

Exploring the knowledge and views of Greek Neurologists regarding Palliative Care Topics

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Abstract— Palliative care for Parkinson's disease is characterized by inconsistency and varies from country to country. Although some countries have taken significant steps to include palliative care in their health programs, others, such as Greece, are still at an early stage. One step towards the widespread adoption of palliative care is the education of all stakeholders, especially clinicians. This paper presents a preliminary version of a curriculum toolkit for Palliative Care education in Parkinson's disease. Also, we explore Greek neurologists' knowledge of Palliative care based on a questionnaire and present their feedback on the topics included in this toolkit.

Clinical Relevance—The toolkit aims to benefit patients in need of palliative care through promoting health literacy and further educating healthcare providers. The proposed toolkit provides all the necessary information to become sufficient knowledge and ultimately translate into clinical practice skills.

Keywords: Palliative care, Parkinson's Disease, Late Stage of Parkinson's Disease, curriculum toolkit for Palliative Care education in Parkinson's disease.

I. INTRODUCTION

Although there is a growing awareness of palliative care for neurological and other chronic disability-related disorders, there remains a substantial unmet need in most parts of the world. As the scale of life expectancy and the ageing population increases globally, so is the proportion of patients with neurological disorders associated with disability. Unfortunately, patients with chronic neurological diseases have no hope of a cure as the disease progresses. Thus, there is an impending need to apply palliative care and symptom management approaches from the disease's early stages. According to the Lancet's call for action (2019), "As the world population ages, comorbidity also increases. A shift from a health system centered in medical specialties to person-centered care is required" [1].

Parkinson's Disease (PD) is a complicated, unpredicted, and debilitating disease. Patients living with PD and their caregivers need guidance for decision-making and planning throughout the condition [2]. Patients need to be treated substantially, based on their profiles, and adapting the

information according to the disease's stage and the mentality of each patient. Thus, care must respect and meet the preferences and values of individual patients [3]. Healthcare services should improve patients' and caregivers' quality of life and provide emotional support and information as the disease progresses [4].

People who provide care to PD patients and support them for an extended period play a vital role in their lives. Carers have never received formal training, and inevitably they lack skills and knowledge. For this reason, they should have at their disposal all the means deemed necessary to handle the difficulties of the disease. Furthermore, they need to be regularly informed and have access to relevant information to learn to deal with stressful situations that are more common in the later stages of the disease [5].

On the other hand, the needs of healthcare providers require more specialization. Due to insufficient knowledge of palliative care, their training should include understanding the principles of palliative care and learning fundamental palliative care skills [6,7]. It is also crucial for health care professionals to develop their communication skills due to sensitive conversations with their patients concerning the diagnosis and issues such as discussing a patient's wishes or symptoms' management [8].

II. METHODS

A. Presentation of the toolkit that was evaluated

The toolkit was developed as part of the EU-funded project 'Palliative Care in Parkinson's Disease' – PD-PAL, based on an extensive literature review and adopting the European Association for Palliative Care Recommendations.

Initially, it covers three key topics/fields, starting with Introduction to Palliative Care, continuing with Parkinson's Disease and finally covering Late-Stage Parkinson's Disease & Palliative Care.

For Palliative Care, an effort was made to cover critical concepts like its' philosophy, policy, and definitions, and the ability to demonstrate the complex symptom assessment and management competencies. Continuing with designing care plans tailored to patients and families wishes seeking to

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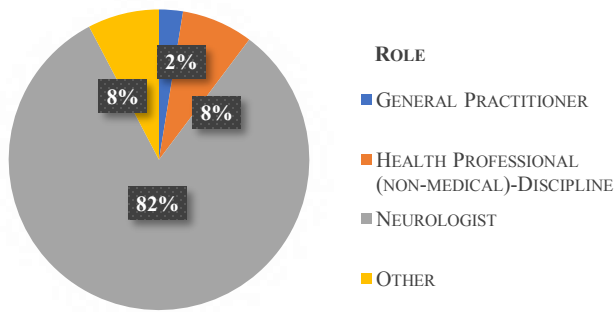


Figure 1. Participant's roles.

incorporate multi-professional and interdisciplinary approaches and ultimately the use of communication strategies.

About Parkinson's Disease, the toolkit addresses the issues of the disease and related disorders starting from some global facts about PD, its symptoms, its causes. Follows the diagnosis and timely integration of Palliative Care. Later the management of PD, meaning the drug treatment for the disease, pumps at an advanced phase and even in the last days. Also, it includes complementary therapies for PD, surgery and refers patients and carers to valuable information sources. Continuing with providing care for caregivers, referring to a care unit, caregivers rights, the importance of eliminating prophylaxes, and finally, the use of validated tools and scales, such as the Zarit scale. Eventually, it mentions the disease's confrontations, which deals with emotions, stress, depression, coping with problems with thinking, reasoning, and memory of patients with PD, besides handling anxiety or depression, sleeping disorders and social needs.

Regarding the Late-Stage Parkinson's Disease & Palliative Care topic deals with the advanced PD, death and dying, referring to some global facts relatively to Late PD Stage, falling out of care and gender gap. It then follows the importance of the advanced death directive in PD, decision making when the patient's ability reduces, the importance and accessibility of a valid advanced directive, power of attorney, will, brain bank and research. Next is the treatment, incorporating Palliative Care guidelines, stiffness, hypoactive delirium, breathing dysregulation, dopaminergic crisis, obstipation and severe vomiting, emergencies and Palliative sedation and closing with the nutrition in advanced Parkinson's Disease ethical social implication of feeding tubes. Ultimately, the loss, the management of grief and bereavement, is a process of each person concerned.

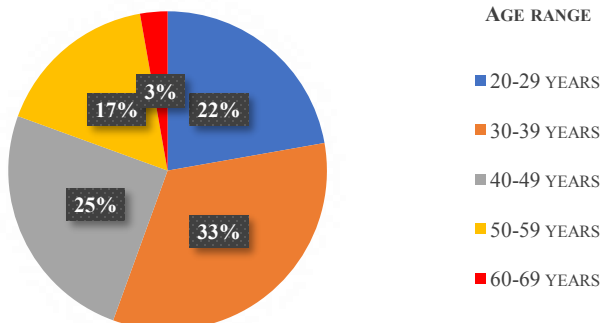


Figure 3. Participant's age ranges.

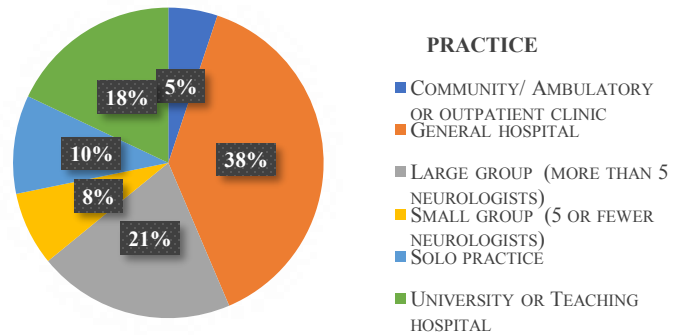


Figure 2. Participant's practice features.

B. Study Design

The proposed toolkit was presented to 40 neurologists who participated in the 9th Winter Clinical Training on movement disorders on November 15-17, 2019, in Volos, Greece. Participants were asked to answer two basic types of questions and choose between five different answers. The first question was "how much do you know about this topic", and the answers ranged from one to five as follows:

1. I have never heard of it
2. I know a few things
3. my knowledge is at a good level
4. my knowledge is advanced
5. I am a specialist

The second question was "How relevant is this topic for your current work", and again the answers ranged between one to five as follows:

1. Irrelevant
2. Slightly relevant
3. Moderately relevant
4. Relevant
5. Very relevant

C. Study population

Most of the participants are neurologists (Fig 1), working in General Hospitals (Fig 2), aged between 30 and 39 years old (Fig 3).

Another interesting statistic is that most of our sample does not have sufficient experience, especially in a ratio of 2/3 with less than ten years of practising Neurology (Fig 4).

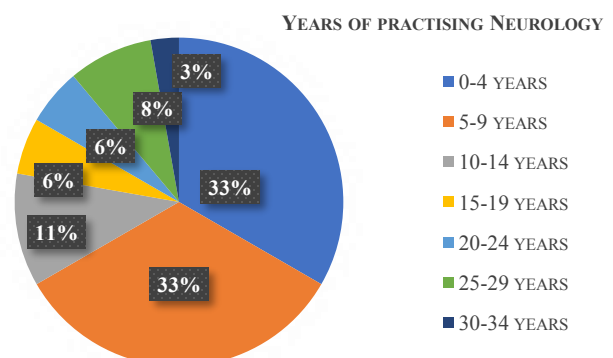


Figure 2. Participant's years' of practising Neurology.

TABLE I. PEARSON CORRELATION OF AVERAGE KNOWLEDGE AND RELEVANCE SCORES

		<i>Average relevance</i>
<i>Average knowledge</i>	<i>Pearson Correlation</i>	.419**
	<i>Sig. (2-tailed)</i>	.007
	<i>N</i>	40

III. RESULTS

Remarkably, each participant's means of knowledge and relevance were moderately correlated (Pearson), as shown in table 1.

According to the results (Fig 5), participants have limited knowledge of Palliative Care (it is worth noting that although they have insufficient knowledge of the subject, they believe that related topics with the Palliative Care concept are very relevant to their work).

Unlike Palliative Care, Parkinson's disease knowledge ranged from very good to an advanced level, and, according to the participants' comments, they claimed the relevance of the topics (Fig 6). Another interesting point is the low relevance score indicated for the issues "providing care for caregivers" and "getting on with life" even if they have a high relevance score to their practice.

Regarding the 'Late-Stage Parkinson's Disease & Palliative Care', the results were like palliative care as participants were unaware of the topics (Fig 7).

It is worth noting that Advance Care Planning scored one of the lower average scores, which can be explained or even justified by the early stage of Palliative Care in Greece.

IV. DISCUSSION

Despite the long history of Palliative Care in Greece, it has not evolved as much as other economically robust European Union countries. The ability to provide Palliative Care today is insufficient compared to the needs. Several initiatives are needed to bridge the gap regarding access to Palliative Care in Greece. Quite a significant step among others is training young health professionals and training many health professionals already employed whose knowledge is insufficient according to the research findings. [9] At the same time, it is immensely encouraging their interest in Palliative Care.

According to the research findings and continuous guidance, the toolkit's final configuration will be made through consensus meetings with experts. Furthermore, we intend to deploy the toolkit in Open edX, a Massive Open Online Course (MOOC) platform. After a trial period, it will be reformed into an even more improved version based on the learners' comments. Undoubtedly the MOOC phenomenon has revolutionized the world of higher education through technological progress. As a result, educational opportunities have expanded dramatically, mainly overcoming geographical and demographical challenges.

INTRODUCTION TO PALLIATIVE CARE

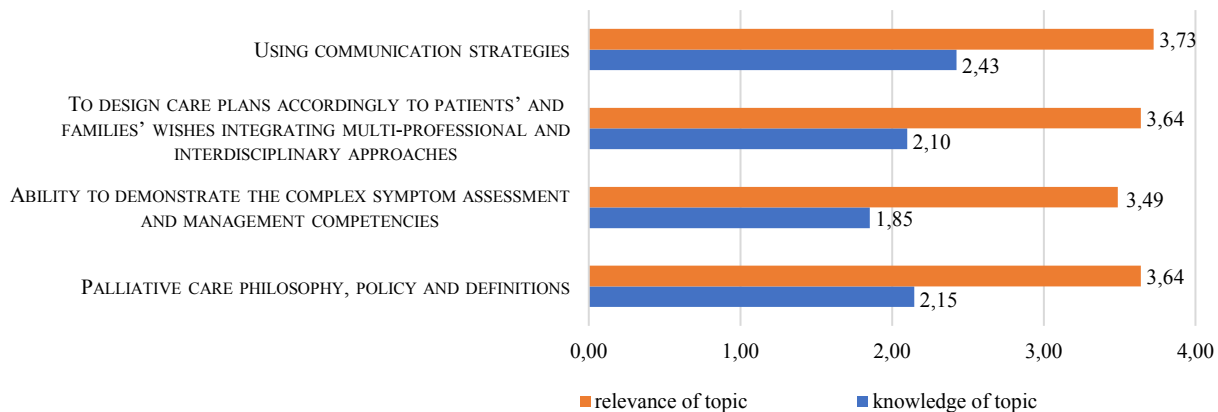


Figure 5. Feedback for the palliative care topics.

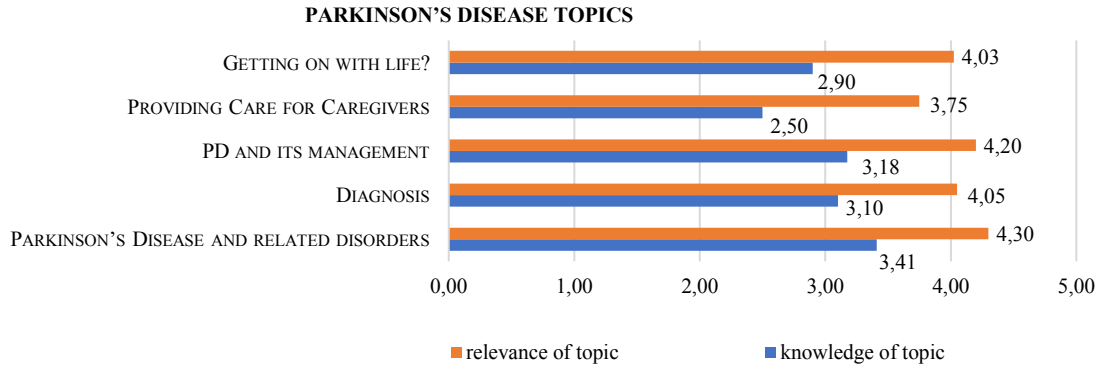


Figure 6. Feedback for the PD topics.

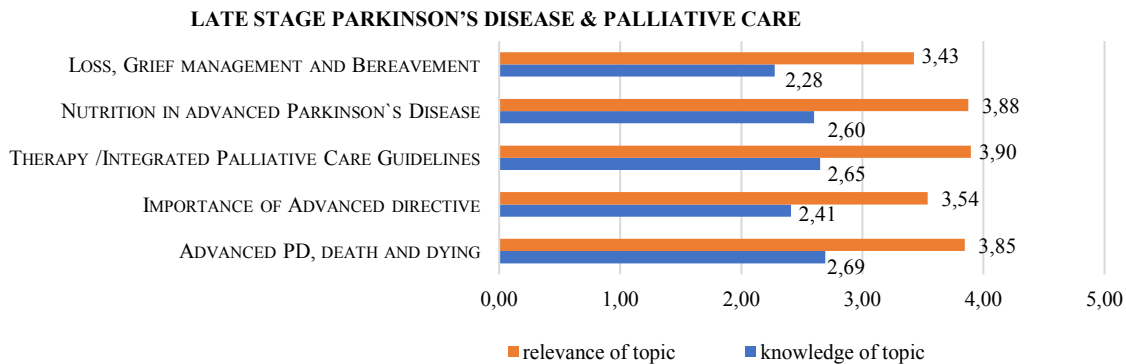


Figure 7. Feedback for the late-stage PD and palliative care topics.

MOOCs are higher education courses that are, in most cases, free or meagre cost open for any Internet user. It is not only the advanced development of e-learning that imposes the need for this type of learning but also, due to the pandemic, the new conditions created reinforcing our proposal even more. Therefore, it is a very promising proposal, especially for those countries where the concept of Palliative Care is still at an early stage. Besides, it is a comprehensive proposal and, most importantly, led by a team of experts in the field and the collaboration of various institutions and universities gives greater value and weight.

V. CONCLUSION

This paper aims to explore the knowledge and views of Greek neurologists on aspects of Palliative care. It also includes a qualitative assessment of a proposed curriculum toolkit for Palliative care education in Parkinson's. Moreover, it highlights the unmet needs for training in Palliative Care for Parkinson's disease globally.

The proposed toolkit itself, which is currently being completed, aims to provide useful, adequate, and sufficient information for those wishing to increase their knowledge of this field. Our proposal is not another common suggestion, but on the contrary, we believe that it can become a complete helping effort on Palliative Care for patients suffering from Parkinson's disease and why not guidance on Palliative Care for other disorders.

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