The Role of the Parkinson Nurse in health care an international perspective

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Parkinson’s Nurse

Inter-professional Team

Patient & Family

Neurologists

Care Setting / Community

Nurse
The role of Parkinson’s nurses

- Great Britain – UK
- Israel
- Canada
- Australia
- Japan
- United States
- The Netherlands
Building A Care Team - Struthers

- Nurse
- Neurologist
- Social Worker
- Physical Therapist
- Speech/Language Pathologist
- Occupational Therapist
The Right Care – Throughout the Continuum

Diagnosis

Management

Disease Progression

Wellness

Communication
Building the continuum

- Acute Care
- Long term care
- Assisted Living Facility
- Rehab Team
- Adult Day Care
- Home Care
- Rehab Team
- Wellness Center
Crossing the Quality Chasm

IOM highlighted the need to redesign healthcare to better serve the needs of the chronically ill for coordinated, seamless care across setting and clinicians over time.

Institute of Medicine 2001
The Case for
A Parkinson’s Care Model

- Complex chronic illness
- HealthCare Delivery System (in US)
  - Fragmented
  - Not designed for chronic care
- Inadequate professional education
  - Individual disciplines
  - Interdisciplinary / interprofessional care

IOM 2001
The healthcare workforce is unprepared to meet the needs of older adults with complex chronic illness.

IOM brief report 2008
National Parkinson Foundation
2000
Allied Team Training for Parkinson

An integrated multi-day training program for professionals including MD, nursing, physical therapy, occupational therapy, speech-language pathology, social work and music therapy through an initial federal grant from HRSA.

Parkinson’s disease
Discipline specific
Integrated interdisciplinary training
• Many never learn about the role of other disciplines or how to work in interdisciplinary teams, a core competency for the 21st century. Institute of Medicine (IOM) 2003

• Many nurses and other healthcare professionals lack understanding of the symptoms and complexities of Parkinson’s disease or the latest assessment and treatment techniques in their own discipline.
# Shifting Paradigm of Competence

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Association of American Medical Colleges (AAMC)
Healthcare organizations must

- Manage the growing knowledge base and ensure that all those in the healthcare workforce have the skills they need
- Design care processes to more effectively serve the needs of chronically ill for coordinated, seamless care across settings and clinicians over time
- Continually advance the effectiveness of teams.

IOM 2001
It is no longer enough for health workers to be professional. In the current global climate, health workers also need to be interprofessional.

WHO 2010
“Interprofessional education occurs when students from two or more professions learn about, from and with each other to enable effective collaboration and improve health outcomes.

Once students understand how to work interprofessionally, they are ready to enter the workplace as a member of the collaborative practice team.

This is a key step in moving health systems from fragmentation to a position of strength.

WHO 2010
Care delivered by intentionally created, usually relatively small work groups... having a collective identity and shared responsibility for a patient or group of patients.

When multiple health workers from different professional backgrounds work together with patients, families, carers and communities to deliver the highest quality of care.

→→WHO
Chronic Care Model

Informed Activated Patients and Families

Productions

Best Care Management Over Time For A Complex Chronic Illness

Prepared Proactive Practice Teams

Adapted from Ed Wagner's Chronic Care Model
A Framework for Action

Collaborative practice ready

Healthcare workforce

Interprofessional education

Collaborative practice

Improved Health Outcomes

Optimal health service

WHO 2010

Fragmented health system
Specialty Nursing
Roles in Parkinson’s Care

- Direct clinical care – clinical expert
- Translator
- Research
- Coach – Educator
- Consultant
- Coordinator

(Skalla, K., Hamric, A., & Caron P. 2005)
Direct Clinical Practice

- The patient-nurse relationship is established
- Health problems are identified
- Advanced assessment
- Goals identified
- Management and Treatment Options explored, discussed, and decisions jointly considered
- Education, support, counseling provided

Brown, S. Direct Clinical Practice, 2005, APN
Translator

- Interpreter of symptoms @ time of diagnosis
- Assessing and interpreting symptoms or changes as the disease progresses
- Often first contact to discern next steps with patient and family and to advocate for appointments or appropriate referrals
- In a unique role to help people through the process
Research Nursing

- Coordinate clinical research trials
- Conducted according to Federal Regulations and Clinical Practice Guidelines
- Clinical drug trials
  Institutional certification required
- Outcome studies
- Nurses may conduct their own nursing research and serve as the study Principal Investigator

Need evidence based guidelines in PD care!
Coach / Educator

- Modeling clinical expertise while helping nurses integrate new evidence into practice.
- Providing education or teaching skills to patients and families
- Formal education such as classes, presentations at workshops, in-services, conferences or community education programs.
Consultant

- Within the context of the practice setting nurses are consulted about a variety of patient and family issues.
- Involves reviewing alternative approaches and implementing planned change.
- In a broader context, nurses have opportunity and insight for innovation and change in the patient care system.
Collaborator

- Nurse plays a key role as facilitator or coordinator of the interdisciplinary or inter professional team.
- Communicates on behalf of patients/caregivers to other providers.
- Facilitates patient care across settings, aids in problem solving, and provides professional opportunities.
Leader

- Coach and mentor to staff in acute, residential, home care, hospice and community wellness programs
- Develops care plans which are patient and family centered – the leader sets the tone for staff
- Integrates knowledge of PD into the process
- Demonstrates critical thinking and sensitivity to individual patient and family as appropriate
- Models an attitude of respect and care in relationship with patients and families
Statistics of American Association of Neuroscience Nurses (AANN)

2007 Practice Setting

- University/Teaching: 44%
- Community Hospital: 31%
- Ambulatory: 8%
- Private Practice: 6%
- Academic: 6%
- Other: 1%
- Rehab: 1%

2007 Years of Experience

- 15+ Years: 42%
- 0-5 Years: 23%
- 6-10 Years: 19%
- 11-15 Years: 16%

2007 Area of Specialization

- Neurotrauma: 28%
- Stroke: 29%
- Spine: 11%
- Pediatrics: 4%
- Neuro-oncology: 9%
- Neuromuscular: 5%
- Movement Disorders: 6%
- Epilepsy: 8%
- Other: 4%

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Parkinson’s Nurse Specialist

1. Direct clinical practice
2. Expert coaching
3. Collaboration
4. Consultation
5. Research
6. Clinical and Professional Leadership
7. Ethical decision-making

Adapted from Sparacino (2005)
Movement Disorders Society (MDS)
Health Professionals
Special Interest Group (SIG)

The mission is to establish within The Movement Disorders Society an international interdisciplinary focus group of professionals in counseling, nursing, rehabilitation and genetics, who enrich and broaden the scope of care, management and research initiatives in Movement Disorders.
“The meeting of two personalities is like the contact of two chemical substances: If there is any reaction, both will be transformed.”

Carl Jung