

**PERSON-CENTRED NURSING CARE & SDM IN RAPIDLY
PROGRESSIVE NEUROLOGICAL ILLNESS: A CASE STUDY
OF SPORADIC CJD**

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1. Introduction

Nursing practices at the neurology and stroke ward are quite critical and person-centred care and shared decision-making form the core of these specialist approaches. The patients suffering prolonged neurological disorders are often unable to communicate with the doctors and nurses. Moreover, the patients also develop comorbidities which affect their treatment in the long run. This situation leads to the increase in the demand for the culturally sensitive patient centered care and collaborative decision-making practices of the nurses. This report is based on a case study of an Indigenous Australian woman suffering from sporadic Creutzfeldt-Jakob Disease (CJD) in a stroke and neurology ward. This case study contains examples which reflect the rapid progression of the symptoms of the patient. Moreover, the clinical challenges faced by the treating team and emotional sufferings of the family are also included in the case. This report thus explores the various aspects related to the importance of specialist nursing knowledge, person centered care and SDM practices in regard to the case study. Strategies to improve the nursing practices are also discussed in this report.

2. Case Description

This case is about a 56-year-old Indigenous Australian woman who has been admitted in the emergency department due to worsening of the symptoms such as confusion, hallucinations, paranoid delusions along with insomnia and drastic behavioral changes. This deterioration of the symptoms has occurred over a period of three weeks. The patient is referred to as Mrs. J to maintain the confidentiality of the case. Furthermore, her husband reported that a severe and fast decline in the coordination and cognitive behaviour of Mrs. J occurred in the past few days. Due to her critical condition, she is admitted in the stroke and neurology ward for further treatment. Medical history of Mrs. J revealed that she was also suffering from hypertension and urinary tract infection and also consumed alcohol. Moreover, after the admission in the stroke and neurological ward, the treating team first

gave attention to Mrs. J's urinary tract infection. Furthermore, Mrs. J got uncomfortable when a male inserted an indwelling catheter (IDC) and this also made her husband upset. During dinner, Mrs. J experienced a choking episode which resulted in the increase in the concerns for dysphagia. Hence her husband and daughter along with the treating team became quite tense about her critical condition. Mrs. J showed no improvements even after one week of treatment and undergoing several medical procedures such as CT brain, MRI, EEG and lumbar puncture. The results revealed that she was suffering from sporadic Creutzfeldt-Jakob Disease (CJD) which is a rare form of nervous disorder caused due to misfolded proteins or prions that knock down the brain cells (Acar et al., 2025, p.2). Since the condition of Mrs. J became worse, a multidisciplinary family meeting was organised from the hospital's end which involved her family members, medical team, nurses, a social worker and an AHLO. In this meeting, the treating team disclosed the seriousness of Mrs. J's condition. Thus, with the help of shared decision-making practices, the family focused on the comfort focused care of Mrs. J by specialist nurses. However, the palliative care unit had no beds available and the patient was kept on the waiting list. This case thus provides immense importance on the issues such as patient centred care, specialised nursing care and shared decision-making practices. Lastly it can be said that these approaches contribute to the better treatment of the patients suffering from prolonged neurological illness.

3. Impact on the Patient and Family

It can be extracted from the case study that the neurological illness of Mrs. J had quite a negative impact on her and the family members. The continuous worsening of the cognition, coordination along with communication of Mrs. J led to her hospital admission. It can be noted that during her treatment, she was taken care of by a male nurse which made her uncomfortable. This event also made her husband upset who complained that a male nurse must not insert a catheter to a female patient without consent. Moreover, the long-term

symptoms of hallucinations coupled with agitation and ataxia lead to distress of Mrs. J and enhanced the emotional burden of her family members. The events such as medical team failing to properly diagnose Mrs. J even after one week of hospitalisation and worsening conditions led to breakdown of the trust of the family members. After the results confirmed that she suffered sporadic CJD, beds were not available in the palliative care unit. This also made it quite difficult for her husband and daughter to get the best treatment facilities for her. However, she was given treatment in the neurological and stroke ward by experienced doctors and specialised nurses which relieved her husband and daughter. The study of Bužgová et al., (2020, p. 7) reveals that palliative care enhances the equality of life of the patients through a multidisciplinary palliative care team. However, Mrs. J was restricted to the neurological ward and this increased the uncertainty of the treatment. Hence it is clearly understood that the husband and daughter of Mrs. J was deeply tensed and impacted due to her condition.

4. Specialist Nursing Role in This Context

It is understood from the case study that special nurses need to take care of Mrs. J in order to provide her a culturally sensitive patient centred care. The symptoms of Mrs. J became worse which indicated the severity of her health condition. The specialist nurses in the neurological and stroke ward are expected to provide proper care regarding both the sporadic CJD and comorbidities such as UTI and hypertension. The study of Ransmayr, (2021, p. 2) reveals that care giving to the neurological patients consumes much of the time of the nurses and this can be regarded as one of the challenges faced by the nurses. Moreover, this study also highlights the fact that neurological disorders occur at old age. Thus, there is a huge burden on specialist nurses to deal with multiple complexities of the patients. According to Acar et al., (2025, p.1), CJD is one of the rarest and fatal neurodegenerative disorders of the nervous system which damages the central nervous system. Sporadic Creutzfeldt-Jakob

Disease is progressive and contagious, which makes it more concerning and complex. This study highlights that the nurses are required to provide “individualised, holistic and humanistic” care for the patients suffering from sporadic Creutzfeldt-Jakob Disease. Moreover, it is also noted that the specialist nurses can deal with the complex comorbidities such as UTI. In case of Mrs. J, the nurses have to insert a catheter since she has almost lost her ability to move. Thus, this can be considered as an example which shows the need of specialist nurses in the stroke and neurology ward.

5. Critical Analysis Using Literature

5.1 Person-Centred Care and Family-Centred Care

According to Janerka et al., (2023, p. 9), patient centered care holds immense significance in acute hospital settings such as neurology and stroke ward. This is because patient centred care interventions provide better quality of care and treatment to the patients suffering from chronic medical conditions. In the case of Mrs. J, she has almost lost her muscle coordination and cognitive abilities and her condition is quite worse. Hence, person centred care must be provided to her in the hospital by specialist nurses. Moreover, her husband and daughter should necessarily give consents for all kinds of medical procedures and this resembles family centered care. The study of Gwaza & Msiska, (2022, p.3), highlights that the presence of family members in the hospital boosts the confidence of the patients. In case of Mrs. J, she herself cannot communicate properly with the nurses and the doctors. Thus, there is an urgent need for her husband or daughter to be present at the hospital such that they can communicate with the doctors and nurses.

5.2 Shared Decision Making (SDM)

Shared decision-making forms a crucial part of the nursing practices taken up for the treatment of patients suffering from neurological illness. As per the study of Guo et al.,

(2025, p. 2), shared decision-making practices help to enhance the diagnosis, quality of treatment and end of life care of the critical patients. The discussions between the medical team and patient's family members improves communication and understanding of the medical procedures being carried out. Another study reveals that the palliative care patients have the right to give their opinions in the discussions regarding medical interventions (Kuosmanen et al., 2021, p.3). However, Mrs. J is unable to properly communicate her opinions with the medical teams and thus her family members take part in the shared decision-making practices. It can be furthermore stated that the principle behind shared decision-making processes is that the care of the patients is done with the collaboration of health care professionals and family members. Thus, in this context, the patients such as Mrs. J receives better treatment facilities by doctors and specialist nurses.

5.3 Cultural Safety & Indigenous Health Considerations

According to Lethborg et al., (2022, p. 1), the cultural safety of the indigenous people must be taken into account for medical interventions. Mrs. J felt uncomfortable and upset when she was provided care by a male nurse. Also, her husband was disappointed with this approach since he was not asked for consent. Thus, the cultural and gender sensitivity of the indigenous patients can be understood in this regard. Mackean et al., (2020, p. 5) notes that the participation of AHWLOs have a positive impact on the communication between the health care professionals and the patients' families . Thus, it contributes to the cultural safety of the indigenous patients such as Mrs. J.

5.4 Specialist Neuro-palliative Knowledge in CJD

According to Zayat et al., (2025, p.3), the prion diseases such as Creutzfeldt-Jakob Disease is quite fatal and disrupts the functioning of the brain cells. The nurses must have adequate neuro-palliative knowledge to provide care to the patients suffering from prion

diseases. This study also reveals that palliative care supports advanced care planning of the patients with prolonged neurological disorders. On the other hand, the study of Wiblin, (2024, p.1), highlights that a key requirement to treat the patients with neurological illness is palliative care. This is because with the help of palliative care, the symptoms of the patients can be controlled and unnecessary interventions can be avoided. In case of Mrs. J, the specialist nurses at the neurology and stroke ward must take care of her since she could not be shifted to the palliative care unit due to unavailability of beds.

6. Proposed Evidence-Based Interventions & Solutions

6.1 Improving Communication & SDM

According to Kuosmanen et al. (2021, p.2), efficient communication and shared decision making (SDM) minimize distress and enhance trust toward families of patients with neurological disorders. In the case of Mrs J, her family was unable to comprehend how quickly she was getting worse and this acted as a form of emotional shock at the beginning of her admission. More formal discussions in the initial half of the admission process i.e., explaining the gravity of the suspected neurological illness would have been useful in orienting the family and decreasing uncertainty. Regular reports by a designated nurse and the use of easy language may have made the decision-making process more transparent and enabled the family to feel more educated and involved in the treatment of Mrs J.

6.2 Ensuring Cultural Safety

As noted by Taylor et al. (2020, p.5), culturally sensitive healthcare settings are linked to high rates of willingness to participate in decision making among the Indigenous patients and their families. In the case of Mrs J, issues with cultural safety, specifically the catheterisation carried out by a male nurse even though the family asked otherwise, had a profound impact on trust. The earlier intervention of the Aboriginal Hospital Liaison Officer

(AHLO) would have given an opportunity to retrieve the cultural values of Mrs J and later have them reflected in her documentation since admission. Gender-sensitive care preferences and culturally appropriate communication would have helped make the family feel heard and respected and avoid distress and mistrust that were evolving due to her hospitalisation.

6.3 Enhanced Family Participation in Care

Mackie et al., (2020, p. 3) revealed active engagement of families to enhance comfort and emotional stability among hospitalised patients. The husband and daughter of Mrs J wanted to get involved but not knowing where to fit in given the situation, not knowing that her condition had deteriorated. Giving them rather straightforward advice, like helping them get to know their setting again, getting her involved in more activities that are familiar to her, or being able to console her in times of panic would have helped ease their fears and enhanced their relationship during a time of such terror. Moreover, it can also be said that discussing the anticipated onset of symptoms in CJD would also have helped the medical team to handle situations such as the one she experienced when she was choking, which would have resulted in less shock and confusion.

6.4 Specialist Neuropalliative Approaches

The study of Harrison et al., (2022, p.2), highlights that neuropalliative approaches are quite essential to treat patients suffering from progressive conditions such as Creutzfeldt-Jakob Disease. In such cases, the advanced care planning and medical interventions would have resulted in a better condition of Mrs. J. Moreover, the neuropalliative approaches could have given clearer understanding of the situation to the husband and daughter of Mrs. J about her condition.

6.5 Staff Support & Debriefing

According to Bloomer et al., (2022, p. 3), the support of the staff and proper debriefing helps to reduce the tension of the family members of the patients suffering from chronic conditions such as CJD. During the initial days of hospitalisation, the medical team of Mrs. J failed to diagnose her condition and provide her appropriate treatment. Thus, the intervention of specialist nurse was quite necessary in case of Mrs. J to improve her condition. Furthermore, it can also be said that proper debriefing by the medical team would have helped to reduce the stress situation of the husband and daughter of Mrs. J.

7. Conclusion

This report concludes that the significance of person centered nursing care and shared decision-making practices to cure neurological disorders. Moreover, this report is based on a case of a patient suffering from sporadic Creutzfeldt-Jakob Disease. A brief mention of the case study is included in this report and the aspects are patient centered care and SDM are explored in this regard. Furthermore, it is observed that specialist nurses working in the stroke and neurology ward can be more efficient in handling patients with prolonged neurological illness such as Mrs. J. Moreover, it can be concluded that proper decisions by the family members and health professionals as well as adequate medical interventions will help to treat patients with long term neurological conditions.

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