

KNOW THEM LIKE THE BACK OF YOUR HAND:
A MODEL OF ASSISTED LIVING CAREGIVER'S KNOWLEDGE OF CARING FOR
ELDERS WITH DEMENTIA

Joyce Rasin, RN, PhD

University of North Carolina, Chapel Hill and Widener University, Chester, PA

Donald D. Kautz, RN, PhD

University of North Carolina at Greensboro

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Purpose: Assisted living facilities, also known as adult care homes and family care homes in North Carolina, have become an alternative to nursing homes for many older adults with dementia. Caring for persons with dementia can be difficult for many caregivers. This analysis is the caregiver's description of the knowledge needed to care for persons with dementia. **Method:** A qualitative descriptive design was used. Twenty-three caregivers from six counties participated in five focus groups. Three focus groups were composed of administrator/caregivers of homes with six beds or less. The other two groups consisted of caregivers from facilities with less than 75 beds. The participants were primarily African American (77%) and middle-aged (median = 53 years of age). Only one group had a male participant. Fifty-four percent of the participants from the small facilities were certified nursing assistants versus 90% of the participants from the larger facilities. Focus groups were tape recorded and transcribed verbatim. Data collection and data analysis were conducted cyclically. Transcripts were initially manually coded independently by the two investigators using content analysis. NVivo software was used to facilitate coding and sorting text. The investigators met regularly to establish coding rules, discuss the themes as they emerged, and reach agreement on the analysis and interpretation of the data. Data were sorted and displayed in a matrix to facilitate comparison of themes across groups. **Findings:** The participants in all of the focus groups talked about the importance of knowing their residents. Three types of expert knowing were identified, with the third level of knowing encompassing both one and two. All participants were able to articulate the first type of knowledge, adapting their approaches to specific behavioral symptoms of the residents. The second type was knowing the meanings behind the behavioral symptoms, and how the feelings of the resident related to behavioral symptoms. One group with less experience believed that the behavioral symptoms were due to the residents attempts to manipulate them. The third type was knowing the person, anticipating their needs, and maintaining their dignity. Caregivers discussed knowing the resident like the back of your hand and establishing reciprocal relationships with the residents. Those who saw the residents as individuals, with hearts, or as family also described their work as their profession or their life's work. A few expressed that they were called by God to provide care. **Discussion:** Little is known about the challenges and educational needs of those providing care in small assisted living facilities like family care homes. These findings demonstrate the potential for high level, compassionate care by caregivers in these long term care settings. These findings suggest the need to shift the emphasis from behavior focused interventions to a more holistic person centered approach. Caregivers need to understand the nature of the disease as well as the meanings and feelings behind the behavioral symptoms in order to anticipate the complex needs of those with dementia.