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Which unmet needs contribute to behavior problems in persons with advanced dementia?



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ABSTRACT

The Unmet Needs Model states that problem behaviors of people with dementia result from unmet needs stemming from a decreased ability to communicate those needs and to provide for oneself. The purpose of this study is to describe the unmet needs of persons with dementia exhibiting behavior problems. Eighty-nine residents with dementia from six Maryland nursing homes were assessed by research assistants and nursing assistants for their unmet needs using multiple assessment tools. Three unmet needs per resident were identified on average, with informants rating boredom/sensory deprivation, loneliness/need for social interaction, and need for meaningful activity as the most prevalent needs. Discomfort was associated with higher levels of verbally agitated behaviors (e.g., complaining). Based on results and independent ratings of pain, the authors estimate notable underdetection of discomfort and pain by both types of informants. The study demonstrates methodologies for uncovering unmet needs among persons with dementia and highlights the importance of developing programs that address those unmet needs, especially social and activity needs of nursing home residents. The detection of pain, and possibly that of discomfort, may require a different methodology.

1. Introduction

Persons with dementia often exhibit inappropriate behaviors, which increases their suffering as well as the burden of caregivers (Cohen-Mansfield, 2001). These behaviors are addressed by both pharmacological and nonpharmacological treatments. There are several theoretical models regarding the etiology of inappropriate behaviors in persons with dementia (Cohen-Mansfield, 2000b), and this paper will focus primarily on the Unmet Needs Model and its implications for the treatment and prevention of these behaviors.

The Unmet Needs Model (Cohen-Mansfield and Werner, 1995; Cohen-Mansfield, 2000b) postulates that the dementia process results in a decreased ability to meet one's needs because of an increasing difficulty in communicating these needs, and a decreased ability to provide for oneself (Hancock et al., 2006). The needs may pertain to pain/health/physical discomfort, mental discomfort, the need for social contacts, uncomfortable environmental conditions, or an inadequate level of stimulation. According to the Unmet Needs Model, problem

behaviors result from an imbalance in the interaction between lifelong habits and personality, current physical and mental states, and less than optimal environmental conditions (Fig. 1). Most of the unmet needs arise because of dementia-related impairments in both communication and the ability to utilize the environment appropriately to accommodate needs. The environment and caregivers, in turn, either do not provide for the needs or do so in a way that does not accommodate one's preferences, habits, and disabilities. Consequently, agitated behaviors, such as pacing, may act to alleviate boredom or repetitious vocalizations may be used to communicate the need. Prior studies have found relationships between certain behaviors and participants' conditions and environments which support the notion of unmet needs. Specifically, verbal/vocal behaviors were more likely to be displayed by persons who were rated as having pain, discomfort, or being alone, whereas physically nonaggressive behaviors were more likely under normal environmental conditions when people with dementia were not engaged with any activity (Cohen-Mansfield et al., 1990; Cohen-Mansfield and Werner, 1995; Sloane et al., 1997; Cohen-Mansfield, 2000a).

Understanding unmet needs is central in formulating treatment plans for nursing home (NH) residents with dementia. Indeed, they form the basis for nonpharmacologic interventions for dementia (Bédard et al., 2011; Kolanowski et al., 2011; Cohen-

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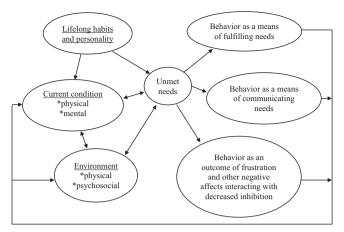


Fig. 1. Unmet needs model of problem behaviors. ©Cohen-Mansfield, 2009.

Mansfield et al., 2012). Thus we examined unmet needs as perceived by nursing assistants (NAs) caring for the residents as well as by research assistants (RAs) involved in implementing a nonpharmacological treatment program. As described in Cohen-Mansfield et al. (2012), the nonpharmacolocical interventions were tailored to participants' needs. In response to need to alleviate loneliness, participants were presented with interventions, such as simulated social stimuli, a respite video, a lifelike baby doll, or one on one interaction. Those who had a need of relieving boredom were provided with stimuli that matched their past preferences, such as reading materials or music. Those who had needs related to discomfort were helped directly with the specific source of discomfort, and an intervention could involve provision of care requested, such as responding to requests to be taken to one's room. The specific research questions are:

- 1) What are the perceptions of unmet needs that contribute to behavior problems? What is the level of confidence in the determination of unmet needs?
- 2) How does RAs' determination of unmet needs compare to that of NAs caring for the person?
- 3) How do the unmet needs relate to residents background information? The following hypotheses were examined:
 - a). The designation by the research assistant of pain relief as an unmet need will correlate positively with ratings of pain (assessed via the PAINE), and to negative affect (Cohen-Mansfield and Marx., 1993).
 - b). Unmet needs due to anxiety will be positively related to observed negative affect at baseline.
- 4) How do the unmet needs relate to the type of agitation manifested? Specific hypotheses are:
 - a). Social needs, pain, and discomfort will be related to verbally agitated behaviors (Cohen-Mansfield et al., 1990; Cohen-Mansfield and Werner, 1995; Sloane et al., 1997; Cohen-Mansfield, 2000a).
 - b). Boredom and need for stimulation will be related to physically nonaggressive agitated behaviors (Cohen-Mansfield, 2000a).

2. Methods

The current study describes the determination of unmet needs within the context of the treatment arm of a randomized placebo controlled repeated measures study of non-pharmacological intervention for behavior problems in persons with dementia (Cohen-Mansfield et al., 2012). The study was approved by the Institutional

Review Board of the Charles E. Smith Life Communities and participants or closest relatives signed an informed consent.

2.1. Subjects

Participants were 89 NH residents (mean age=85.9) with a diagnosis of dementia, according to their medical chart, from six NHs in Maryland, USA. The inclusion criteria were: (a) the resident had been at the facility for at least three weeks so that nursing staff members knew the resident well enough to accurately assess him or her; (b) the resident had been identified by nursing staff as exhibiting either verbal agitation or physical non-aggressive agitation at least several times a day; and (c) the resident had a diagnosis of dementia. Exclusion criteria were: (a) a nursing staff member responsible for direct care of the resident judged him/her to have a life expectancy of less than 3 months due to obvious causes; (b) the resident had an accompanying diagnosis of bipolar disorder or schizophrenia; and (c) a score of 25 or higher on the Mini-Mental State Examination (MMSE; Folstein et al., 1975).

2.2. Procedure

For all study participants, informed consent was provided by the attorney in fact or the closest family member (Cohen-Mansfield et al., 1988). The ABMI observations and the MMSE were administered by trained RAs. After obtaining data on participants' background, cognitive function, and medical status, baseline observations of agitation using the ABMI (Cohen-Mansfield et al., 1989) were recorded on a Palm Pilot Zire™. Direct observations were chosen because these are more objective and more accurate than other forms of assessment. Three minute observations of each participant were performed by several RAs during three consecutive days for a total of 13 h per day. Each RA observed one resident at a time and recorded one observation for each participant in every consecutive half-hour period. The PAINE was administered to each resident's primary staff caregiver. Both the RAs and NAs assessed the participants' unmet needs after the RAs completed the above assessments and the RAs conducted the intervention as described in Cohen-Mansfield et al. (2012).

2.3. Measurements

2.3.1. Background

Data regarding age, gender, ethnicity, and marital status were collected from each resident's chart at the NH. Information from medical records included prescribed medications (including pain relievers and psychotropic drugs) and confirmation of the diagnosis of dementia as well as other medical diagnoses.

2.3.2. Cognitive functioning

The diagnosis of dementia was obtained from a physician or nurse practitioner. Cognitive status of the participants was assessed using the MMSE (Folstein et al., 1975). Scores ranged 0 (severe cognitive impairment) to 30 (normal cognitive functioning).

Pain was assessed by the Pain Assessment In Elderly Persons (PAINE), consisting of a list of pain symptoms rated by direct caregivers (Cohen-Mansfield, 2006). Validity data are provided in Cohen-Mansfield and Lipson, (2008).

2.3.3. Agitation

Direct observations were recorded via the Agitated Behaviors Mapping Instrument (ABMI; Cohen-Mansfield et al., 1989). An RA recorded the frequency of occurrence of 14 items describing problem behaviors, characterized as physical agitation (e.g., pacing), or verbal/vocal agitation (e.g., groaning). Inter-rater reliabilities regarding agitated

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