The clinical and ethical aspects of mobile health and AI in Parkinson’s care

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Parkinson disease (PD) and care

• PD is a chronic condition with complex care needs

• Standard of care:
  ✓ Outpatient clinic
  ✓ General neurologist/movement disorder specialist
  ✓ Once every 6 -12 months

• Multispecialty care is intuitively attractive

• Access to community resources is ill-organized
Burden of care in PD

• In Canada:
  • estimated direct total costs of PD - $600 million in 2011
  • out of pocket for care partners - $214.8 million
  • *per capita* cost - $25K annually

• PD is one of the top ten most costly brain disorders in Europe
• The incidence of PD is expected to double by 2030 worldwide

• Due to an ageing population, the need for PD services will increase and consequently the burden on healthcare systems
Integrated Parkinson’s Care Network (Ottawa)

Shifting PD care from an in-outpatient model to home-based and community-centred care
Integrated Parkinson’s Care Network

CORE VALUES

- Care integration
- Personalized care
- Self-management support
- Technology-Enabled Care

CO-DESIGN
An example of co-design

Propensity for self-management in people with Parkinson’s
What is the role of technology in PD care?

NOT IF, BUT HOW!
### TABLE 1. Examples of available and needed technologies relevant to the diagnosis and clinical management of patients with Parkinson’s disease

<table>
<thead>
<tr>
<th>Clinical problem</th>
<th>Available/needed technologies</th>
<th>Clinical objective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improving diagnosis</td>
<td>Needed: sensors for prodromal features (e.g., constipation, REM sleep behavior, anosmia); blood sensors for biomarkers (β-synuclein, proteinomics, etc.)</td>
<td>Enable population screening for PD, including the earliest possible (prodromal) stages</td>
</tr>
<tr>
<td>Monitoring response to therapy and motor complications</td>
<td>Available: accelerometers, gyroscopes, magnetometers, electrogoniometers, surface EMG sensors; Needed: small patches onto the skin or other sensors that improve patient adherence</td>
<td>Collect ecologically valid data of motor fluctuations, falls, freezing of gait episodes; Implement sensor-based closed-loop technologies capable of delivering treatments (eg, infusion pump)</td>
</tr>
<tr>
<td>Monitoring nonmotor symptoms and progression</td>
<td>Available (but requiring improvements): sweat sensors, skin conductance sensors, heart rate sensors, blood pressure sensors</td>
<td>Collect ecologically valid data of nonmotor symptoms and progression</td>
</tr>
<tr>
<td>Improving medical treatment</td>
<td>Available (but requiring improvements): oral capsules, subcutaneous and gastrointestinal infusion pumps</td>
<td>Implement adjustable extended-release drug formulations, smart (self-adjusting) levodopa delivery infusion systems</td>
</tr>
<tr>
<td>Enhancing surgical treatment</td>
<td>Available (but requiring improvements): STN DBS, GPi DBS, Vim thalamus DBS</td>
<td>Implement closed-loop STN and GPi DBS (variable stimulation based on local field potentials)</td>
</tr>
<tr>
<td>Improving rehabilitation interventions</td>
<td>Available: accelerometers, gyroscopes, magnetometers, electrogoniometers, surface EMG sensors, pulse oximetry sensors, respiratory rate sensors, blood pressure sensors</td>
<td>Implement closed-loop cueing and feedback systems validated for home use</td>
</tr>
</tbody>
</table>

**Abbreviations:** DBS, deep brain stimulation; EMG, electromyography; GPi, globus pallidus pars interna; PD, Parkinson’s disease; REM, rapid eye movement; STN, subthalamic nucleus; Vim, ventrointermedial nucleus.

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**FIG. 1.** Schematic representation of a subject undergoing monitoring in the home setting using wearable and ambient sensors. The technology shown includes a wireless unit strapped around the wrist, Band-Aid-like sensors attached to the lower limbs, a wearable camera worn as a pendant, a smart watch, and a mobile phone clipped on the belt used as gateway to relay the data to the cloud to assess specific functions (using its embedded sensors) as well as to communicate with the patient (using customized apps). Ambient sensors and computer technologies are used in the home settings to gather additional information or replace wearable sensors when wearable sensors cannot be used. The integration of wearable technology with smart devices enables the remote monitoring of patients with PD and real-time feedback to clinicians, family/caregivers, and the patients themselves. [Color figure can be viewed in the online issue, which is available at wileyonlinelibrary.com.]

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**Online Health tracking**

- Continuous monitoring
- Validation of data
- Value for clinical practice
- Ownership and sharing of data

**not if, but how!**
What is the role of technology in PD care?

Main barriers to using TEC:

- Social acceptability
- Ease of use
- Disease progression
- Socioeconomic status

Grosjean et al.
eCARE PD (IPCN patient portal)

DIGITAL HEALTH PLATFORM

MODULE  MODULE  MODULE  MODULE

Funding source:

Parkinson Research Consortium

Speech therapy

Gait/Falls

Exercise monitoring
Developing the eCARE PD with PD community

**Process**

**Participatory Design Workshops**
- **Workshop 1** – December 2018
  - Participants: N = 9
- **Workshop 2** – January 2019
  - Participants: N = 7

**Data Collected**
1. Audio recordings
2. Trajectory maps
3. Feedback sheets
4. Observations (notes)

**Data Analysis**
1. Qualitative content analysis (focus on themes)
2. Interactive analysis (focus on knowledge produced collectively)

**Main Findings**

**Care Plan**
- Reorganize information more clearly (e.g., Tree structure)
- Improve instructions on interface navigation
- Connect Care Plan to Care Priorities page

**Priority Tracker**
- Make tracking adaptable to disease fluctuations
- Keep happy/sad faces
- Provide active feedback (personalized tips/advice)

**Care Priorities**
- Information overload
- Offer option to add personal Care Priorities
- Provide clearer instructions about Care Priorities selection

**Resources**
- Simplify interface by creating 3 resource categories:
  1. Educational
  2. Community (geo-located)
  3. Medical (care teams)
- Add communication tool to answer questions (e.g., Virtual agent)
- Make resources customizable to individual interests

**Collaboration with:**

- uOttawa researchers
- Macadamian software consultancy.

**Participants:**
- **Workshop 1**
  - N = 9
- **Workshop 2**
  - N = 7

**TAWA (Personalized, Straightforward, Responsive)**

**Observations**
- Feedback sheets
- Trajectory maps
- Audio recordings

**Data Collected**
- 3 resource categories:
  1. Educational
  2. Community (geo-located)
  3. Medical (care teams)
The IPCN beyond Canada

Integrated Parkinson Care Networks: addressing complex care in Parkinson disease in contemporary society

Lead partner

HESOCARE-329-073

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A) **ASSESSING** NEEDS AND BARRIERS for CARE in PD:

- **HEALTH ECONOMY**
  - Nadége Costa
- **HEALTH GEOGRAPHY**
  - Richard Dodel
- **TECHNOLOGY ENABLED CARE**
  - Álvaro Sanchez-Ferro
- **HOLISTIC MEASURES**
  - Angelo Antonini
- **CARE MODEL EVALUATION**
  - Carsten Eggers

B) **DEVELOPING** TOOLS TO ADDRESS NEEDS AND OVERCOME BARRIERS:

- **HEALTH ECONOMY**
  - Eric Crighton
- **HEALTH GEOGRAPHY**
  - Richard Dodel
- **TECHNOLOGY ENABLED CARE**
  - Álvaro Sanchez-Ferro
- **HOLISTIC MEASURES**
  - Angelo Antonini
- **CARE MODEL EVALUATION**
  - Tiago Mestre

C) **IMPLEMENTING** THE RESULTING PD CARE DELIVERY MODEL IN REAL LIFE:

- **HEALTH ECONOMY**
  - Nadége Costa
- **HEALTH GEOGRAPHY**
  - Richard Dodel
- **TECHNOLOGY ENABLED CARE**
  - Álvaro Sanchez-Ferro
- **HOLISTIC MEASURES**
  - Angelo Antonini
- **CARE MODEL EVALUATION**
  - Tiago Mestre
  - Olivier Rascol
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<th>WORK PACKAGES</th>
<th>HEALTH – ECONOMY</th>
<th>HEALTH – GEOGRAPHY</th>
<th>TECHNOLOGY ENABLED CARE</th>
<th>HOLISTIC MEASURE</th>
<th>CARE MODEL EVALUATION</th>
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<td>Luc Bonneville</td>
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<td>ETHICAL/LEGAL</td>
<td>Joaquim Ferreira</td>
<td>Jennifer Chandler</td>
<td>Christiane Woopen</td>
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<td>TRAINING AND MENTORING</td>
<td>Jennifer Chandler</td>
<td>Sylvie Grosjean</td>
<td>Evžen Růžička</td>
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**Decentralization**

- Home-based services
- Self-Management

**Technicalization**

- Metamorphosis of physician-patient relationship as a „benevolent partnership“
- „Virtualization“ of patients
- Demystification by medical facts and figures
- Possible standardization of patients’ way of life and individual preferences

**Un-Cocooning**

- Sharing of personal/“family“ life automatically with others
- Information includes that of close others and care-givers
- Increase of privacy by enabling home care instead of in-patient care
Ethics and Law: iCare-PD Model

1. Continuous monitoring of (health) parameters
   - Privacy, Autonomy, Social and Psychological effects

2. Data collection
   - Freedom of choice to consent into data collection, extent to which data collection is reasonably required

3. Data safety and security
   - Reliability of data storage and transmission systems
   - Confidentiality and integrity
   - Safeguards against malicious or inadvertent compromise

4. Responsibility for errors
   - For technology not functioning as intended
   - Lack of data quality, erroneous or interrupted information

5. Data ownership
   - Secondary uses
   - Discrimination effects, e.g. insurance decisions
Ethics and Law: iCARE-TEC

The Ecosystem of Technology
Integrated Parkinson Care Networks: addressing complex care in Parkinson disease in contemporary society

2019 - 2022

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