

SUPPLEMENTARY MATERIAL

Moving towards integrated and personalized care in Parkinson's disease: proposing a framework for training Parkinson Nurses

Table S1. Search Strategy and In- and Exclusion Criteria

Question	What are the care priorities for PD?
Inclusion	<ul style="list-style-type: none"> Study Type: <ul style="list-style-type: none"> Clinical Study Quantitative or Qualitative Study Literature Review Conceptual or theoretical paper Clinical Guidelines Study Population: <ul style="list-style-type: none"> Patients with Parkinson's Disease diagnosed as per United Kingdom Parkinson's Disease Society Brain Bank criteria and of either sex Setting: any setting Thematically: <ul style="list-style-type: none"> Describing an existing care model for Parkinson's Disease Scientific guidelines regarding Parkinson's Disease care Interventions implementing a care model for Parkinson's Disease Theorizing care concepts or aspects of care Publication Date: no restriction Geographical location: no restriction Language: English or German
Exclusion	<ul style="list-style-type: none"> Study type: <ul style="list-style-type: none"> Study Protocol Perspective/ Editorial Thematically: <ul style="list-style-type: none"> Models focusing on palliative care Systematic Literature Review not describing or theorizing a care model
Database:	MedLine; Web of Science
Search terms:	parkinson's disease; concept; theory; model; care
Search Strategy (MedLine)	("parkinson disease"[MeSH Terms] OR ("parkinson"[All Fields] AND "disease"[All Fields]) OR "parkinson disease"[All Fields] OR ("parkinsons"[All Fields] AND "disease"[All Fields]) OR "parkinsons disease"[All Fields]) AND (("concept"[All Fields] OR "concept s"[All Fields] OR "concepts"[All Fields] OR ("theorie"[All Fields] OR "theories"[All Fields] OR "theory"[All Fields] OR "theory s"[All Fields]) OR ("model"[All Fields] OR "model s"[All Fields] OR "modeled"[All Fields] OR "modeler"[All Fields] OR "modeler s"[All Fields] OR "modelers"[All Fields] OR "modeling"[All Fields] OR "modelings"[All Fields] OR "modelization"[All Fields] OR "modelizations"[All Fields] OR "modelize"[All Fields] OR "modeled"[All Fields] OR "modelled"[All Fields] OR "modeller"[All Fields] OR "modellers"[All Fields] OR "modelling"[All Fields] OR "modellings"[All Fields] OR "models"[All Fields])) AND "care"[All Fields])
Search Strategy (Web of Science)	ALL=(parkinson disease OR (parkinson* AND disease) OR parkinson*) AND ALL=(concept* OR theorie* OR theory OR model*) AND ALL=(care*)

Table S2. Overview of Theoretical Concepts

Concept	Content
The Picker Institute Concept [64]	<p>Patient-centeredness consists of:¹</p> <ul style="list-style-type: none"> • Accessibility • Information & communication • Partner & family involvement • Respect & autonomy • Organization of healthcare • Continuity of care • Physical comfort • Emotional support
A novel paradigm of continuous care in Parkinson's Disease [73]	<p>Care for PD should be enabled by three foundation pillars:</p> <ul style="list-style-type: none"> (i) Integrated care (ii) Self-management support (iii) Technology-enabled care
Active Aging Model for Parkinson's Disease [70]	<p>Components of active aging, that are influenced by Parkinson's Disease:</p> <ol style="list-style-type: none"> 1. Physical activity 2. Mental well-being 3. Social communication <p>Potential consequences for:</p> <ul style="list-style-type: none"> -> Ability to learn over a lifetime -> Employment status -> Quality of life security <p>Modifying caring approaches: palliative care; self-care; patient-centered care & personalized care</p>
A multi-element definition of continuity of care [72]	<p>To experience continuity, care delivery services need:</p> <ul style="list-style-type: none"> • Continuity of information; continuity & coherence of medical record • Cross-boundary and team continuity • Flexible continuity • Longitudinal continuity • Relational or interpersonal continuity
Five A's of self-management support [71]	<p>Five A's describe how the health-care professional can deliver SMS to the patient:</p> <ul style="list-style-type: none"> • Assessing beliefs, behaviors and knowledge • Agreeing collaboratively on goals based on the patient's interest and confidence • Advising the patient on health risks and benefits of change • Arranging follow-ups • Assisting the patient to identify personal barriers and develop problem-solving techniques
An Implementation Model for Integrated Care [74]	<p>Variables for care integration:</p> <ul style="list-style-type: none"> • Type (i.e., organizational, professional, cultural, technological) • Level (i.e., micro-, meso- and macro-) • Process (management and organization of integrated care) • Breadth (whole population vs. specific client group) degree/ intensity (informal linkages vs. fully integrated teams) <p>Key forms of integration: Horizontal, vertical, sectoral, people-centered, whole-system</p>
The Knowledge-Translation Framework [80]	<p>Eight steps for translating knowledge:</p> <ol style="list-style-type: none"> 1. Identify a problem that needs addressing

	<ol style="list-style-type: none"> 2. Identify, review, and select the knowledge or research relevant to the problem 3. Adapt the identified knowledge or research to the local context 4. Assess barriers to using the knowledge 5. Select, tailor, and implement interventions to promote the use of knowledge 6. Monitor knowledge use 7. Evaluate the outcomes of using the knowledge 8. Sustain ongoing knowledge use
The Web of Needs and Demands Model [65]	<p>Living with PD means balancing within a web of needs and demands regarding:</p> <ol style="list-style-type: none"> 1. Competence 2. Relatedness 3. Autonomy <p>-> A needs-based approach represents an important starting point to better understanding the consequences of living with PD</p>
Five C's for video-based therapy [28, 98]	Care; convenience; comfort; confidentiality & contagion
The Development Model of Integrated Care [66]	<p>Nine-cluster model for quality management in integrated care:</p> <ul style="list-style-type: none"> • Patient-centeredness • Delivery system • Performance management • Quality of care • Result-focused learning • Interprofessional teamwork • Roles and tasks • Commitment • Transparent entrepreneurship <p>Organizational development happens across 4 phases where different priorities need to be addressed</p>
World Health Organization responsiveness model [67]	<p>Patient-centeredness consists of:¹</p> <ul style="list-style-type: none"> • Confidentiality of information • Communication • Access to family and community support • Autonomy • Freedom to choose your own healthcare provider • Dignity • Prompt attention • Quality of basic amenities
Orem's Self-Deficit Theory and the Nursing Process [68]	<p>Nursing is needed when the client's therapeutic self-care demand exceeds the available self-care agency</p> <p>The Nursing Process presents involves a method to determine self-care deficits and defining the roles of persons or nurses to meet the self-care demands:</p> <ol style="list-style-type: none"> 1. Assessing (patients' health status; physicians and patients' perspective on the health status; goals within the context of life history, lifestyle, and health status; the person's requirements for self-care; the person's capacity to perform self-care) 2. Designing a care plan by organizing the patient's self-care demands and selecting a combination of helping methods 3. Implementation and evaluation

The Quality of Care Framework for Home-Based Medical Care [79]	<p>Home-based care comprises categories of quality:</p> <ul style="list-style-type: none"> • Provider and practice activities • Provider characteristics • Outcomes for patients, caregiver and provider <p>➔ Can be assessed in 10 domains and 49 standards</p>
Proactive and Integrated Management and Empowerment in Parkinson's Disease (PRIME) [75]	<p>Proactive and Integrated Management and Empowerment in Parkinson's Disease has five main components:</p> <ol style="list-style-type: none"> 1. Personalized care management 2. Education and empowerment of patients and carers 3. Empowerment of healthcare professionals 4. A population health approach 5. Support of the previous four components by patient- and professional-friendly technology
The Rainbow Model [76]	<p>Care Services can be integrated across four domains:</p> <ol style="list-style-type: none"> 1. Clinical 2. Professional 3. Organizational 4. Systems <p>And on different scales (individual <-> population) whereby functional and normative enablers play a role.</p> <p>Ultimately, integration follows three aims: improving population health and experience of care while optimizing cost and utilization.</p>
Six core elements of patient-centered care [27]	<ol style="list-style-type: none"> 1. Emotional support, empathy and respect 2. Knowledge of PD treatment among caregivers 3. Provision of tailored information 4. Involvement in decisions and respect for patient preferences 5. Continuity and collaboration of caregivers 6. Accessibility of healthcare
Five Core Elements of Personalized Care Management for Parkinson's Disease [78]	<ol style="list-style-type: none"> 1. Information provision 2. Proactive monitoring of early detection signs and symptoms 3. Process monitoring 4. Care coordination 5. Patient navigation
The Chronic Care Model [77]	<p>There are six elements, which can be addressed to improve chronic care:</p> <ul style="list-style-type: none"> • Organization of health care • Design of the delivery system • Decision support • Clinical information system • Self-management support • Community resources <p>In order to deliver good self-management support, healthcare professionals should have knowledge about structures and available resources.</p>

¹ adapted from [27]