsuccessful people, identifying positive (“redemption”) and negative (“contamination”) plot sequences in their narratives. In a similar vein, Frank (1995) analyzed illness stories prominent in American culture, grouping them into three overall types—“restitution,” “chaos,” and “quest”—on the basis of plot.

This study used women’s narratives as a method for identifying a cultural model for long-term, female UI. The model that emerged provides a framework for the meanings that women assign to, or construct for, UI.

Theoretical framework

Cognitive anthropology (CA) provided the overall framework for this study. CA emphasizes how culture structures meaning and is based on the assumption that culture is learned and transmitted by individuals and groups (Dressler & Oths, 1997; Dressler et al., 1998). As cognitive anthropologists understand it, *cognitive schemas* are learned by individuals as a result of exposure to external and interpersonal stimuli and are affected by life experiences and memories (Garro, 2000). When individual schemas are shared by members of a group with similar experiences, those shared experiences become cultural. *Cultural models* are thus schemas about a domain that are shared by members of a group having shared problems, shared task solutions, and similar life experiences (D’Andrade & Strauss, 1999). The concept of a cultural model rests upon Goodenough’s (1994) concept of culture as that which one needs to know to get along in a group of people. Groups of people with shared experiences tend to interpret life occurrences and public messages in similar ways; thus, shared experiences lead to the notion of cultural meaning (Strauss & Quinn, 1997).

From this perspective, the meaning of UI may be constructed as a result of “learned” understanding of the diagnosis and influenced by social, cultural, and physiologic factors. Within a biomedical framework, UI may be conceptualized as a “disease” or “illness”. Within the framework for CA, a condition such as UI may be more appropriately conceptualized as encompassing “the human experience and perceptions of alterations in health as informed by their broader social and cultural meanings” (Brown, Barrett, & Padilla, 1998, p. 11). From a lay perspective, experience with a chronic health condition is subjective and may be influenced by social, cultural, and physiological processes. To fully understand these experiences they must be examined within a cultural context (Kleinman, 1988). Thus, use of a cognitive framework allows one to examine individual differences in the meaning of UI and the influence of cultural models on the experience.

Significance and review of the literature

UI affects more than 17 million adults in the United States (National Association for Continence, 1998). The overall prevalence in community-dwelling

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