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Dementia Caregiving: Be Prepared and Keep It Light

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Dear Editor,

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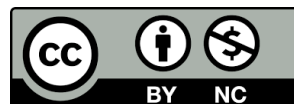
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Caregiving for people living with dementia is a complex, long-term responsibility extending beyond medical management, encompassing emotional, social, and cultural dimensions (1). In many Asian countries, including Brunei Darussalam, caregiving is predominantly family-based, with limited structured caregiver support (2). Despite the expanding global literature on dementia caregiving, evidence regarding culturally embedded support models remains limited in Southeast Asia, particularly in Brunei Darussalam (3,4). Research remains disproportionately skewed toward Western settings, with insufficient analysis of how sociocultural and spiritual frameworks influence caregiving within Asian populations (5). This letter aims to share insights from dementia caregiver support groups in Brunei, highlighting the need for culturally responsive caregiver support models in Southeast Asia.

In Brunei, Demensia Brunei, a non-governmental organisation established caregiver support groups, with nine sessions held between 2024 and 2025. Twelve caregivers, primarily family members of people living with dementia, participated in the sessions. Each two-hour session combined creative activities, including art and music therapy (6), with facilitated group discussions led by a trained nurse and life coach. These sessions provided an opportunity to examine how caregivers interpret, adapt to, and sustain their roles within a culturally embedded caregiving context.

Caregivers were supported using structured approaches that emphasised reframing of challenging situations, processing of past caregiving experiences, and the development of emotional regulation strategies (7). For example, behaviours such as repetitive questioning were reinterpreted as manifestations of neurological decline rather than intentional actions, enabling more adaptive and compassionate responses. These approaches appeared to support caregivers in developing practical coping strategies and greater emotional resilience.

Insights were drawn from facilitator observations, caregiver discussions, and structured post-session debriefings. Although a formal qualitative analysis was not undertaken, recurring themes were identified through review of the caregivers' narratives. Two key aspects that characterised the caregiving experience were identified: the need for preparedness and the importance of "keeping it light." Many caregivers initially approached dementia care reactively, seeking support primarily during crisis points such as behavioural escalation, wandering, or physical decline. Limited prior knowledge of dementia was reported to contribute to delays in recognition and adaptation, with symptoms frequently interpreted as normal ageing. This reactive pattern may reflect broader structural gaps, including the absence of an explicit national strategy for dementia caregiver support in Brunei, a challenge similarly observed across many low- and middle-income countries in the Southeast Asian region (8). Through the activities, followed by discussions with anticipatory guidance, caregivers were supported to understand the progressive nature of dementia and to anticipate future challenges. This shift from reactive to proactive caregiving reduced uncertainty and appeared to increase caregivers' sense of preparedness. This understanding also appeared to enable caregivers to respond with greater patience, reduced emotional distress and importantly, greater clarity.

Another key insight was the role of humour, storytelling, and emotional "lightness" in sustaining caregiving over time. Caregivers described an emotional burden, often compounded by cultural expectations of endurance and silence. Within the Brunei context, caregiving is closely linked to the concept of *Redha* (acceptance of God's will), which can provide spiritual strength and resilience but may also delay help-seeking if interpreted primarily as enduring hardship without seeking external support (9). Support group interactions created a space where caregivers could reinterpret this concept as active resilience rather than passive endurance. The use of humour in shared narratives allowed caregivers to reframe challenging situations, maintain relational connection with the person living with dementia, and experience moments of emotional relief. The creative activities added elements of play, fostering positive emotional

experiences and strengthening social bonds among the members (10).

Although structured group meetings integrating practical activities and facilitated reflective discussions are likely contributory, improvements in caregiver coping may also be attributed to broader mechanisms such as peer and family support, social connectedness, and enhanced knowledge, rather than the specific techniques in isolation (11,12).

Several limitations should also be noted regarding this work. The findings, stemming from a restricted number of sessions, have limited generalizability beyond the Bruneian context. Additionally, the self-selection of participants introduces potential bias, while the absence of formal outcome measures constrains the ability to quantitatively evaluate intervention effectiveness. Future iterations of this support framework should incorporate standardized metrics, such as those evaluating stress reduction and self-efficacy, to better capture the longitudinal impact on caregiver well-being (13).

Based on these experiences, there were several learning points that may be applicable for dementia care in similar contexts. Caregiver support should prioritise early engagement and anticipatory guidance, enabling families to transition from crisis-driven to proactive care. Interventions should extend beyond information provision to address emotional and cognitive coping processes, including reframing and meaning-making. Culturally grounded concepts such as *Redha* indicate the necessity of integrating cultural frameworks, such as the importance of filial piety, into support modules, to foster more positive caregiving experiences in similar Asian contexts (14). Thus, structured caregiver support combining facilitated discussion with simple psychosocial techniques may represent a feasible and scalable approach in similar settings. Future programmes should incorporate structured evaluation using validated caregiver outcome measures, while also examining culturally specific positive aspects of caregiving, including filial piety and *Redha* (14,15).

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