Self Management for people with psychotic vulnerability

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Personal Control in Rehabilitation

- Grant from Transition Program Chronic Care of the Dutch Ministry of Health Welfare and Sports

- Participating institutions:
  - Mental Health Care WNB
  - Mental Health Care Breburg
  - Trimbos Institute
  - Julius Center for Health Sciences and Primary Care
  - Vital Health Software
Ideas behind PCR

- Growing importance of self management in MHC
- Disease model focuses on dependency on treatment
- Self management model focuses on:
  - possibilities,
  - actively seeking a new way of life,
  - partnership between patient and caregiver,
  - patient makes decisions, caregiver is a facilitator, coach and advisor
Ideas behind PCR

Six principles of self management:

Patients:

- Have knowledge of their condition
- Follow a care plan agreed with their caregivers
- Actively share in decision making
- Monitor and manage signs and symptoms
- Manage the impact of their condition on their physical, mental and social life
- Adopt lifestyles that promote health

Lawn, 2007
Ideas behind PCR

**Self management:** much experience, limited scientific knowledge

Tentative conclusions:
- patients feel more empowered to become an equal partner and expert in the management of their health
- Become more goal focussed
Ideas behind PCR

**Rehabilitation**: restoration of social and community functioning

**Recovery**: self directed process of healing and transformation, caregiver should have a supportive role

⇒ **Empowerment**: has a central role

- Making informed choices
- The increased use of evidence based methods
- Need for cost reduction
Introduction

Internet application: **Personal Control in Rehabilitation**

- One open portal and three private portals
  - *For people with psychotic vulnerability*
  - *Their informal caregivers*
  - *Their formal caregivers*
Personal Control in Rehabilitation

**Participating patients**

1. People after their first psychosis
2. People with psychotic vulnerability for 2-5 years
3. People with long term psychotic vulnerability
4. People avoiding care
Elements of PCR for patients

• An overview of treatment and rehabilitation options
• e-consults with caregivers
• Chat function and safe email contact
• Safe, fast and easy communication
• Sharing experiences about illness, treatment, rehabilitation and recovery

• Look into their personal treatment, signal, crisis and care plan
• Information about social and daily activities
• Reliable information

• Preparing discussions with caregivers
• Consulting and participating in forums
• Receiving prescriptions, support and advice from caregivers
Elements of PCR for formal caregivers

- Easier and faster communication with patients and their informal caregivers
- Complete overview of the actual situation of each patient
- Overview of the care plan
Elements of PCR for informal caregivers

• Exchange of information and experiences
• e-consult, easier and faster communication
• Access to treatment plan, care plan, crisis plan of the patient
Time schedule of PCR

- Development phase: October 2008 - April 2009
- Production phase: April 2009 – November 2009
- Pilot phase: December 2009 – December 2010
- Upgrading phase: January 2011 – June 2011
Demonstration of PCR

- Personal Control in Rehabilitation

https://testers.vitalhealthsoftware.co.in/
Social Business Case

- Comparing investments and benefits of PCR
- Important for the exploitation of PCR after the pilot
  - *The number of short contacts will increase*
  - *The number and duration of face to face contacts will decrease*
  - *The number of social contacts will increase*
  - *More participation in community*
Obstructions, limitations and lessons learned

- The national guidelines and the monitoring of clients: too ambitious.
- Emphasis in the pilot: self management
- Development of the application took much more time
- Too many aspects to be handled

- Communication between software developers and local ICT workers
- No professionals in steering committee

- Very short testing period => take ample time for testing
- Safety problems => safety should have top priority
- Many different disciplines involved => someone with generalist knowledge
Critical success factors of the ER-platform

**Preconditions:**

- Clients should have a computer, and access to the internet.
- Clients should be able to trust the safety of the site.
- There must be a well functioning helpdesk.
- The application must be maintained.
- Sufficient time for all target groups to work with the application.
Critical success factors of the ER-platform

**Innovation**

- The innovation should be user friendly
- The innovation should have benefits for all target groups (clients, relatives, caregivers, managers)
- Stakeholders should attach importance to the innovation
Critical success factors of the ER-platform

Motivation/involvement
• Caregivers should be prepared to change familiar routines
• There should be full commitment of the management of the institute

Knowledge
• Clear functioning of the site, clear instructions on use of the site
• Training of users of the site
The future of PCR

• At the moment we are in the upgrading phase of PCR.
• We have submitted a grant application for a cluster-randomized controlled trial

New functionalities now being planned:
• Shared Decision Making
• Three modules for self management:
  •  *Optimistic Thinking*
  •  *Healthy Living*
  •  *Grip on your Life*
• E-persist: tool for sending sms-reminders
• Screen to screen communication
Any questions or comments?

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