

PRESERVING AND PROTECTING SELF-PERCEPTIONS: RESPONSES TO THE STIGMA ASSOCIATED WITH CONTINENCE DIFFICULTIES IN OLDER WOMEN

Hypothesis / aims of study

Understanding incontinence-related stigma is essential to any intervention program targeting older women with urinary incontinence difficulties (CD). In Western societies, the elimination of bodily waste is a private endeavor that is done in a tidy way. Failure to do so risks being stigmatized or being perceived as 'different' because of CD. The onset of CD is often accompanied by embarrassment, shame, and elevated stress levels because attempts to conceal leakage may be thwarted by accidents, smells and the visibility of the product used to manage the condition¹. It is therefore common for individuals who fear stigmatization to withdraw from social participation and conceal identifiers of their health condition.

While the stigma process is frequently cited in health care literature, the prevailing conceptual models of disability creation provide inadequate reference to this phenomenon. As a consequence, health care educators lack necessary guidelines on how stigma should be accounted for in rehabilitation intervention design and implementation. Stigma can impede upon the recognition and early identification of health conditions, and serves as a barrier to help-seeking including for assistive technology devices as well as to rehabilitation programs. In order to design and implement effective rehabilitation intervention programs for this population, a better understanding of stigmatization is vital. The purpose of this study was to describe and better understand how the CD diagnosis and symptoms influence self-perceptions of older women.

Study design, materials and methods

As this is a new area of investigation, a qualitative description research paradigm was adopted.

Participants

Participants were recruited from a pool of individuals who enlisted to take part in a larger parent study. Participants had to have untreated urinary incontinence with leaks occurring 2 to 3 times a week, be 65 years old or more, and not have a diagnosis of dementia or other condition that would affect their ability to provide accurate information during the interview. Nineteen women agreed to participate in the study. The mean age of the participants was 75.57 years (range 67-92 years; SD = 6.93 years). Eight women reported being diagnosed with Stress Incontinence, five Urge Incontinence, four some combination of diagnoses (Stress & Urge Incontinence, Nocturia & Stress, Nocturia & Urge), and two participants reported other diagnoses (general urinary incontinence, and leaks due to bladder surgery).

Interviews

Participants were advised that investigators were interested in learning more about the experience of CD, and situations in which they may have been stereotyped. The format of the interviews was informal, much like a conversation. The interview guide was designed to produce a detailed account of life with CD, including how the onset of the condition has influenced self-perceptions.

Analysis

The transcripts of the interviews were analyzed using content analysis². Content analysis has three steps: open coding, creating categories, and abstraction. During open coding, the investigators immerse themselves in the data, reading and rereading the transcripts in search of text that answers the fundamental research question (i.e., "How has continence difficulties impacted upon self-perceptions?"). Once meaningful text is identified, the investigators assign labels in the margin of the interview transcript. The aim is to assign the requisite number of labels so as to describe fully the content of the text. Next, categories of headings are created. The final step of content analysis is abstraction, when the investigators prepare general descriptors of the data.

Results

Participants described living with CD in conflicted terms. While the diagnosis and associated symptoms of incontinence were described as an important 'threat' to their self-perceptions, management of CD was portrayed as 'not a big deal'.

The onset of CD and associated symptoms were perceived as threatening due to associations with 1) old age, 2) a change in femininity, and 3) poor hygiene. Participants also described threats associated with CD accidents, and the probability of the condition worsening over time.

In order to preserve and protect self-perceptions as a 'not old and healthy woman', participants described responses to threats that included compensatory and self-protective behaviours and strategies. These included a variety of coping strategies including comparisons with other people whose health status was perceived to be worse than their own, and comparisons to other health conditions that they are presently managing that require more attention. Participants also engaged in strategic interpretations, including ascribing to the belief that 'CD is normal with age', or that 'I have no choice but to live with it'. Strategic interpretations also took the form of blaming symptoms on non-medical factors, such as liquid intake or

Interpretation of results

The findings of the present study are consistent with recent studies concerning responses to stigmatization³. The participants in this study described a range of responses to identity threats which depended on the situation and nature of threat.

Concluding message

To optimally serve the needs of older women, a better understanding of stigmatization is vital. The results of this research study expand our understanding of CD stigma, and may inform suitable supports for older adults, as well as guidance for practitioners and policy-makers. These findings may also guide efforts to diminish the negative effects of stereotyping, and decrease social isolation of older adults with continence difficulties, and to facilitate ageing in place by increasing functional independence through assistive technology device use.

References

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Disclosures

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