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Feature Article

Resident challenges with daily life in Chinese long-term care facilities: A qualitative pilot study

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ABSTRACT

As traditional family-based care in China declines, the demand for residential care increases. Knowledge of residents' experiences with long-term care (LTC) facilities is essential to improving quality of care. This pilot study aimed to describe residents' experiences in LTC facilities, particularly as it related to physical function. Semi-structured open-ended interviews were conducted in two facilities with residents stratified by three functional levels ($n = 5$). Directed content analysis was guided by the Adaptive Leadership Framework. A two-cycle coding approach was used with a first-cycle descriptive coding and second-cycle dramaturgical coding. Interviews provided examples of challenges faced by residents in meeting their daily care needs. Five themes emerged: staff care, care from family members, physical environment, other residents in the facility, and personal strategies. Findings demonstrate the significance of organizational context for care quality and reveal foci for future research.

Introduction

Historically, families in China have provided long-term care (LTC) for older adults in their homes.[1] Filial piety, a fundamental Confucianist philosophy, is a key virtue in Chinese culture.[2] Due to the emphasis on respect for one's elders, China has always valued family-based care.[3] More recently, the 2012 *Rights Protection Law of Older Adults* upholds the central role of family and outlines the expectation that adult children will care for their aging parents.[4,5]

However, the traditional, family-based caregiving model no longer meets the needs of older adults in China. The population is rapidly aging, while the number of available family caregivers is decreasing as a result of the one-child policy and increasing mobility among young people.[1,6,7] These factors have created a demand for formal LTC services, including community-based services and residential facilities,[8,9] serving individuals 60 years and older.[10] The number of beds in residential care facilities has been increasing in the last decade[9] and the institutionalization rate increased from 0.5% to 0.8% between the interval of 2002–2005 and 2008–2011.[11] While the sudden growth of these facilities represents an attempt to meet the needs of older adults in China, there has been little regulatory oversight or research into the kind of care residents are receiving.[1,12] Thus, empirical knowledge is needed to inform the growth and development of this sector and ensure quality of care.

The limited existing literature on LTC facilities in China indicates that care quality may be suboptimal due to a number of system-level barriers, including a lack of regulations,[6,13] insufficient funding,[14] a poor staff-to-resident ratio,[14] and lack of staff training.[6,13,15] Research on LTC policy development in China has indicated that national regulations are sketchy on quality standards, staff training and credentials, and scope of services.[12,15] Limited research has focused on residents' experiences with physical function in residential LTC even though this knowledge is essential to inform high-quality care.[16] Of the limited research that focused on individual-level residents' experiences with living in Chinese LTC facilities, one study explored those in four LTC facilities in Shanghai.[17] However, this study largely focused on instrumental activities of daily living (IADL), rather than residents' experiences with activities of daily living (ADL). Also,

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residents' experiences might differ in LTC facilities across geographic areas in China. Studies have reported large variations across geographic areas in terms of developmental stages of LTC facilities,[12,13,18,19] as well as different levels of enactment of the limited national policy that govern this section.[15] Shanghai, as one of the most developed cities, has been reported to lead LTC development in China, with higher levels of staff training[15,18] and better implementation of available regulations on standards of care.[15] Residents' socioeconomic status might differ in Shanghai and other areas in China, with Shanghainese having the highest per capita income in China.[20] In addition, socioeconomic status might also influence attitudes of residents and their family toward LTC facility placement,[21] which could potentially influence residents' experiences with living in these facilities. For residents who live in LTC facilities in less developed areas, their experiences might differ from those residents in Shanghai. Thus, research is necessary to explore residents' experiences with living in LTC facilities in less developed areas.

Strategies for meeting the rapidly growing demand for formal LTC services in China are still being developed, making this study timely. Findings may inform future research and have an impact on industry development. To that end, this study asked: What are residents' self-described challenges with daily life related to ADL and IADL in LTC facilities?

Theoretical framework

We employed the Adaptive Leadership Framework to guide this study.[22] This framework, when applied in a healthcare context, supports the idea that individuals work in collaboration with their caregivers to achieve optimal functioning.[23] There are five key concepts: technical challenges, technical work, adaptive challenges, adaptive work, and adaptive leadership.

Technical challenges are situations in which both the problem and the potential solution can be clearly defined.[24,25] In contrast, *adaptive challenges* occur in situations where there are no straightforward solutions for the problem, and the person who has the challenge must cope with loss, change his or her behavior, or develop new skills. Challenges often include both technical and adaptive elements. An example of a challenge might be that residents are unhappy with a mealtime experience. The technical component of this challenge might be the low quality of food[26] or an unsatisfying physical environment.[27] The adaptive component might be that residents miss interacting with their families as they did when they ate at home.[28]

Facility administrators may choose to address such challenges by improving the quality and variety of food and modifying the physical environment (*technical work*).[27] Residents might need to change their expectations and establish new patterns of social interaction during mealtime (*adaptive work*). Facility staff also may undertake adaptive work by creating opportunities for residents to interact during mealtimes and supporting residents as they interact with other residents (*adaptive leadership*).

The Adaptive Leadership Framework provides a useful lens through which to focus not solely on the limitations of the facility and residents' functional abilities, but on how to identify and enhance opportunities for residents to work with formal and informal caregivers to meet their needs.[23,29]

Design and methods

Overview of the study design

This qualitative pilot study used semi-structured open-ended interviews[30] to explore residents' challenges with daily life.

Chinese versions of Evaluation to Sign Consent, consent form, and interview guide

The modified Evaluation to Sign Consent (ESC) (Items 1 and 2 out of the 5 items of the full ESC) is a measure of residents' ability to communicate and provide informed consent.[31] The two items address the potential risks of participating in the study and outline what is expected from participants, and are most applicable to this qualitative interview study. Also, these two items "have the largest percentage of agreement with the full ESC".[31] The consent form and interview guide were developed in English by the research design team, then translated by the first author from English to Chinese. To ensure the accuracy of the translation, another qualified person back-translated the Chinese version into English,[32] and the back-translated version was then compared with the original English items by two native speakers (KNC and RAA).[33]

Sampling procedures and subjects

This study was conducted in Jinan, China, which is the capital of Shandong province in Eastern China. There were 63 LTC facilities with a total of 6556 beds in Jinan at the end of 2009, according to the most recent data available.[26] Given the rapid development of LTC facilities in China,[9] the number of facilities and beds had increased considerably by 2013, when this study was conducted. This study was conducted in two, 200-bed LTC facilities in Jinan. One was government owned and the other was privately owned.

Potential participants 1) were 60 years or older; 2) could understand Mandarin; and 3) had lived in the current facility for at least a month. Purposive stratified sampling was used to recruit participants, using dependent, semi-dependent, and independent levels of mobility as strata to maximize variation.[34] The first author asked facility staff members to identify residents at each of the three levels of mobility whom they thought would be able to complete the study. Residents were excluded if they had: 1) difficulty understanding Mandarin; 2) dysphasia; 3) severe deafness not improved with hearing aids; and/or 4) a visual deficit not improved with glasses. Participants were further screened using the Chinese version of the modified ESC. Residents who could not pass the ESC were excluded.

Ethical considerations

Institutional Review Board (IRB) approval was obtained from Duke University Health System and Shandong University. Informed consent was obtained from each of the six eligible residents who expressed interest in this study.

Data collection and preparation

At each facility, the first author reviewed each participant's medical record and recorded demographic data by hand, including age, gender, level of physical function, admission date, marital status, number of living children, and education level. This information was later entered into the REDCap[35] electronic data capture tool hosted at Duke University.

Semi-structured interviews were conducted using the Chinese version of the interview guide. The first author began with, "What has been the impact of living in this facility on your life?" followed by prompts that encouraged participants to reflect on their feelings and experiences. Participants were then asked four key questions: 1) "In your daily life, what is easy for you?" 2) "In your daily life, what is difficult for you?"; 3) "Tell me about a time when staff or family members helped you with things you do each day, such as eating or dressing" 4) "Tell me about a time when you wanted help