SPECIAL ARTICLE

Second meeting between neurological patients and associations from the Spanish Society of Neurology Nursing

Noelia López a,*, Isabel Manzanares b, Raquel Vallejo de la Paz c, Eulalia Giné Ciprés d, Paloma Muñoz Pedrazuela e, Tania Herrera Barcia f, Henar Garzón López g, Ana Sofía Fernandes Ribeiro h, Carmen Funes Molina i, Alejandro Lendínez Mesa j, María Palanca Cámara k, Mercè Salvat Plana l, Lourdes Bermelló López m, Ana María Duro Martínez n, Fidel López Espuela o, Alejandro Lendínez Mesa f

a Enfermería, Consultas Externas, Hospital Universitario Son Espases, Servei de Salut de les Illes Balears, Departamento de Enfermería y Fisioterapia, Universitat de les Illes Balears, Palma de Mallorca, Spain
b Enfermería de Práctica Avanzada, Unidad de Epilepsia, Hospital Clínico de Barcelona, Institut d’Investigacions Biomèdiques Pi i Sunyer (IDIBAPS), EpiCARE Network, Barcelona, Spain
c Enfermería, Servicio de Neurología y Unidad de Ictus, Hospital Universitario de Jaén, Jaén, Spain
d Enfermería de Práctica Avanzada, Unidad de Cefalea, Hospital Universitario Vall d’Hebron, Barcelona, Spain
e Enfermería, Unidad de Traumatología, Urología y Cirugía Torácica, Hospital Universitario Getafe, Vicepresidenta SEDENE, Getafe, Madrid, Spain
f Enfermería, Servicio de Neurología, Hospital Universitario 12 de Octubre, Presidente de SEDENE, Madrid, Spain
g Unidad de Medicina Interna, Endocrinología y Reumatología, Hospital Universitario de Getafe, Madrid, Spain
h Escuela Universitaria de Enfermería y Fisioterapia de San Juan de Dios, Universidad Pontificia Comillas, Madrid, Spain
i Unidad Consultas Externas Pediátricas, Hospital Universitario Gregorio Marañón, Madrid, Spain
j Departamento de Enfermería, Servicio de Neurología, Hospital Universitario 12 de Octubre, Madrid, Spain
k Unidad de Epilepsia Refractaria, Hospital Universitari i Politécnic La Fe, ERN EpiCARE, Valencia, Spain
l Pla director de les Malalties Vasculars Cerebrals, Departament de Salut, Agència de Qualitat i Avaluació Sanitàries de Catalunya (AQuAS). CIBER en Epidemiología y Salud Pública (CIBERESP), Barcelona, Spain
m Unidad de Neurología/Neurocirugía del Hospital Lucus Augusti de Lugo, Lugo, Spain
n Consulta de Enfermería de Esclerosis Múltiple, Servicio de Farmacia, Hospital Universitario Fundación Alcorcón, Madrid, Spain
o Facultad de Enfermería y Terapia Ocupacional, Universidad de Extremadura, Cáceres, Spain

Received 13 January 2023; accepted 24 February 2023

Abstract Empowerment is known as enabling the patient to manage their self-care. In this process patients acquire knowledge, attitudes, and skills regarding their disease in a facilitative environment. Neurology nurses are fundamental in educating and motivating this population.
Nevertheless, collaboration between professionals and patients is the key to patient empowerment and coping. This is why SEDENE held the second meeting between neurological patients and associations in the context of the XXIX National and V International Congress of SEDENE in the city of Granada in 2022. The nurse Pedro Soriano and patients’ associations of multiple sclerosis (AGDEM), epilepsy (APICE), Parkinson’s disease (Parkinson Granada), stroke (NEUROAFEIC), headache (AEMICE), and ALS (AGRAELA) collaborated. Soriano spoke about helping relationships where patients can express emotions, feelings, and healthcare professionals are able to create an environment of trust to develop patient empowerment. Concerning patient coping skills, they talk about their fears regarding the diagnosis process, resilience, and strategies to improve their abilities in a special visit. The social and work circumstances that are affected in these patients’ lives were discussed, and their difficulties trying to balance their symptoms and their jobs or exams. They explained to us how changes in roles due to their disease affect social integration and family relationships. They reiterated how they had lost their personal identity with the diagnosis of their disease and its progression. Neurology nurses are a point of reference in their care, essential in interdisciplinary teams, and they highlight inequalities in care according to communities and areas. We would therefore like to thank all the attendees for their testimonies and participation, and hope that these activities will influence nursing practice in the care of neurological patients.

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Empowerment, understood as enabling the patient to manage their self-care, is a paradigm that neurological nurses are adapting to their nursing models to improve aspects such as care, satisfaction, and excellence in care. This patient process includes patient understanding of their role, knowledge acquisition, patient-acquired skills, and a facilitative environment.

The neurological nurse plays a key role in the dimensions of empowerment in assisting the patient by providing health education to help decision making and in fostering effective
communication for motivation and confidence. However, an important part of these dimensions of empowerment, such as coping skills and sharing, and enabling others, requires peer-to-peer collaboration. The neurological nurse is aware of the need to work on this goal with patient associations. Associative movements of neurological patients are important to integrate these people into society, and create a sense of belonging and alignment for individuals and their families Fig. 1.

In this sense, and understanding that empowerment is a patient-centred process, the patient experience is a phenomenon of interest to nurses. Nurses create health education programmes as part of our healthcare practice, therefore developing these types of experience is an indispensable tool to achieve the goal of empowering people living with a chronic illness.

At the Spanish Society of Neurological Nursing (SEDENE) we are committed to this vision, and that is why we have organised, as part of our annual congress 2nd Meeting with Neurological Patients and Associationsto share these experiences, concerns, and knowledge of the needs of people living with neurological disease, to improve their care.

The aim of this meeting was to deepen and make visible aspects in the group of neurological patients, such as the patient’s training to manage their disease, barriers, and difficulties in labour market or student integration, strengths to manage family and social situations, and expectations of the neurological nurse.

In this latest session, held as part of the 24th National and 5th International Congress of SEDENE in the city of Granada, we enjoyed the participation of the nurse Pedro Soriano, who, in the context of the helping relationship, spoke of situations closely linked to nurse accompaniment of people through their health process. In the introduction to the meeting, he spoke of the need to establish a climate of trust in which to express the emotions that arise at these times, and how unexpressed emotions can trigger physical symptoms, or maladaptive attitudes. He also recalled some emotional situations where the warmth of human contact with the health professional helped the patient feel safe within the turbulent experience of chronic disease. He reminded us that closeness and empathy are inherent qualities in nurses, and therefore it is important that we ensure all the information we give is followed up, to enable patients and those close to them to assimilate and act when necessary. Finally, it is important to encourage patients to become active patients; emphasising that this model not only implies empowerment at an individual level, but also achieves movement at a social level, due to the relationship of help established between people and the change of mentality in the community to an active role.

We had representatives from patient associations: María Caridad Peregrín González, president of AGDEM (Multiple Sclerosis Association of Granada), Marisa Mayorgas Fortis, speech therapist and secretary of NEUROAFEIC and AGRAELA (Association of Relatives and Patients of Ictus Granada and Association of ALS patients Granada), Inmaculada Martín, member of AEMICE (Spanish Migraine and Headache Association), María Angustias Díaz, president of the Granada Parkinson Association, and Susana Rodriguez, social worker from APICE (Andalusian Epilepsy Association).

All these issues were debated during the meeting. In many situations they are presumed to be common to neurological diseases and create a climate of fraternity among patients. In the course of this debate, the most relevant testimonies were collected for later discussion.

Regarding the patient’s ability to cope with the disease, circumstances such as the uncertainty of the diagnosis of a chronic degenerative disease were discussed, and that these are diseases that have no cure... and sometimes no treatment: Much was said about the importance of the age at diagnosis: these are not diseases for old people. Statements were made such as it is much more bearable if you prepare for the consultation with your doctor and you can collaborate with professionals in the management of your illness; leading to the concept of shared decisions with health pro-
professionals. They also stated that there are diseases that come at once and others that take a long time to be diagnosed... and that creates a lot of fear. This demonstrates that these patients have acquired the competences to cope with the chronic nature of their diagnoses.

They went on to talk about work and student issues, where they highlighted that there are situations where you feel that you are labelled as incapable when you are capable of going about your daily life, supporting your family, and providing care for your family: There was much talk of fears, stigma, and lack of knowledge of society at large, with some patients saying: I prefer not to tell them, because I don’t know how they will take it. In terms of students, they reported missing school because they were unable to take exams or classes because they couldn’t foresee the symptoms of the disease, despite the disease being controlled, especially in terms of headaches. They spoke with sadness about disqualifying labels, such as this person has been out on the town... or situations of missing social and family events: you lose days of your life. They called for business support and workplace education programmes. They paid special attention to the need for an interdisciplinary team with social workers to be able to deal with these situations, as they imply a loss of identity for people with these diseases.

Regarding the sphere of family relationships or friendships, the role changes that occur in families or relationships when the diagnosis is made were discussed, sometimes leading to break-ups in couples due to the uncertainty of the diagnosis and sometimes isolation because they lack the psychological and physical strength for the activities that they used to be able to undertake. Much was said about the difficulty of social integration from childhood and throughout the lives of people affected at these stages, and about peer support between people living similar situations, which fosters acceptance and alignment. One of the speakers concluded the section with the lovely phrase, it is important to realise the important things in life.

In terms of expectations of the neurological nurse, they emphasised that our role is very important, they are the closest person and the easiest to communicate with, using simpler language: They spoke of the nurse as the reference person: doctors inform, nurses educate. We were touched by the testimony of the patient who told us that sometimes because of a little pill, we can’t eat, we can’t talk, we can’t shower... we don’t want to go to the ED: Nurses who advocate health education understand that certain situations that cannot be solved in the emergency department find their answer in the nurse’s office. We all agreed that for patients with multiple comorbidities, the nurse is indispensable for interdisciplinary communication.

Finally, the inequality in distribution and access to advanced practice nurses was highlighted, “sometimes within the same city they do not have the same services and feel the need for follow-up, clarification of concerns, presence of crises...”. "Neurology clinic nurses don’t exist in all communities.”

In line with the Astana Declaration, where countries around the world committed to strengthen their primary care systems to achieve universal health coverage, our health system should provide our neurological patients with an accessible, available, and affordable service of quality neurological nursing care, in this case delivered by the advanced practice nurse or expert in neurological care. National health policies, strategies, and plans should focus their efforts on giving patients answers: only thus can they foster an enabling environment for patient empowerment and improvement of their health and well-being.

Funding

No funding was received for this article.

Acknowledgements

We would like to make special mention and thank all the people who made this meeting possible from the associations of patients with neurological disease. Their dedication to the people they care for supports and reinforces our conviction that the care of the person must be comprehensive and interdisciplinary. With this article we want to highlight their work and effort, and the enthusiasm they expressed to us when we suggested this activity to them. We thank you sincerely thank you.

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.sedene.2023.02.003.

References