

Research Advances on Resistance to Care in Dementia Patients: Postprint

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Abstract

Resistance to care is a current issue in the caregiving process for patients with dementia. Through a review of international literature, this article elaborates on the overview, assessment tools, current research status, and intervention strategies for resistance to care in dementia patients, aiming to provide a reference for further research.

Full Text

Preamble

Research Progress on Resistance to Care in Dementia Patients

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Abstract

Resistance to care represents a significant challenge in dementia patient management. This review synthesizes international literature to elucidate the concept, assessment instruments, current research status, and intervention strategies for

resistance to care in dementia patients, aiming to provide a foundation for future research.

Keywords: dementia; resistance-to-care; review; nursing

Dementia is a neurodegenerative condition prevalent among older adults, characterized primarily by cognitive impairment. As the disease progresses, patients experience declining self-care abilities and require assistance with daily activities. However, negative experiences during care provision can trigger resistance to care behaviors [1-3]. Louise et al. [4] define resistance to care as “refusal, avoidance, or other actions that prevent or undermine care services provided by hospitals and social support offered by family caregivers.”

Managing patients who resist care presents complex ethical and practical challenges for healthcare providers [5-6] and increases risks of coercive treatment and caregiver injury [7]. Person-centered care has emerged as a crucial approach for preventing and reducing resistance to care, emphasizing the need for high-quality interpersonal support that addresses fundamental personal needs. Unfortunately, some caregivers misinterpret resistance to care as aggressive rather than protective or defensive behavior, potentially leading to inappropriate interventions such as forced care, physical restraints, or medication misuse, which may exacerbate the situation [8].

While international scholars have actively explored this phenomenon, targeted research remains scarce in China. This review examines the concept, assessment tools, research status, and intervention strategies for resistance to care in dementia patients to enhance healthcare professionals’ understanding and inform effective intervention development.

1 Overview of Resistance to Care

Resistance to care (RTC), also termed care resistance, refusal of care, or non-cooperation with care [9-10], is particularly common among dementia patients. It represents a frequent manifestation of behavioral and psychological symptoms of dementia (BPSD) [11] and constitutes a major source of stress for caregivers [12]. RTC encompasses any behaviors that avoid or obstruct caregiver assistance with daily care, including turning away from caregivers, refusing entry into rooms, rejecting specific care activities (bathing, dressing), clenching lips (to avoid food, medication, or oral care), ignoring caregiver requests, or yelling during care provision [11,13,14].

These behaviors correlate with other BPSD such as agitation and aggression but remain distinct phenomena. While agitation may occur in any situation, including when patients are alone, resistance to care represents a specific behavioral response to care activities [15]. Research indicates they are fundamentally different constructs requiring distinct management strategies [16]. Agitation is more prominent in mild dementia and diminishes with disease progression,

whereas resistance to care increases as dementia severity worsens, with studies reporting an eightfold increase in severe dementia stages [17].

Recent conceptualizations have shifted from viewing RTC as a symptom of cognitive dysfunction to understanding it as communication of unmet needs [18]. Many dementia patients desire home-based care from family members with dignity, inclusivity, and humaneness [19], yet not all wish for social care services [20]. Some resist care due to fear of losing independence or negative care experiences. Additionally, families may be reluctant to provide care due to perceived limited efficacy or cost concerns [21], making RTC a complex phenomenon involving patient, caregiver, and societal factors.

2 Current Research Status

2.1.1 Impact on Dementia Patients

Resistance to care poses a primary barrier to safety and comfort during personal care [22]. From caregivers' perspectives, RTC creates additional distress and burden, potentially leading to abusive behaviors such as forced care procedures or physical/chemical restraints, which further harm patients [8,23]. Negative care experiences intensify resistance, ultimately reducing quality of life and increasing care costs [24]. RTC also contributes to malnutrition, skin damage, constipation, weight loss, and other health complications [10].

2.1.2 Impact on Professional Caregivers

RTC negatively affects emotional connections between caregivers and patients, fostering distrust while increasing care costs, caregiver burden, and work stress through care disruption and prolongation [25]. Many professional caregivers lack confidence and skills to address RTC, making it a significant stressor when caring for hospitalized dementia patients [2]. Unexplained resistance may lead to caregiver burnout or attitude changes toward patients [26], ultimately reducing quality of life and increasing negative emotions. No studies have examined RTC's impact on Chinese professional caregivers; future research should investigate their understanding of RTC and its incidence during emergency admissions.

2.1.3 Impact on Family Caregivers

Due to dementia's prolonged and progressive nature, family caregivers bear primary responsibility for care [27]. Often lacking necessary knowledge, skills, or time, they may overlook RTC behaviors. Spigelmyer et al.'s [28] phenomenological study identified five components of family caregivers' lived experience with RTC: signals of increasing future caregiving responsibilities, self-doubt, altered self-perception, unexpected emotional responses, and changes in the patient. Family caregivers frequently experience guilt and inadequacy, affecting

care quality. Future research should support family caregivers in fulfilling their roles to reduce distress.

Given China's dementia distribution patterns—higher prevalence in rural, remote western, and economically disadvantaged regions—care often relies on family caregivers constrained by limited medical resources and economic conditions. Xu et al. [29] found family caregivers' education and income levels correlate with caregiving capacity, suggesting lower capacity in remote areas may increase RTC incidence and limit medical support. No studies have examined RTC's impact on Chinese family caregivers or compared different economic regions. Future research should focus on RTC occurrence and management among rural family caregivers.

2.2 Influencing Factors of Resistance to Care

Understanding RTC's influencing factors can help caregivers adopt flexible management approaches emphasizing understanding and reassurance rather than restriction or isolation. RTC is associated with unmet basic needs such as hunger, pain, or fatigue [30], or simply refusal to interact with unfamiliar caregivers [31]. Caregiver factors are also critical; some lack fundamental dementia knowledge and may ignore, isolate, or discriminate against patients. Negative experiences are a key factor, highlighting the need for education on geriatric and cognitive impairment management to enhance humanistic care capacity [24]. Environmental factors should also be considered, including noise reduction, appropriate temperature and lighting, familiar faces, respect for lifestyle habits, and personal space during interactions [32].

3 Assessment Tools

3.1 Resistiveness to Care Scale for Dementia of the Alzheimer's Type (RTC-DAT)

Developed by Mahoney et al. [33] in 1999, this scale demonstrates good reliability (Cronbach's $\alpha = 0.82-0.87$) and validity. The 13-item instrument quantifies RTC behaviors in Alzheimer's dementia, including "turning away," "refusing attention," "threatening," and "clenching mouth," scoring both duration and intensity of 13 behaviors. Duration uses a 5-point scale: 0 (none), 1 (<16 seconds), 2 (16-59 seconds), 3 (1-2 minutes), and 4 (>2 minutes). Intensity is quantified as: 1 (mild), 2 (moderate), and 3 (severe). Severity is calculated by multiplying duration and intensity scores for each item, then summing all items (total range: 0-156), with higher scores indicating more severe RTC [14].

As the first RTC assessment tool, RTC-DAT provides detailed differentiation of common behaviors. However, recording all RTC incidents and durations is

time- and labor-intensive, making it impractical for routine clinical use. The scale has not been translated or validated in China. Future development of culturally appropriate tools should prioritize convenience and reliability while objectively reflecting RTC severity.

3.2 Resistiveness to Care Scale-Revised (RTC-r)

Dementia patients frequently exhibit RTC during oral care [34]. Jablonski et al. [14] revised the RTC-DAT and validated its reliability for other care activities. Real-time recording of duration during oral care proved impractical, so the duration category was removed, retaining only intensity. Caregivers record RTC frequency and intensity during oral care, with total scores calculated by multiplying frequency by intensity for each item, then summing all items. Consequently, RTC-r's maximum score exceeds 156.

Jablonski et al. [35] argued that Cronbach's α is not optimal for assessing internal consistency because individual items don't contribute to the overall RTC concept—patients exhibiting one behavior need not display all others. Interrater reliability represents the best reliability measure for RTC-r, confirming it as a valid assessment tool. RTC-r provides a practical tool for recording RTC in specific situations, though removing duration may limit severity assessment. Clinicians should select appropriate tools based on context. Video recording technology can help retain comprehensive data. The scale has not been introduced in China; future consideration should be given to introducing both versions to create a flexible assessment toolkit for different situations.

4 Intervention Strategies

4.1 Patient-Level Interventions

Non-pharmacological interventions are recommended as first-line treatment since psychotropic medications increase adverse outcomes in dementia patients [13]. These include sensory stimulation, cognitive-emotional orientation techniques, behavioral management, and multi-component comprehensive interventions [36].

4.1.1 Digital Screen-Based Calming Tools Mindful Garden (MG) is a novel personal sensory stimulation tool aligned with person-centered care, originally developed to manage delirium-related agitation in emergency settings. MG is a mobile flat-screen television with non-contact sensors that capture, analyze, and respond to patients' verbal and motor behaviors [37]. Using the Unity gaming platform, it displays calming videos whose imagery intensifies based on captured sound and motion stimuli.

Gloria et al. [38] conducted a randomized controlled trial with 13 dementia patients exhibiting RTC. The intervention group received routine care plus MG

observation, while the control group received routine care only. MG was positioned 2 feet from patients within their line of sight during care procedures and removed afterward. Results showed reduced RTC in the intervention group, though differences were not statistically significant, likely due to small sample size. This pilot study suggests MG's potential benefits, warranting larger-scale research exploring enhanced sound and human-computer interaction effects.

4.1.2 Video-Simulated Presence Video-simulated presence (VSP) is a cognitive-emotional orientation technique developed from simulated presence therapy (SPT) [36], first proposed by Woods and Ashley [39] as a person-centered approach. VSP involves family caregivers creating 30-60 second personalized videos requesting patients to comply with caregivers and cooperate with specific care activities (medication, feeding, bathing). VSP is played on portable devices (phones or iPads), with caregivers always obtaining verbal permission first ("Would you like to watch a video of your daughter?").

O' Connor et al. [40] used a single-system ABA withdrawal design to evaluate VSP's impact on RTC. A family member pre-recorded videos for use during RTC episodes. Results demonstrated significant RTC reduction during basic care activities (feeding, medication administration), with effects reversing upon intervention withdrawal. This family-based, person-centered VSP approach shows promising results [41]. Future research requires more rigorous designs, such as large-scale randomized controlled trials, to determine optimal video types, long-term effectiveness of repeated use, and whether audio alternatives are equally effective for patients with visual impairment.

4.2 Caregiver-Level Interventions

4.2.1 Fundamentals of Care Framework The Fundamentals of Care (FOC) framework, developed by the International Learning Collaborative, aims to improve basic care quality and ensure qualified fundamental care for individuals in healthcare facilities [42]. FOC involves nursing actions that refocus attention on basic needs to ensure physical and psychosocial well-being through positive, trusting relationships with patients and families [8]. The framework centers on five relational elements:

1. **Trust:** Requires compassionate, respectful, and empathetic behaviors with clear explanations and patient consent. Trust is an ongoing process strengthened during each care interaction.
2. **Attention:** Once trust is established, caregivers must be fully attentive, accepting and responding to all communication, including non-verbal cues [43].
3. **Anticipation:** Caregivers must predict patient needs to support unique physical, psychological, and emotional goals.
4. **Knowing:** Understanding patients' and families' needs to adapt communication approaches accordingly [43].

5. **Evaluation:** Assessing relationship quality and identifying expectations and improvements [43].

FOC ensures continuous, safe, thoughtful, and dignified care addressing holistic needs during each interaction [42,44]. These concepts are crucial for dementia patients exhibiting RTC. As cognitive and functional abilities decline, patients become increasingly dependent on caregivers, particularly in advanced stages when RTC is most common [17]. Memory impairment may cause patients to forget caregivers' roles, accompanied by emotional vulnerability, poor medication adherence, and communication difficulties. Caregivers must earn trust through respectful interactions and maintain reliable, continuous relationships. Communication difficulties require caregivers to understand patient needs through non-verbal cues, particularly unmet care, activity, and emotional needs. Professional dementia care competence and confidence are essential for accurately predicting needs—a key distinction from other conditions.

For patients with mild symptoms and minimal RTC, family caregivers can provide primary care, potentially collaborating with professionals during hospitalization. For advanced-stage patients with prominent RTC, adjustments are needed: if patients retain recognition of primary family caregivers, professionals should guide family members in care delivery to minimize unnecessary RTC; if patients lose recognition of core individuals, professionals must establish trusting relationships through FOC to meet needs and reduce RTC.

4.2.2 Abilities-Focused Care Education Intervention The abilities-focused approach, developed under person-centered care philosophy, respects dementia patients' dignity and humanity [45]. It maximizes retained physical and psychosocial functioning by creating supportive environments [46]. The approach includes activities of daily living interventions based on psychosocial needs models and psychological interventions focusing on communication, self-esteem, and security needs [47].

For patients with relatively preserved cognition and function, family caregivers—typically the most trusted individuals—can facilitate daily activities, with communication, self-esteem, and security needs generally well-supported. For end-stage patients prone to RTC, interventions should leverage retained abilities while building trust. Psychological interventions identify and predict unmet needs for communication, self-esteem, and security. Care should prioritize meeting unmet needs rather than task completion to reduce RTC. Theoretically, abilities-focused care engages patients according to their capabilities, shifting them from passive to active participants, potentially reducing RTC [48].

4.3 Societal-Level Interventions

4.3.1 Multidisciplinary Collaborative Approach Managing RTC places substantial burden and capability demands on healthcare professionals. Åshild et al. [49] proposed a multidisciplinary approach involving home healthcare staff,

general practitioners, dementia specialists, and family members. This method requires healthcare professionals to understand collaboration benefits and maximize home healthcare structures. Research demonstrates that multidisciplinary collaboration enables appropriate RTC assessment by integrating team competencies and knowledge to adjust care content and improve quality [49].

Although comprehensive medical services are particularly important for dementia patients, studies reveal that multidisciplinary collaboration is not regularly or systematically implemented in current home healthcare contexts, posing practical challenges [50]. Given China's underdeveloped home healthcare system and reliance on family caregivers, particularly during advanced-stage dementia when RTC incidence and caregiver burden peak, greater family caregiver support is needed. China's healthcare services currently focus on macro-level (population health policies) and micro-level (individual health education) approaches, while meso-level family-based services lag [51]. Current family healthcare 主要包括 three forms: family health records, family reproductive health services, and community-based family healthcare services and management [51].

Future directions should integrate dementia care into family healthcare frameworks by: training community-based family healthcare professionals; innovating family healthcare promotion models tailored to dementia needs; strengthening community education on dementia care knowledge and skills; utilizing family health records for regular home visits; applying information technology to build smart healthcare systems enabling caregivers to access knowledge or schedule home visits efficiently; and learning from international experiences to develop a distinctive Chinese dementia family healthcare system.

4.3.2 Dementia-Friendly Society Construction As population aging progresses, dementia prevalence increases, making it essential to examine whether dementia-friendly social environments influence RTC, particularly regarding outdoor facilities and social acceptance [49]. Woodbridge et al. [52] suggest special building and transportation design, community dementia education, strengthened neighborhood relationships, and digital society integration.

In 2019, Shanghai's Pudong New Area Tangqiao Subdistrict established a "Cognitive Disorders Care Alliance" through multi-channel, multi-form community mobilization and education, creating community awareness and support for dementia prevention and care. This initiative formed a preliminary dementia-friendly community, advancing dementia prevention, screening, acceptance, and inclusion processes, providing a foundation for China's dementia-friendly society construction [53]. However, development must consider China's context, as most patients live in rural areas with insufficient medical and social support. Learning from diverse international experiences to build a context-appropriate dementia-friendly society is crucial. Societal acceptance and inclusion, rather than exclusion or isolation, along with support for family caregivers' material, psychological, and social needs, can help reduce RTC.

5 Future Directions and Conclusion

As China's aging population intensifies, dementia prevalence rises rapidly, imposing heavy burdens on individuals, families, and society. Resistance to care is a common yet overlooked issue in dementia management. Due to China's unique context, with long-term home-based care and family caregivers lacking knowledge and skills to identify and manage RTC, insufficient attention may create a vicious cycle of deteriorating caregiver-patient relationships with adverse outcomes for both parties. Current domestic research and attention remain inadequate, lacking localized assessment tools and interventions. We recommend learning from international research to introduce or develop culturally appropriate assessment tools and support effective intervention development. Multi-center, large-scale cross-sectional surveys are crucial for understanding RTC incidence in China, though none currently exist.

Future research directions should examine practical ethical issues in care provision, essential for healthcare decision-making when encountering RTC. Most previous studies lack a conceptual framework for RTC, requiring refinement to advance research. This review did not differentiate RTC between long-term settings (home, nursing homes) and emergency admissions, though RTC incidence is high in acute care environments. Research is needed on RTC causes, impacts, and management strategies in acute settings, and how caregivers balance care demands and pressures. Multidisciplinary collaboration and family healthcare systems offer promising directions, though clinical application lacks a complete, effective response system. More researchers must engage in developing systematic, effective multidisciplinary collaboration and family healthcare measures.

Literature Search Strategy

Computerized searches were conducted in PubMed, Web of Science, CNKI, and Wanfang Data Knowledge Service Platform through May 2022. Chinese search terms included: dementia, family caregiver, resistance-to-care, refusal of care, nursing resistance. English search terms included: dementia, Alzheimer disease, family caregiver, resistance-to-care, resistance to care, nursing. Inclusion criteria: Clinical studies, reviews, meta-analyses, cross-sectional studies, and qualitative studies addressing clinical manifestations, mechanisms, and interventions for RTC in dementia patients. Exclusion criteria: Irrelevant studies, duplicate publications, or unavailable full text.

Author Contributions

Wang Xinyuan: First author, conceptualized the research question, designed the study framework, drafted and wrote the manuscript.

Liu Yanli: Corresponding author, provided guidance throughout the research process and manuscript conceptualization, revised the final version, and takes responsibility for the manuscript.

Zhou Lijun: Determined specific viewpoints, methods, and objectives, and revised the manuscript.

Zhang Qi, Wei Qifei, Yan Xingyu, Luo Jiao, Liu Xiaofei: Collected and organized relevant literature, searched domestic and international databases, and provided foundational material support.

Conflict of Interest

The authors declare no conflict of interest.

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