MedCrave
Step into the World of Research

Hospice & Palliative Medicine International Journal

Research Article

Palliative care for people with long term neurological conditions: practices and reflections based on comprehensive care

Abstract

The care for people with Long Term Neurological Conditions (LTNC) isn´t recognized as a major practice in Palliative Care (PC) scientific production; in daily basis, the assistance is focused on hygiene´s care and clinical observation. However, from the perspective of PC, the health professionals´ role is to promote the dignity of the human person. The concept of LTNC covers neurological diseases with a prognosis of long-time life with significant disabilities, end-of-life stage that is difficult to identify, with many symptoms and physical and cognitive impairments. In this paper, we considered the following situations: persistent vegetative state, minimal consciousness state and locked-in syndrome. This is a theoretical study of a qualitative nature, which aims to describe a new kind of PC practice with this population, based on first author PHD study. The concept of Comprehensive Care is the main theoretical framework for the paper. It is proposed a practice reconstruction based on the person´s biography occurs by several perspectives, especially through sensory stimuli related to prior patient´s occupational repertoire. Along with the detailed evaluation, the therapist does a careful and continuous monitoring, proposing activities, giving special attention to their reactions, being able to discriminate what pleases or not, and expanding the possibilities of encounter of people with LTNC and the environment which surround them. Therapist should also provide support and guidance to the family, which is in a vulnerable situation. Regardless of neurological reactions presented by the patients this practice helps reconstructing the meanings of the daily life of person with so severe disability. Sensory stimuli are shown as potential tools for a rehabilitation practice. Memory, history, identity, dignity, and subjectivity qualify the assistance for people with LTNC.

Keywords: palliative care, long term neurological conditions, comprehensive care, psychoanalysis, vegetative state, locked-in syndrome

Volume 6 Issue 2 - 2023

Marilia Bense Othero,[1] José Ricardo Carvalho de Mesquita Ayres[2]
[1]Professor at University of São Paulo, Medicine School, Occupational Therapy, Brazil
[2]Professor at University of São Paulo, Medicine School, Social and Preventive Medicine, Brazil

Correspondence: Professor Marilia Bense Othero, Rua Cipotanea, 51 – São Paulo, São Paulo, Brazil, 05360-160, Tel +55 11 30917453, Email marilia.other@usp.br

Received: August 14, 2023 | **Published:** August 24, 2023

Abbreviations: LTNC, long term neurological conditions; PC, palliative care; LIS, locked-in syndrome, OT, occupational therapist

Introduction

This article aims to describe a proposed intervention with people with long-term neurological conditions (LTNC), by demonstrating new possibilities for clinical practice, as well as presenting its theoretical foundation. It is based on the first author PhD research entitled: "Production of care for patients with very serious neurological conditions: interdisciplinary contributions to a theoretical foundation", Othero MB[1] by the Department of Preventive Medicine of the Faculty of Medicine of the University of São Paulo, supervised by Prof. doctor José Ricardo C. M. Ayres and co-supervised by Prof. Dr. Leny Magalhães Mrech. The research was approved by the Ethics Committee of the Hospital das Clínicas of the Medicine School of the University of São Paulo, number 27348514.0.0000.0065.

Long term neurological conditions

"Long Term Neurological Condition" (LTNC) is a clinical situation defined as: condition resulting from a disease, injury or damage to the nervous system (central or peripheral) that will affect the individual and his family for the rest of their lives.[2] LTNC includes conditions of sudden onset, such as stroke; progressive conditions such as Parkinson's Disease and Motor Neurone Diseases; intermittent conditions such as epileptic syndromes; stable conditions with or without age-related degeneration, such as sequelae of poliomyelitis and cerebral palsy[2]. These patients have permanent sequelae, whether mental or physical (and usually both), dependent on at least one person for their daily activities.[3] They represent a challenge in symptoms assessment and management, due to their cognitive and functional disability; and they are also more likely to die in the hospital, with less ability to make decisions.[4] The main rehabilitation proposals focus on post-injury neurological recovery, especially for patients with functional recovery prognosis. The scientific literature summarizes the care needs of these people:[5–8] environment for recovery; prevention and treatment of secondary complications; physical therapy, medical, psychological and technological treatments; family support.

The main approaches are sensory stimulation for neurological recovery and increased awareness/perception, postural changes, of contractures and joint stiffness prevention through adequate mobilization and positioning.[5,7,9,10] Sensory stimulation is often used as an attempt to keep the brain functioning, but there is no strong evidence of real benefits in this situation. There are no randomized controlled studies, or sensitive/valid instruments for evaluation of results, requiring many studies in the área.[11] As future perspectives, the emphasis is placed on the technological evolution, functional imaging tests and other computer interfaces for diagnosing and communicating with such patients.[12]

In end-of-life care for patients with LTCN, the care is related to symptom management and physical comfort measures. Family support is described in detail, and big relevance is place at advanced care planning, including procedures discontinuation.[13–15]

Ethical and philosophical aspects of caring for people in such a serious condition are also discussed: even though consciousness and behavior may be deeply impaired, their human condition continues and must be considered by professionals involved in the health care.[16]

Comprehensive care as a theoretical framework

Having Brazilian theoretical framework as reference, comprehensive care should be understood as a human right, affiliating it with values of life defense, pursuit of happiness and fuller communication between subjects involved in health assistance. Happiness can also be understood here as a qualified way of go through life.[17] It is a posture, an attitude, and involves theoretical-practical knowledge and services management and organization. Therefore, it is a concept that involves complexity and intersubjectivity, apprehending the needs for health work based on a dialogical approach between professionals and patients.[17] It is not an isolated act. Comprehensive care involves concern, radical accountability, sensitivity to the human experience and recognition of other realities, with all their singularities and differences.[18]

Ayres[19] defines it as the designation of health care interested in the existential sense of the illness experience, including aspects such as listening, embracement, interpretation of meanings and meanings of the illness process. This allows professionals and patients to rebuild their perceptions of themselves from and during care. This perspective seeks to expand the normative horizon of health practices beyond the protection or recovery of clinical states or functional conditions.[19]

In this perspective, someone's existence always matters, regardless of their clinical or functional conditions, and care is achieved through dedication, availability and responsibility for the patient and their family.[20] And, for its effectiveness, it is necessary to build new practices, based on the aforementioned ethical values, with a commitment to human rights, advocacy and empowerment.[18]

Regarding PC for people with LTNC, all these aspects will be radicalized, with obstacles not only to their care and inclusion process, but even to the questioning of what kind of life is possible and how it is worth living. These are conditions that pose the difficult challenge of building innovative languages and alternative interventions to establish effective encounters.

Comprehensive care is a possible approach to expand and rebuild palliative care assistance, since the patients with LTNC will continue to be subjects of their own history, to matter for their significative ones, even with many disabilities. As a way of demonstrating this, Manoel's story will be presented below, with further comments and reflections.

Manoel´s history and new perspectives of care

Manoel (fictional name) had about 40 years old at the time of events. He used to work as a transit operator in the city of São Paulo, Brazil. When he was at middle 20´s, he had an accident while working and stayed with severe motor and cognitive impairments. After 13 years placed in a general hospital, he was transferred to our hospice and, at that time, I was his occupational therapist (OT) and was also responsible for and rehabilitation management care. At the first contact with Manoel, the most impressive for me were his physical deformities: his arms and hands absolutely deformed, feet and hip were stiffened, his neck was stuck in a position where his eyes only see the room ceiling. The care plan started with discovering what were his likes, knowing more about his life story and how was Manoel personality before the trauma. The hospice team didn´t have at the time any information regardless his life story and his family support were precarious. As his OT, I kept trying to get in touch with him, in some kind of "trial and error" basis. The whole team began to identify different vocalizations in Manoel, based on the proposed sensory stimuli.

The family was called several times for a conference. After a few weeks, Manoel´s mother came to talk with the hospice team. She was a very religious woman, with no financial conditions to visit him often. She told us that Manoel was a cheerful young man, who lived together with his girlfriend, that worked as a transit operator and dreamed of being an airplane pilot. He liked music and party.

In our process, I had an insight: This man stayed for so many years in a bed, so I ask myself what was his contact with the world? He just stared at the ceiling at the time. So, I took him to visit the hospice garden! It was a difficult process. There wasn´t wheelchair that fits him, manly because of his physical deformities.

So he was taken to the garden on the patient transport stretcher. This event caused strangeness in all people at the hospice: the team, me and perhaps Manoel on his own. He stayed well, comfortable and seemed to like the ride, although there was a clearly lightness discomfort (he closed his eyes , but slowly opened as time passes by). After this Day, I´ve realized that we started to developed a patient-therapist relationship and I started to identify meanings in his reactions, especially things that bring pleasant or those which are unpleasant.

The work goes on.. My next step was to prescribe a wheelchair adapted for Manoel. After some negotiation with the hospital CEO, we could purchase it for him. Meanwhile, Manoel and I continued going to the garden, once per week. On his first day at the wheelchair, it was very exciting to see Manoel: he looked very comfortable and fell asleep. I waited next to him until he wakes up, so we could go back to his room.

In the hospital bed, I worked with other stimuli to Manoel: music, readings, massages, etc. I paid attention to what he seemed to like and dislike and, somehow, I founded some sense for that moment. I always named what I observe to Manoel. What amazed me the most was that we had developed some kind of therapeutical relationship together. He taught the whole team about how someone in such a limited situation can being in the world, with his own personality and also having pleasant situations in daily life.

We kept learning about his likes and dislikes, and about his life history. The sounds emitted by Manoel when he heard his favorite songs were completely different from when he hears other, for example. Manoel died in May 2013, when I was on leave from activities on the rehabilitation team. However, coincidentally, I was at the hospice in his death day for a business meeting. It was an opportunity to say goodbye, thank him for all learning that he brought me and somehow finish our process.

Manoel had Locked-in Syndrome (LIS), a neurological condition characterized by the presence of voluntary eye opening, quadriplegia or quadriparesis, aphasia, preserved cognitive functions, and communication through blinking or eye movement[6].This is a condition very hard to identify, being correctly identified just in 55% of cases, usually by members of the patient's family.[5]

People with LIS depend on alternative communication strategies to interact with other and the environment, using resources such as blinking the eyes or moving the fingertips. Caring for these patients is a challenge, due the fact that they are fully intellectually productive, but with significant functional loss, making them prisoners of themselves.[5,6]

It is necessary to think about the production of care for people with serious sequelae, since, even if their daily lives are very limited, without the possibility of choices and actions, life cannot lose its meaning.

The traditional care has its actions specifically aimed at the clinical, physical and neurological condition of the patient. However, Comprehensive Care as the theoretical framework allows the possibility of the therapist to work for the patient to be the protagonist of his life, regardless the functional condition, by allowing his life history validation. It is essential to emphasize the importance of starting the integrative rehabilitation program early, to achieve better results.

The reconstruction of a patient's biography will therefore take place based on the therapist-patient encounter and the enrichment of their daily life with meaningful activities. Creativity, inventiveness, movement, news, ambiguities, limitations and voids are inherent. In this perspective, there is a premise of the singularity of the subjects, always having the possibility of bonding with another. The person is composed of his history and his records, which can be lost in a very radical way in the face of serious neurological impairments. However, as Laurent[21] says: "A person never ceases to be a person, even if his body is 'deficient'.

Observation will be one of the main evaluation and intervention tools used by professionals. The role of observation in the continuity of care for this type of patient is fundamental, always constant, attentive, active, subtle and contextualized. From the patients' reactions, it is possible to perceive and name reactions of pleasure and displeasure, which will later be shared with the team for better care. It is also up to the professional to assign, a posteriori, hypotheses of meanings for that process experienced, especially in these cases in which the patient is unable to communicate.[1,22]

The careful look becomes central in the reconstruction of the therapeutic intervention. The therapist must be involved in this relationship, so that the patient can perceive his remaining potentialities, or even be in the relationship as a human subject that he is, and not simply as an inanimate body (something that is the reality in most health services).[1,22,23]

From this new perspective, the attentive and continuous presence of the professional should not be linked to the stimulation of functions, but rather with the reconstruction of the meaningful daily life of those who are so severely disabled, regardless of their lifetime. The way in which the therapist relates to the patient will leave memories, allowing or not the emergence of potentialities and aspects not related to the disease, also affecting the body.[22,23]

Therapists should also provide support and guidance to the family, which is in a vulnerable situation.

In Table 1, we summarize the new care strategies for people with LTNC mentioned, which were developed from the comprehensive care framework.

It should be noted, however, that there are no cause-effect relationships in the process, but rather a unique relationship that is built little by little, in a non-verbal way. The presence of organic affections does not devalue the being as a subject in the world, and Manoel's story exemplifies this. For the reconstruction of the care provided to someone severely disabled, it is essential to exercise observation, mediation, interpretation, translation, and inference. Subtle ways of evaluating and acting are central axes of work with people with LTNC.In this framework, health professionals get in touch with their own emotional anxieties and require intense reflection. To overcome a possible initial paralysis, you must daily reorganize your clinical reasoning and your care plan, not only considering motor or neurological functions. But allowing oneself to learn from the patient is also a unique and invaluable adventure.

Table 1 Comprehensive care and interventions for people with LTNC

Interventions for people with LTNC – The comprehensive care framework contribution
Continuous observation and presence
Propose of meaningful stimuli
Sensory stimulation based on people previous interests
Investigate signs/reactions and create hypothesis for them
Meaningful daily living activities
Family guidance / Family assistance

Conclusion

The beginning of the reconstruction of the patient´s biography occurs by several perspectives, especially through sensory stimuli related to prior patient´s occupational repertoire. Along with the detailed evaluation, the therapist does a careful and continuous monitoring, proposing activities, giving special attention to their reactions, being able to discriminate what pleases or not, and expanding the possibilities of relationship of people with LTNC and the environment which surround them.

In case of people with LTNC, the therapist intervention is to reassure and validate possible remaining capacities, resulting in the emergence of the subject, fragmented by disease processes. The therapist's role is related to the idea of motherhood and safety. The investment helps subject emergence, hidden behind its limitations. As mentioned, there is no cause-effect relationships in the process, but rather a unique relationship that is woven slowly. Memory, history, identity, dignity, and subjectivity qualify the practice of LTNC rehabilitation.

There are limitations in this study: it was an initial approximation and reflection, requiring further research to deepen it, either from the point of view of palliative care or comprehensive care. At the same time, new possibilities open for assistance to people with LTNC, for the reconstruction of health assistance, based on a qualified life and dignity.

Acknowledgments

This article is based on first author PhD thesis. The second author was the guidance. Both are responsible for written and revision of all this article. We´d like to thank Prof. Dr. Leny Magalhães Mrech for the contributions to the thesis.

Conflicts of interest

The authors declare that there are no conflicts of interest.

References

1. Othero MB. *Care for patients with very severe neurological conditions: interdisciplinary contributions to a theoretical framework.* Teses São Paulo, Brasil, Faculdade de Medicina, Universidade de São Paulo. 2016;1–127.

2. Royal College of Physicians. Long-term neurological conditions: management ate the interface between neurology, rehabilitation and Palliative care. Reviewed. Great Britain: The Lavenham Group. 2011.
3. Graham DI, Adams JH, Murray LS, et al. Neuropathology of the vegetative state after head injury. *Neuropsychol Rehabil.* 2005;15(3-4):198–213.
4. Laureys S. The neural correlate of (un)awareness: lessons from the vegetative state. *Trends Cogn Sci.* 2005;9(12):556–559.
5. Lule D, Zickler C, Häcker S, et al. Life can be worth living in locked-in syndrome. *Prog Brain Res*. 2009;177:339–351.
6. Laureys S, Pellas F, Eeckhout PV, et al. The locked-in syndrome: what is like to be conscious but paralyzed and voiceless? *Prog Brain Res.* 2005;150:495–511.
7. Turner-Stokes L, Sykes N, Silber E, et al. From diagnosis to death: exploring the interface between neurology, rehabilitation and palliative care in managing people with long-term neurological conditions. *Clin Med*. 2007;7(2):129–136.
8. Folley KM, Carver AC. Palliative care in neurology. an overview. *Neurol Clin*. 2001;19(4):789–799.
9. Borthwick C. Ethics and the vegetative state. *Neuropsychol Rehabil*. 2005;15(3-4):257–263.
10. Multisensorial stimulation in comatose patients: a literature survey estímulo multi-sensorial en pacientes comatosos: encuesta sobre la literatura. *O mundo da Saúde*. 2008;32(1):64–69.
11. Lombardi F, Taricco M, De Tanti A, et al. Sensory stimulation for brain injured individuals in coma or vegetative state. *Cochrane Database of Sys Rev*. 2002;2002(4):CD001427.
12. Dolce G, Riganello F, Quintieri M, et al. Personal interaction in the vegetative state: A data-mining study. *Journal of Psychophysiology*. 2008;22(3):150–156.
13. Gosseries O, Di H, Laureys S,et al. Measuring consciousness in severely damaged brain. *Annu Rev Neurosci.* 2014;37:457–478.
14. Bodart O, Laureys S, Gosseries O. Coma and disorders of consciousness: scientific advances and practical considerations for clinicians. *Semin Neurol*. 2013;33(2):83–90
15. Rousseau MC, Karine B, Marine A, et al. Quality of life in patients with locked in syndrome: evolution over a 6 year period. *Orphanet J Rare Dis*. 2015;10:88.
16. Rocha JA. Neuropata agudo de mau prognóstico. In: Carvalho RT et al (org). *Manual da Residência de Cuidados Paliativos: Abordagem multidisciplinar*. 2nd ed. São Paulo, Brazil: Editora Manole. 2022.
17. Deslandes S. O cuidado humanizado como valor e ethos da prática em saúde. In: Pinheiro R, Mattos RA. Razões públicas para integralidade em saúde: o cuidado como valor. 2^{a} ed. Rio de Janeiro: IMS/UERJ: CEPESC: ABRASCO, 2009;385–395.
18. Zoboli E. Cuidado: práxis responsável de uma cidadania moral. In: Pinheiro R, Mattos RA. Razões públicas para integralidade em saúde: o cuidado como valor. 2^{a} ed. Rio de Janeiro: IMS/UERJ: CEPESC: ABRASCO. 2009;63–78.
19. Ayres JRCM. O cuidado, os modos de ser (do) humano e as práticas de saúde. *Saúde e Sociedade.* 2004;13(3):16–29.
20. Ayres JRCM. Integralidade do cuidado, situações de aprendizagem e o desafio do reconhecimento mútuo. *Biblioteca virtual em saude*. 2010;1:123–153.
21. Laurant E. *A batalha do autismo. Da clínica à política*. Rio de Janeiro, BR: Zahar Editora, 2014;224.
22. Othero MB, Ayres JRCM. Resgate biográfico como estratégia de assistência a pacientes com condições neurológicas muito graves. *Rev Ter Ocup Univ São Paulo*. 2014;25(1):80–87.
23. Othero MB, Rocha JA. Clinical management and care planning of patients with locked-in syndrome in palliative care. In: Abstracts of the 14th World Congress of the European Association of Palliative Care. Copenhagen, Dennmark. European Journal of Palliative Care. 2015;8–10.

Citation: Othero MB, Ayres JRCM. Palliative care for people with long term neurological conditions: practices and reflections based on comprehensive care. *Hos Pal Med Int Jnl.* 2023;6(2):53–56. DOI: 10.15406/hpmij.2023.06.00218