

## Patient-centered care in precision medicine and end-of-life care in neuro-oncology: The role of nursing in enhancing quality of life and treatment outcomes

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### Abstract

Central nervous system (CNS) tumors are a leading cause of cancer-related deaths in children. While advances in pediatric neuro-oncology have improved survival rates through surgery, radiation, and chemotherapy, these treatments often lead to long-term side effects—such as cognitive impairments, endocrine issues, and secondary cancers—that can significantly affect a child's quality of life. Precision medicine offers hope by tailoring treatments based on the tumor's molecular and genetic profile, targeting cancer cells while minimizing harm to healthy tissue. Equally important is patient-centered care (PCC), which addresses not only the clinical but also the emotional, psychosocial, and ethical needs of patients and families. Nurses play a pivotal role in integrating precision medicine and PCC, managing treatment-related symptoms, guiding shared decision-making, and supporting families—especially during end-of-life (EOL) care. Their role is critical as many patients experience cognitive and functional decline from the disease or its treatment.

This article explores the expanding role of nurses in pediatric neuro-oncology, particularly in EOL care, and emphasizes the need for a holistic approach that aligns with patients' values and well-being. Future efforts should focus on strengthening interdisciplinary collaboration, improving communication, enhancing access to psychosocial support, and addressing ethical challenges. Continued education and support for nurses are essential to deliver personalised, compassionate care.

**Keywords:** Precision medicine; Pediatric neuro-oncology; Patient-centered care; End-of-life care; Nursing

### 1. Introduction

In neuro-oncology, PCC is essential to individualize treatments according to each patient's unique needs and values. This is particularly important when it comes to precision medicine and end-of-life (EOL) care. Precision medicine is all about individualized treatment plans according to a person's genetic makeup, but it is more than the science; it incorporates the patient's wishes, hopes, and overall well-being. Nurses are central to this through facilitating patients in making decisions, controlling symptoms, and meeting emotional and psychosocial needs. From assisting patients with difficult treatment choices to delivering compassionate care in the terminal phases of illness, nurses have a valuable contribution to make in enhancing treatment outcomes and making care effective and compassionate [1]. This model of care improves clinical results while allowing patients to preserve their control and dignity throughout their experience.

The promise of precision medicine in neuro-oncology, however, lies not just in its technological or molecular advances. Another equally basic component of precision medicine's success is integration with patient-centered care principles.

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Patient-centered care requires top priority to include values, preferences, and a patient's sense of well-being in the decision-making process (Barry & Edgman-Levitan, 2012). In neuro-oncology, where the stakes are often high due to the aggressive nature of most brain tumors, particularly gliomas, the need for treatment modalities to become patient-goal-directed grows. Precision medicine's ability to target tumors at the molecular level should be balanced with a process that also respects the individual's unique needs. This entails the assessment of the influence of a patient's values, social circumstances, emotional health, and support group on their treatment decisions. One of the primary frameworks of patient-centered care in neuro-oncology is shared decision-making, which is an exchange that involves active participation of the patient in treatment planning. Shared decision-making makes it possible for patients to know about the hazards, advantages, and possible effects of different therapeutic methods, whereby they can formulate appropriately informed decisions according to their personal preferences [2].

For example, a patient presenting with a high-grade glioma may choose more aggressive treatment aimed at possibly increasing lifespan, while another patient, in contrast, may prioritize quality of life and prefer less vigorous measures directed toward symptom management.

This is why it is essential that clinicians, particularly nurses, become facilitators to enable patients to make these difficult choices by providing education, emotional support, and lucidity on all the choices accessible to them (Epstein & Street, 2017). Besides treatment decisions, neuro-oncology patients usually have complicated end-of-life (EOL) care options. Many neuro-oncology patients with very aggressive malignancies such as glioblastoma multiforme experience a rapid decline of their disease, leading to cognitive decline, loss of function, and severe emotional distress. This is too often inadequate to fulfill the demands of conventional palliative care or EOL interventions and therefore requires an approach to EOL in neuro-oncology that is more holistic and individualized. High-quality EOL care not only takes care of bodily symptoms but also addresses the psychological, emotional, and spiritual distress of both patient and family members (Temel et al., 2017). Decision-making at this phase is complex and typically involves the balancing act between continuing aggressive therapies that may prolong life at the cost of quality of life, or changing to comfort care that focuses on palliation of pain and emotional support. Nurses play a key role in ensuring EOL care in neuro-oncology is compassionate and ethically sound [3].

Due to the significant neurological damage and mental decline that typically occur with high-grade gliomas, patients and families can struggle to fully understand the progression of the disease and implications of treatment choices [4]. Nurses are invaluable in this respect by serving as the voice of the patient's wishes, facilitating communication among patients, families, and the multidisciplinary treatment team, and helping families navigate complex emotional and ethical challenges. They also provide comfort care, which can include symptom management like pain, nausea, and seizures, along with emotional and psychological requirements of. Similarly, because neuro-oncology often involves patients with serious neurological decline, effective and compassionate EOL care is paramount. The study aims to highlight how nurses are involved in this multifaceted strategy by dealing with clinical, psychosocial, and ethical care dimensions of patients and families.

## 1.1. Data Sources and Search Strategy

To ensure a thorough review, the following databases were searched: PubMed: A leading resource for peer-reviewed articles in medical and clinical research. CINAHL (Cumulative Index to Nursing and Allied Health Literature): A database that provides access to literature in the nursing and allied health fields, focusing on healthcare interventions and practices.

- Google Scholar: A comprehensive database that includes academic articles, theses, books, and conference papers.
- Scopus: A multidisciplinary database that includes peer-reviewed literature, including articles and conference proceedings.

These databases were selected due to their breadth and the relevance of the sources they provide in the fields of neuro-oncology, nursing, precision medicine, and palliative care.

### 1.1.1. Inclusion Criteria

To ensure the review focused on the most relevant and applicable studies, the following inclusion criteria were applied: Studies examining nursing roles in the context of precision medicine and EOL care in neuro-oncology. This includes articles that highlight how nurses contribute to patient-centered care, symptom management, and decision-making in these areas. Peer-reviewed articles published within the last 12 years (2012-2024). This time frame ensures that the study includes the latest evidence, particularly as advances in precision medicine and neuro-oncology care have

occurred rapidly over this period [5]. Studies discussing key patient-centered care elements, such as shared decision-making, symptom management, and psychosocial support for neuro-oncology patients. These elements are crucial to understanding the multifaceted role of nursing in this setting.

### 1.1.2. *Exclusion Criteria*

Certain studies were excluded from the review to maintain a focus on patient-centered care in neuro-oncology: Studies that focused solely on molecular and genetic mechanisms of precision medicine, without addressing the patient-centered aspects, were excluded. While the genetic and molecular components of precision medicine are essential, this review focuses specifically on the integration of these treatments with patient-centered care[5]. Non-English publications were excluded to ensure that the studies could be thoroughly assessed by the research team.

### 1.1.3. *Data Extraction and Synthesis*

The process of data extraction focused on identifying and extracting relevant information regarding: Patient-centered care strategies employed in neuro-oncology, especially in relation to precision medicine and EOL care. Nursing interventions that contribute to improving patient outcomes, including symptom management, treatment adherence, psychosocial support, and end-of-life decision-making [6]. Ethical considerations that arise in the context of neuro-oncology care, such as shared decision-making, balancing treatment options with quality of life, and navigating complex moral dilemmas at the end of life.

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## 2. **Nursing Interventions in Precision Oncology**

Nurses in precision oncology perform a critical and multifaceted role in the care of patients, particularly those with neuro-oncological conditions. Their responsibilities extend across symptom management, patient education, treatment adherence, and ethical advocacy, all of which are essential in the delivery of personalized care that aligns with the principles of precision medicine [7]. As neuro-oncology treatments such as targeted therapies and immunotherapies introduce specific side effects, nursing interventions are designed to manage these unique challenges effectively, improving the patient's overall experience outcomes.

### 2.1. **Symptom Management**

Symptom control is one of the key nursing interventions in precision oncology, which can be extremely heterogeneous due to the individualized nature of treatment protocols [8]. Neuro-oncology patients, and especially those on precision therapies, often experience side effects requiring specialized management. Cognitive impairment, for example, is a frequent condition in neuro-oncology, both resulting from the disease process and from the effect of some treatments (Weller et al., 2021).

Nurses aid in the treatment of such cognitive impairments by instituting cognitive rehabilitation interventions, structured daily regimens, and pharmacologic interventions designed to optimize cognitive functioning and mitigate the cognitive decrement seen in such patients. Such interventions attempt to augment the patient's ability for activities of daily living and maintain independence for as long a period as possible. In addition to cognitive decline, fatigue and pain are also significant problems in patients undergoing aggressive treatments like radiation, chemotherapy, or immunotherapy [10]. Nurses assess these symptoms ongoing and collaborate with patients to develop individualized fatigue and management strategies. Interventions include organized exercise programs tailored to the patient's capabilities, dietary modifications to increase energy levels, and integrative therapies such as acupuncture, mindfulness, and yoga to address fatigue in a holistic manner (Mitchell et al., 2020). Pain management is also a cornerstone of nursing practice, especially in neuro-oncology, where the severity of pain can be severe and prolonged. The nurses employ an interdisciplinary approach to pain management, wherein they adopt pharmacologic measures in the form of corticosteroids and opioids in combination with non-pharmacologic means such as physical therapy, relaxation therapies, and counseling to treat the physical and psychological aspects of pain (Hui et al., 2020).

### 2.2. **Enhancing Treatment Adherence**

Nurses are also responsible for improving treatment adherence, crucial to achieving optimal outcomes in precision oncology. The complexity of precision treatments, such as targeted therapies and immunotherapies, may be difficult for patients to understand and navigate complicated drug regimens. Nurses provide valuable patient education, explaining the goals, how they work, and potential side effects of prescribed therapies [11]. Through educating patients on how adherence is important, nurses inform them that the right use of therapy and medicines can maximize the effectiveness of treatment, ultimately leading to better survival and quality of life (Hlubocky & Daugherty, 2022) [12]. In addition to in-person education, digital health technologies have increasingly played a crucial role in enhancing precision treatment

adherence. Nurses leverage AI-powered patient portals and telemedicine platforms to facilitate remote monitoring and self-care, with patients having real-time access to healthcare professionals [13]. Such technologies offer patients an easy way of tracking their progress, asking questions, and receiving timely tweaks to their treatment plans without having to visit the clinic. This convergence of digital technology facilitates a more tailored and dynamic care approach, enhancing both compliance and patient interest in taking care of themselves.

### 2.3. Ethical Advocacy and Decision-Making

Ethical concerns are particularly pertinent in precision oncology, and notably so in genetic screening and enrollment into clinical trials. The majority of patients with neuro-oncology are given the option of undergoing genetic screening, which not only informs their direct treatment but may also offer data relevant to their relatives, potentially having implications for the medical management of their families. Nurses have a pivotal role in supporting patients through the decision-making process, providing direct and unbiased information about the risks and benefits of genetic testing (Vayena et al. 2018). Nurses ensure that patients are well informed and able to make decisions consistent with their values and preferences. Participation in experimental treatment and clinical trials also poses ethical concerns.

Nurses support patients in such conundrums through comprehensive risk-benefit counseling, informing them of the potential outcomes of participating in clinical trials, and emphasizing patient autonomy in decision-making (Hlubocky & Daugherty, 2022). Nurses encourage the patient's right to make independent decisions in such a scenario while ensuring that patients are well informed of the potential risks associated with experimental treatments. Through these interventions, nurses uphold ethical principles of autonomy, beneficence, and justice in terms of ensuring the respect and dignity of patients through their care process.

### 2.4. End-of-Life Care in Neuro-Oncology

End-of-life (EOL) care is a very crucial aspect of neuro-oncology, especially in patients with high-grade gliomas and other malignant intracranial tumors. These patients are expected to reach a stage of terminality in their disease when control of symptoms and management of palliative care become most crucial. At the end of life, patients have an overwhelming symptom burden of pain, seizures, shortness of breath, and progressive cognitive impairment that all worsens their quality of life and interpersonal interaction with their family members (Weller et al., 2021). Nurses play an important role in ensuring optimal symptom control and protecting the dignity and comfort of such a challenging patient [14].

### 2.5. Advance Care Planning

Advance care planning (ACP) is an integral component of EOL care, particularly in neuro-oncology. Because most neuro-oncology patients experience loss of decision-making capacity due to disease progression, early conversations on advance directives, goals of care, and end-of-life decision preferences are crucial (Epstein & Street, 2017). Nurses play an important role in facilitating these tough conversations, walking patients and families through the conversations regarding hospice, DNRs, and transition from curative to palliative care. These conversations can be draining emotionally because families will often struggle with the harsh reality of a terminal diagnosis and the difficult choices that come with it. However, nurses provide essential emotional support, education, and reassurance so that patients and families are able to make informed decisions that match the patient's values and wishes (Temel et al., 2017). Studies have revealed that interventions in palliative care in the early stage improve the quality of life of patients as well as relieve distress among caregivers by giving open information on symptom management and changes in care (Ferrell et al., 2018). Nurses ensure that such decisions are taken collectively and in a sympathetic, patient-centered manner.

### 2.6. Ethical Considerations

Ethical concerns rank first in EOL care in neuro-oncology, particularly if healthcare providers and families need to make distressing choices concerning life-sustaining treatments. Artificial nutrition, hydration, and ventilatory support are trying choices for many families, particularly if the patient is already unable to communicate his or her wishes (Williams & Anderson, 2018). Nurses have a key role as advocates during these discussions so that choices are made with the patient's comfort and dignity foremost, rather than needlessly protracting suffering. Ethical dilemmas typically arise when family members are uncertain about withdrawing or withholding interventions for fear of "giving up" on their loved one. Nurses help the families by providing empathetic counseling, helping them to weigh the benefits and burdens of continued intervention and keep the focus of the conversation on the patient's previously expressed values and preferences for care (Hlubocky & Daugherty, 2022).

When palliative sedation is being considered for patients with refractory symptoms, nurses collaborate with the interdisciplinary health care team to promote ethically sound sedation and according to the patient's end-of-life goals

(Santos & Goulart, 2023). Nurses also navigate the challenging ethical terrain of the withdrawal of life support or comfort-focused care. These decisions require a compassionate, personalized, and extremely sensitive reaction to the patient's wishes and the needs of the family. Nurses work to maintain the patient's voice, albeit non-verbal, at the forefront of these kinds of discussions, providing ethical guidance and emotional support for patient and family.

### **3. Challenges And Future Directions in Neuro-Oncology Nursing**

In the rapidly changing field of neuro-oncology, patient-centered care (PCC) is pertinent to ensure that the treatment emphasis goes beyond the molecular targeting to cater fully to the physical, emotional, and psychological needs of patients. While precision medicine has great potential in individualizing treatments based on genetic and molecular profiles, incorporating it with palliative care, shared decision-making, and holistic nursing interventions remains an issue demanding persistent effort and ingenuity [15]. Nurses play a key role in bridging these gaps, speaking up for the patients, and ensuring that care is tailored to meet the individual needs of each patient.

#### **3.1. Challenges in Implementing Patient-Centered Care**

With advances in neuro-oncology care, there are several challenges that still remain in the integration of patient-centered care, more specifically with respect to precision medicine. One of the major challenges is the complexity of treatment regimens associated with targeted therapies and immunotherapies, which is daunting to patients. These therapies often come with unique side effects requiring professional symptom management, including the management of cognitive decline, fatigue, pain, and psychosocial distress (Mitchell et al., 2020; Weller et al., 2021).

Nurses are key in helping patients navigate these complexities with information and reassurance through individualized care planning. But making sure that these complexities are managed properly by making the right interventions in the form of support to the patients is not an easy job with more and more changing technologies and therapies. Equitable access to precision medicine to a wide variety of patient populations is yet another challenge. Access differences, particularly for the underserved populations, may limit the opportunities for the patients to access genomic testing, tailored treatments, and directed therapies. The majority of patients are met with cost, geographic, and social discrepancies in accessing high-tech care, thus creating sweeping gaps in outcome across groups [16].

Nurses must argue for equitable access to healthcare and the capacity for all patients to engage in precision medicine regardless of socioeconomic status or geographical location. Additionally, health disparities involve not only access but also the ability to provide patient-centered care culturally. Neuro-oncology patients comprise a diverse range of cultural backgrounds with some unique values, beliefs, and preferences for their care. Nurses should be ready to provide culturally sensitive care, being continuously in training and learning about the ways that cultural concerns could affect treatment modalities, particularly in relation to genetic testing and end-of-life care (Williams & Anderson, 2018).

Creating an environment of understanding and trust together is essential to maximize compliance with patient preference as well as personalized care in regards to what resonates with them.

#### **3.2. Future Directions in Advancing Neuro-Oncology Care**

To overcome these challenges and enhance the standard of care in neuro-oncology, future directions must prioritize the integration of new technologies, increased education and training for clinicians, and improved patient advocacy. One of the areas of growth is the integration of palliative care early in treatment. Historically, palliative care has been introduced late in the illness trajectory; however, with the increasing recognition of its contribution to quality of life, there has been movement toward earlier initiation. There is supporting evidence that early palliative care intervention can improve both symptom management and patient satisfaction (Ferrell et al., 2018). Nurses must continue to advocate for the integration of palliative care early so that the patient receives holistic care throughout their treatment course and not just at the end-of-life stages. The other future direction is closing the disparities in access to genomic testing and targeted therapies.

As precision medicine becomes more accessible, it is essential that measures are put in place to make these innovative treatments available to all patients, regardless of their background. This may include policy efforts to broaden insurance coverage for genomic testing, along with initiatives aimed at reducing geographic and socioeconomic disparities in care [17]. Nurses must be the leaders in advocating for these changes, so that all patients, regardless of background, are able to benefit from the progress in neuro-oncology. The expansion of nursing education in the areas of genomics, genetic counseling, and AI-facilitated care is also critical to the future of neuro-oncology nursing. With AI-powered technologies and precision medicine still evolving, nurses must have a solid understanding of these new developments to be able to interpret extensive genomic data and communicate effectively with the treatment plans for patients [18-22]. AI-enabled

tools such as patient portals, telemedicine, and predictive algorithms have the potential to take the quality of care to the next level by providing nurses real-time data, facilitating remote monitoring, and allowing personalized care (Snyder et al., 2019). However, for their effective use, nurses require training and ongoing support to implement these in practice in a way that enhances patient benefits.

Challenges in neuro-oncology care, including healthcare disparities, gaps in nursing education, and difficulties in implementing patient-centered approaches in precision medicine and palliative care. Once the relevant data was extracted, findings were synthesized into themes to provide a holistic understanding of the subject. This thematic synthesis allowed for the identification of patterns, challenges, and gaps in the current knowledge, and enabled the study to highlight the areas where nursing practice can have the most significant impact.

### **3.3. Methodological Rigor**

The systematic approach ensures that the study adheres to rigorous research standards. All articles were screened for quality and relevance, and data extraction was performed using a standardized form to minimize bias and inconsistencies [24]. The use of multiple databases further strengthens the robustness of the findings by ensuring the inclusion of a diverse range of studies, including those from different disciplines within healthcare.

The synthesis of the data into themes provides a comprehensive analysis of the key areas where nursing interventions are crucial, allowing for a detailed understanding of the role of nursing in facilitating patient-centered care in neuro-oncology.

### **3.4. Respecting Patient Preferences and Values**

A core element of PCC in neuro-oncology is respecting and aligning treatment plans with the patient's personal values and preferences. Precision medicine enables highly individualized treatments, but these must be aligned with patients' goals, cultural beliefs, and lifestyle considerations (Barry & Edgman-Levitan, 2012). Nurses are pivotal in ensuring that treatments do not solely focus on the biological aspects of the disease but also consider the patient's emotional, social, and ethical preferences. For example, some patients may opt for aggressive treatments even with known side effects, while others might prioritize maintaining a good quality of life over pursuing life-extending options. Nurses engage in ongoing conversations with patients and families to assess their preferences and ensure that treatments align with these goals. Cultural sensitivity plays an essential role, as patients from diverse backgrounds may have varying perspectives on genetic testing, aggressive treatments, and palliative care options (Williams & Anderson, 2018). By fostering open dialogue and tailoring care to individual needs, nurses contribute significantly to establishing trust and enhancing adherence to treatment plans, which leads to better patient satisfaction and outcomes.

### **3.5. Effective Communication and Shared Decision-Making**

Effective communication is foundational to shared decision-making, a central component of PCC. Precision medicine often involves complex treatment regimens, such as targeted therapies and immunotherapies, that can be challenging for patients to fully understand. Nurses play a key role in simplifying complex medical terminology, translating it into accessible language, and clarifying any uncertainties (Epstein & Street, 2017). In addition to providing information, nurses actively engage patients and their families in discussions about treatment options, ensuring that they are well-informed and able to make decisions that reflect their values and preferences. This is especially important in neuro-oncology, where cognitive decline may impair a patient's ability to make informed decisions. The involvement of family members in these discussions becomes critical, as they can help advocate for the patient's wishes when the patient's cognitive abilities are compromised (Vayena et al., 2018).

Through clear and compassionate communication, nurses ensure that patients and their families feel heard, respected, and actively involved in their care journey. Managing Symptoms and Enhancing Quality of Life: Beyond addressing the tumor itself, managing the physical and emotional burden of the disease is crucial to maintaining a patient's quality of life. Neuro-oncology patients often experience debilitating symptoms such as cognitive dysfunction, fatigue, and chronic pain, all of which significantly impact their daily functioning and emotional well-being. While precision medicine offers targeted treatments, symptom management remains a vital component of comprehensive care [25]. Nurses play a critical role in implementing evidence-based interventions to alleviate these symptoms and improve quality of life (Ferrell et al., 2018). For example, cognitive rehabilitation strategies, such as structured routines, memory aids, and pharmacological support, are recommended to help patients manage cognitive deficits (Weller et al., 2021).

Fatigue, one of the most distressing symptoms in neuro-oncology, can be alleviated through individualized exercise programs, nutritional counseling, and complementary therapies such as acupuncture and mindfulness-based stress

reduction (Mitchell et al., 2020). Pain management strategies, including opioid therapy and adjuvant pain management techniques, are also essential in enhancing comfort [26]. Additionally, addressing the psychosocial distress that often accompanies a neuro-oncological diagnosis is crucial. Many patients face anxiety and depression as they navigate the uncertainties of their illness.

Nurses provide emotional support, facilitate peer support groups, and connect patients with mental health professionals, ensuring comprehensive care that addresses both the psychological and physical challenges of the disease (Penedo et al., 2018).

### 3.6. Seamless Care Coordination

Seamless care coordination among multiple healthcare providers is essential to ensure the effective implementation of PCC in neuro-oncology. Patients undergoing precision medicine often require input from oncologists, neurologists, genetic counselors, rehabilitation specialists, and palliative care teams. Nurses play a central role in integrating these various components of care, ensuring continuity and a cohesive treatment experience (Temel et al., 2017). Acting as care coordinators, nurses facilitate communication among the interdisciplinary team, ensuring that all healthcare professionals are aligned in their approach to the patient's care. They bridge the gap between advanced, technology-driven precision medicine and the human-centered care that focuses on compassion, communication, and respect for patient preferences. This role is especially important in neuro-oncology, where the complexity of treatments and the severity of symptoms require coordinated, collaborative efforts to optimize patient outcomes [27].

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## 4. Conclusion

Patient-centered care (PCC) is a pillar of precision medicine and end-of-life (EOL) neuro-oncology care in a way that not only tackles the molecular and genetic profile of the disease but also is the expression of patients' personal values, preferences, and interests. It emphasizes the importance of integrative care in which the cure of the body and the healing of the emotional aspects of patient experience are embraced. Nurses have a central role in providing this care, acting as patient advocates through shared decision-making, symptom management, and ethical support along the treatment and end-of-life journey. With the ongoing advancement of neuro-oncology through the incorporation of precision medicine, nurses are crucial to ensuring technological innovation is employed to improve patient outcomes while still being a caring, human-centered discipline.

Their function of speaking on behalf of patients, managing problematic symptoms, and making patient-preferred treatment decisions remains a significant aspect of the provision of care. Closing healthcare disparities, such as access to genomic testing and targeted therapies, will be critical to ensuring that all patients can participate in progress within the field independently of background or socioeconomic status. Expanded nursing education in areas such as genomics, palliative care, and AI-based technologies is needed to prepare nurses to address the complexities of contemporary neuro-oncology care.

Digital health technologies, including telemedicine and AI-based platforms, can further improve patient care by allowing real-time monitoring and patient-specific treatment adaptation. Nurses must be provided with education on the effective use of these tools to optimize patient outcomes.

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## Compliance with ethical standards

### *Disclosure of conflict of interest*

No conflict of interest to be disclosed.

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