

# Family Role in Care of Patients With Neurological Conditions: International Neuroscience Nursing Research Symposium Proceedings



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## ABSTRACT

**BACKGROUND:** Discussions during the 2022 International Neuroscience Nursing Research Symposium highlighted the impact of family in the care of neuroscience patients. This sparked conversations about the need for understanding global differences in family involvement in the care of patients with neurological conditions. **METHODS:** Neuroscience nurses from Germany, India, Japan, Kenya, Singapore, Saudi Arabia, the United States, and Vietnam collaborated to provide a short summary of family involvement in caring for patients with neurological conditions in their respective countries. **RESULTS:** Family roles for neuroscience patients vary across the globe. Caring for neuroscience patients can be challenging. Family involvement in treatment decisions and patient care can be affected by sociocultural beliefs and practices, economic factors, hospital policies, manifestation of the disease, and long-term care requirements. **CONCLUSION:** Understanding the geographic, cultural, and sociopolitical implications of family involvement in care is of benefit to neuroscience nurses.

**Keywords:** culture, family role, global views, hospital care, neuroscience patients

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## Background

During the 2022 International Neuroscience Nursing Research Symposium (INNRS), the topic of family engagement in care stimulated an important discussion. Family-centered and patient-centered care has been endorsed by the Institute of Medicine and the American College of Critical Care Medicine.<sup>1</sup> Over 100 neuroscience nurses from across the globe participated in the discussion at the INNRS, and this article presents a collective perspective of neuroscience nurses regarding the role of family across the trajectory of care for neurological conditions across different countries.

Neurological disorders are the leading cause of disability and the second most common cause of death worldwide.<sup>2</sup> Many of the disorders that result in impaired function and dependence also impact the family. Family participation is a vital element of treatment decision making, accessing healthcare services, provision of care, use of medical technology to support daily functions, and ongoing safe, quality, and efficient care. There is a growing understanding that families form an integral part of the life and well-being of patients when they are most vulnerable.<sup>3</sup> The purpose of this article is to describe neuroscience nurses' collective perspectives on family involvement in the care of neuroscience nurses through a global lens.

## Methodology

Neuroscience nurses who attended INNRS 2022 and expressed interest in the project engaged in additional discussion to illustrate family involvement in various countries. This article is based on the perspective of the coauthors who reside and work in the healthcare setting in their respective countries. No formal data collection was undertaken, and because family is defined differently throughout the world, we neither imposed nor provided a singular guiding definition for *family*.

## Results

Family involvement in the care of patients with neurological conditions ranges along a continuum from no involvement to maximum involvement. Factors that contribute to family involvement can be classified as illness specific, provider specific, or national. Illness-specific factors include etiology of neurological disorder, symptom manifestation, patient age, and dependence in activities of daily living. Provider-specific factors include integration of families in patients' care, involvement in decision making, and patient care. National aspects include healthcare system; social, religious, and cultural beliefs and expectations; and financial-economic pressure. Although individuals living with disabling neurological diseases often depend on others for their various needs, in certain parts of the

world, maximum family involvement also means dependence on family for physical, emotional, and financial support.

## Treatment Decisions

The patterns of treatment decision across the treatment trajectory vary by geographic location across the globe. In many countries in Africa and Asia, treatment decisions are often made by people living with the disorder in consultation with family members. In patriarchal societies, especially in rural settings across Asia and Africa, men or older adults in the family and in the community have an important say in treatment initiation and continuation.

In Kenya, family dynamics affect treatment decisions. Men are involved in most critical decisions including type of treatment, treatment providers to be consulted, and where to seek hospital admission if that is needed.<sup>4</sup> Before admission, most patients in Kenya do not identify a surrogate decision maker, power of attorney, or family spokesperson to make key decisions involving care issues such as high-risk surgical interventions, levels of resuscitation, and end-of-life care, including withdrawal of treatment in cases of brain death.<sup>5</sup> In rare circumstances, family members make care decisions without patient involvement, especially when the patient's autonomy is compromised by their neurological state. Communication of treatment decisions to this large family tree is at times not effective and may lead to dissatisfaction. This is also impacted by religious and cultural values as well as patient rights to autonomy.<sup>6</sup>

In India and Singapore, family is typically involved in treatment decisions, especially during the acute phase of disease or illness. The severity of function loss and patient's age, sex, and significant comorbidities are important factors that contribute to family involvement in treatment decisions. Treatment decisions are made in consultation with the patient's family. Although an advance directive is a highly desirable tool to inform patient preferences, it is not widely implemented because of underlying barriers. A key challenge includes the lack of awareness and conversations about advance directives in several societies.

Family engagement in Asia, Africa, and India is contrary to the practices in many countries such as North America, Australia, and Europe where family involvement in decision making may be minimal—despite often being encouraged by nurses and other healthcare professionals. In Germany and the United States, decisions about treatment initiation and continuation are often made by the patient unless the disease is too debilitating for the individual to make appropriate decisions. In both these countries, individuals are encouraged to proactively identify their preferred proxy in case they become unable to convey their own wishes.

For example, legal avenues such as durable power of attorney for healthcare outlining who is to make treatment decisions when an individual is unable to make those decisions independently can be used. In the absence of a durable power of attorney for healthcare, efforts are made to identify the responsible decision maker among family members who may or may not agree with who that decision maker is and/or the decisions that are made. This often requires family conferences and even the involvement of hospital ethics committees to determine goals of care and implement appropriate treatments.

In several cultures, the nature of specific neurological disease, such as epilepsy, can also contribute to treatment decisions. In India, rejection, even within the family, is strong when a person with such a neurological disorder joins through marriage. Individuals living with epilepsy conceal their disease status and thereby the treatment.<sup>7,8</sup> In both rural India and Kenya, epilepsy is often considered to be supernatural, and traditional or faith/religious healers are consulted first for a “cure.”<sup>9</sup> Thus, stigma related to certain neurological diseases is a significant factor in treatment decisions.

## Hospital Care

The involvement of families in the care of critically ill patients is increasingly discussed and debated across the globe. Specific rules, regulations, policies, and guidelines in relation to different aspects of care can vary by country; details of these are not discussed and are beyond the scope of this article. In Kenya, Germany, India, Singapore, the United States, Vietnam, and Japan, the involvement of family in acute care settings is mostly driven by hospital policies and can restrict family involvement in direct caregiving. In Kenya, culturally, extended family and members of the community serve as a strong support system and take turns to care for the hospitalized patient.<sup>6</sup> However, the turnover of these caregivers without previous knowledge of the primary nurse can negatively affect care delivery. For instance, if a caregiver is replaced at points of care transition including immediate preoperative or postoperative timeframe, this might affect continuity of care because they have no previous information regarding plan of care and communication is variable across caregivers.

In Vietnam, India, the United States, Singapore, and Kenya, a family member may be encouraged to be with the patient to ensure patient safety (ie, fall prevention) and basic needs are met. Family members may be involved in a range of care activities including assisting in daily activities, preventing self-harm for confused patients, providing emotional support to patients, and procuring needed supplies.<sup>10</sup> The ability of family members to understand complex medical situations and/or their

confidence of the treating team in involving untrained family members in caregiving also become a barrier for family participation in acute care settings. Families are involved in end-of-life and transitional care with less involvement in active caregiving in critical care units. In India, family is usually present in the hospital round the clock and is always available for any patient-related matters but has restricted entry based on hospital policies. When the patient is in a critical care unit, the family member uses waiting rooms, separate facilities, or rented rooms for the stay. Family is involved in discharge teaching and care at home because most patients are discharged directly to homes as there are hardly any transitional care facilities in India.

In Saudi Arabia, the family, not the individual, is viewed as the fundamental unit of society. The extended family system can offer security as well as emotional and physical support when needed. The purpose of involving the family in a hospital setting is to satisfy the family members' informational and support requirements as well as to provide them the chance to be near the patient.<sup>11</sup> In the United States, family involvement is encouraged but nurses show reluctance in involving family as caregivers in hospital settings. In Germany, family involvement is seen as an unnecessary disturbance to routine care and the nursing staff show reluctance in including the family in providing direct care. Families are integrated in end-of-life decisions, treatment decisions, and supporting care, for example, to prevent and treat delirium, to offer comfort care, or, in patients with coma, to stimulate with familiar activities. Family is seen as an important link between the patient and healthcare professionals and is essential to manage the nursing process successfully,<sup>12</sup> provided that the family is available and there is an intact relationship within the family. Patients' advance directives are highly valued, and in case these are not available, families are asked for the likely wish of patients.

In the United States, family involvement in patient care, although considered important, is not operationalized in a standard manner. This leads to disparities in how families may access their hospitalized family members. Family members are often confronted with varied visitation policies and rules governing their presence at the bedside. In California, for instance, 2 hospitals in the same city have different visitation policies. In 1 hospital, there are strict visiting hours in place and family members are not allowed to spend the night, and in a different hospital, in the same town, families have unrestricted access to their hospitalized family member 24 hours a day. It is notable that during the COVID-19 pandemic, visitation policies excluding family visitation were standardized across the country following guidelines issued at the state and federal level.

In critical care settings, family involvement has been highlighted through its inclusion in the evidence-based ABCDEF Bundle approach to care (Assess, prevent, and manage pain; Both spontaneous awakening and breathing trials; Choice of analgesia and sedation; Delirium: assess, prevent, and manage; Early mobility; and Family engagement and empowerment), which aims to improve the outcomes of patients experiencing critical care.<sup>13</sup>

Visitation policies and family involvement in patient care have changed in several countries since COVID. For example, in Japan, to avoid infections, including COVID-19, family visits are not allowed at many facilities. Family members are not involved in any care activities in either acute or critical care settings. In Germany, hospitals have restricted visitation times and visitors are limited to 1 or 2 close relatives. However, because of nursing shortages in certain hospitals, family involvement is recommended to enhance patient observation. In the United States, visitation policies vary depending on local infection rates.

### Family Burden

Neurological disorders can create a burden on the family who provides assistance as care partners or caregivers.<sup>14</sup> Caregiver burden is increasingly recognized as a consequence of family involvement in provision of direct care.<sup>15</sup> In the acute care setting, most patients with neurological disorders require assistance in activities of daily living, and this poses biopsychosocial caregiver strain.<sup>16</sup> Within a hospital setting, the greatest challenge is injury prevention for the confused neuroscience patient who can hardly be restrained without causing secondary injury. These patients require round-the-clock assistance causing strain on the caregiver because time spent in the hospital also means loss of daily wages and subsequent financial constraints. Financial costs associated with caregiving include frequent transportation to and from hospital, alternative accommodation, and meals that are not provided by the hospital or insurer. Most caregivers report experiencing moderate to severe depression during the hospitalization of a family member.<sup>17</sup> This compounds the overall stress transferred to the patient's support system. As a result of family unavailability, the patient with neurological deficits may be left unattended and experience long-term outcomes of septic pressure ulcers, disuse myopathy, or contractures.

Many neurological diseases are chronic in nature, and patient care needs may vary based on consequences of the disorder. For example, the needs of stroke patients vary in nature from mobility, communication, self-care, and emotional and psychological changes to adapt to the consequences of stroke. In India, one-third of stroke survivors stay at home and take domiciliary care. This can

put considerable strain on the family who provides care, leading to caregiver burden.<sup>18</sup> Significantly high burden and psychological distress are observed among family caregivers of patients with neurological illness admitted to critical care units.<sup>19</sup> Thus, the social construct of family care in countries such as India is in direct contrast to other countries where financial support through employment is a cultural norm and necessary.

In some Kenyan communities, early death (due to HIV, other infectious diseases, or road traffic accidents) or work-related demands in the middle-aged group make them unavailable to take care of elderly relatives. In these circumstances, school-age family members are involved in caregiving at the expense of education. Caregiver burden is often associated with self-blame, substance use, and behavioral disengagement.<sup>20</sup> A recent study conducted in Singapore highlighted that spousal caregivers of persons with stroke prioritized work resumption over caregiving tasks to meet the financial needs of the family.<sup>21</sup> Another study reported that the uncertainty around recovery from stroke heightened patient and caregiver perception of stroke recovery as facing the "storm."<sup>22</sup>

It should be considered, especially in the case of critical care, that family members have a high risk of symptoms such as anxiety, depression, or posttraumatic stress disorder, due to the sudden burden of critical illness. Some may also be affected by complicated grief.<sup>23</sup> On the other hand, family members are seen as "lifeline into reality."<sup>24</sup> Findings of a study from Germany emphasize the significant need to strengthen the role of families and to enable them to cope with critical situations.<sup>24</sup> Depending on the healthcare system, the role of family can be complex with multiple, sometimes heterogenous and competing roles and expectations.<sup>25</sup>

### Conclusion

This evaluation of the impact of family in neuroscience nursing demonstrates that there is variability across and within countries in how families are engaged in the care of persons with neurological disorders. Allowing family members to visit the patients can benefit the patient, family, and, in turn, the healthcare system.<sup>26</sup> Common factors that impact family engagement include individual values, beliefs, and preferences; socioeconomic pressures; and culture. Dialogue about patient- and family-centered care was sparked during an INNRS, which has highlighted other common global neuroscience nursing concerns. Through scholarship of practice, neuroscience nurses can inform and impact nursing practice on a global level.<sup>27</sup>

There are opportunities for neuroscience nurses to render first-line defense for both patients with neurological conditions and their family through interventions

aimed to promote resilience, decrease burden, and enhance coping and knowledge. Establishment of coordinated care services through shared decision making with patients, family caregivers, and nurses is pivotal to minimize caregiver strain. Research on strategies to support family involvement and interventions to alleviate the related burden is needed.

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