Framework for Training Parkinson Nurses

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Delivering healthcare to people living with Parkinson's disease (PD) may be challenging in face of changing care needs during a PD journey and a growing complexity. In this regard, integrative and personalized care models may foster flexible solutions to patients' care needs whereas Parkinson Nurses (PN) may be pivotal facilitators. However, existing training frameworks do not include aspects of personalized care for PD although there is a great deal of literature on patient needs and the resulting care requirements. The conceptualization of a need-based training framework may thus be achieved by synthesizing theoretical concepts on care priorities from existing literature. Following, a novel framework for training PN is presented, which is based on a line of reasoning. In this approach, different hypotheses are formulated which then are integrated into a proposed model.

1. The importance of training Parkinson Nurses for personalized care

Parkinson's disease is the most common movement disorder and affects more than half a million Americans with a national annual cost of more than almost six billion dollars annually.[1] The complexity of PD implies specific requirements for the design and delivery of care. Nevertheless, to date, personalized care delivery models are rare [2]. While it has been shown that integrated and multidisciplinary care delivery models following a personalized care approach have positive implications for persons living with PD (PwPs), care partners and care providers, their implementation is difficult due to several reasons [2][3][4]. When it comes to delivering personalized care approaches, Parkinson Nurses (PN) may be pivotal facilitators. There is a scientific consensus that PNs will take a significant and prominent role in integrated, patient-centered home-/and community-based care in the future [5]. The PN is widely considered to be an important primary point of contact for PwPs and care partner alike. PNs are also recognized to be very helpful in the role of a multidisciplinary care team coordinator [6]. When PNs are available to provide home-based care, it has been shown that patients' quality of life improves [7][8]. Also, the importance of professional education can be identified in both theoretical and intervention-based models [9]. Globally, there are various definitions and descriptions not only of the PNs role in the care team but there are also multiple approaches on the training of PNs. Even though specialized training for PN on the delivery of personalized care services has been recommended [10], no framework has been proposed yet and existing curricular do not explicitly incorporate it. The proposed training framework for PN was derived from reviewing the specific requirements for the design and delivery of personalized care in PD.

2. Presenting a novel Framework for training Parkinson Nurses for personalized care

A detailed description of the reviewed literature and the line of argument can be found in the publication itself [11]. Based on the review of conceptual models, the following requirements to a training framework for PNs were identified:

1. PN ought to be competent to identify needs and preferences. Additionally, they must be able to decide their implications for the care plan.
2. PN require training in communicating with patients and care partners
3. PNs, as part of the professional care team, should be able to design and implement a flexible routine network of service providers to support patients and their care partner in inpatient and outpatient settings.
4. The quality of care provided by PN may be influenced by specific training in the coordination of different stakeholders in the health care system and knowledge about local healthcare resources. Thus, PN should be trained to map available community resources and navigate PwPs towards them.
5. In order to advise and assist patients properly, an understanding of the disease and its complexity is indispensable, making it an essential part of a PN training. Considering the Knowledge Translation Framework, we propose that a PN

training should include aspects of motivational interviewing[12] in order to facilitate knowledge use .

6. Education on telemedicine should be incorporated whenever possible and applicable.

In summary, PNs should be trained in three central aspects in order to deliver a personalized care approach: i. understanding PD, ii. health coaching and iii. delivering comprehensive care. These aspects form the framework of the PN training displayed in **Table 1**.

Module	Topic	Components	Goals
1	Understanding Parkinson's disease	• **Understanding Parkinson's disease symptoms and care requirements** • **Parkinson's disease stages and care needs** • **Aspects of Parkinson's disease management**	Acquire fundamental knowledge about PD and management principles of motor and non-motor symptoms
2	Being a health coach	• **Clinical assessments for people living with Parkinson's disease and care partners and their implications for care requirements** • **Acquire understanding of what's important when managing Parkinson's disease in a day-to-day practice and at home** • **Aspects of clinical conversations (identifying care priorities etc.)**	Acquire skills and knowledge to assess patient-outcomes and identify personal care requirements
3	Aspects of care delivery for people living with Parkinson's disease and care partner	• **Acquiring an overview of local care resources and important contact points for people living with Parkinson's disease and care partner** • **Building a local care network** • **Conversation training to motivate patients and care partners** • **Delivering self-management support based on the 5-As** • **Learning about the role of care partners as support person**	Acquire knowledge about available local care resources and methods to motivate patients and care partners to use them
4	Telemedicine	• **Adapted to the specific technology** • **Identify role of technology in care model: online monitoring, self-management support, enhance communication**	Acquire knowledge about the technology

Note: the modules and their components are elaborated in detail can be found in the publication itself [11].

3. Aspects to consider when implementing the framework

When it comes to educating PN, a variety of training pathways exist in various countries. Also, the recognition of nurses as important care coordinators differs. As it has been stated elsewhere, funding mechanisms and the structure of healthcare systems play an important task for defining a nurse's role [13]. This is also reflected in different education programs. Therefore, it is necessary to address country-specific requirements when implementing the framework. Also, the structure of healthcare systems affects the availability of resources, which is why a sound understanding of the overall context is essential for implementing the framework presented here. We emphasize that module 3 of the framework should be adjusted to the country-specific context. Future research may aim to further define this module and adapting it to a country-specific context. For countries with extensive training opportunities and high resources, such as the United States [13], we suggest, that single modules of the proposed training framework could be implemented in the basic training of nurses as a prerequisite for later specialization in the field. This would enable nurse students to better understand PD

and prepare them to be empowered nursing advocates for PwPs in inpatient and outpatient settings. For countries, where the profession of PN is less well developed, such as Germany [14][13] the framework may be fully implemented and also be utilized to build an agenda for future research on how the role of PN can be strengthened.

When implementing the framework into pratice, one might face challenges and barriers. In some countries, the PN has been an integral part of the multidisciplinary care team for a long time [15], while in others PN are not present in every care team [10][14]. Also, it is necessary to clarify funding issues for implementing the framework and hire staff, such as experienced PN, to deliver the framework. Additionally, the lack of certification of such training could be another barrier [14]. However, the framework introduced here may represent a crucial step towards a universal consensus on certification.

Concerning the fourth module, the framework is deliberately kept open. Telemedicine represents an increasingly studied and apparently beneficial instrument for the provision of medical care to the chronically ill. [16][17][18]. However, telemedicine must always be evaluated in the context of its application, i.e., the technical prerequisites for widespread use must also be accessible to individual patients [19]. Therefore, telemedicine is not yet part of this framework, but we strongly encourage its future integration. Due to the emerging possibility of remote patient monitoring (i.e., smart glasses, smart beds or wearables [20][21]), we emphasize future research on up-to-date tech-based home-based care solutions and the future role a PN may hold in this scenario of increasingly tech-based medical and social care delivery. This demand would also meet the need of care approaches to not only being responsive to specific care situations but to incorporate proactive elements, such as the utilization of telemedicine [5][6].

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