Designing Personal Health Records for Cognitive Rehabilitation

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Research interests: where information technology meets individuals, organizations, and society. Co-design and mutual learning for a sensible digital society and future for all.

Research question

“How to design a PHR for cognitive rehabilitation?” and “How can this contribute to conceptualize PHRs?”

Conceptual grounding

Personal Health Records

Internet-based, lifelong health records that are controlled by the individual and are meant to promote the individual's engagement in his or her health and healthcare.

- PHRs should be controlled by the patients who should as well enter at least part of the information.
- Different types of PHRs.
  - PHRs tethered to EMR
  - PHRs fully controlled by patients, who enter and maintain their own health data. This health data can be brought over to be discussed with the healthcare practitioners during consultations, and the collaboration and interaction happen outside of the PHR
  - PHR platforms/ecosystems - supposed to be a mix between standalone PHRs and tethered to EMR PHRs, but with a distinction to be untethered from a specific healthcare provider

PHR conceptualization in CSCW

PHRs as hubs where patients and healthcare practitioners meet to enhance a collaborative relationship. In CSCW have been conceptualized as:

InterPersonal Health Record (IPHR)

> Hybrid electronic record that merges the typical EMR and PHR related features that aim at enhancing “relationships, communication, and collaboration between citizens/patients and their healthcare practitioners

Information spaces of a hybrid character.

> “PHR can be more than a private tool, serving as CIS that straddles work and non-work contexts, bringing together participants – patients and professionals – in a collaborative relation

Common Information Spaces

CIS is a conceptual framework in CSCW which highlights the relationship between actors, artifacts, information, and cooperative work. The aim is to provide an analytical tool that can inform developing systems that can support cooperative work.

CIS “encompasses artifacts that are accessible to a cooperative ensemble as well as the meaning attributed to these artifacts by the actors”

Seven parameters of CIS: the degree of distribution; the multiplicity of webs of significance; the multiplicity and intensity of means of communication; the level of required articulation work; the web of artifacts; the immaterial mechanisms of interaction and the need for precision and promptness of interpretation.

- “web of artifacts” described as material mechanisms of coordination to make possible cooperation among the distributed actors and having a better overview of the state of the work possible. Based on this definition, a PHR as a material artifact in the hand of the patient in which the patient can communicate, collaborate, cooperate with the healthcare practitioners, is a mechanism which materializes a CIS between the patient and healthcare practitioners.

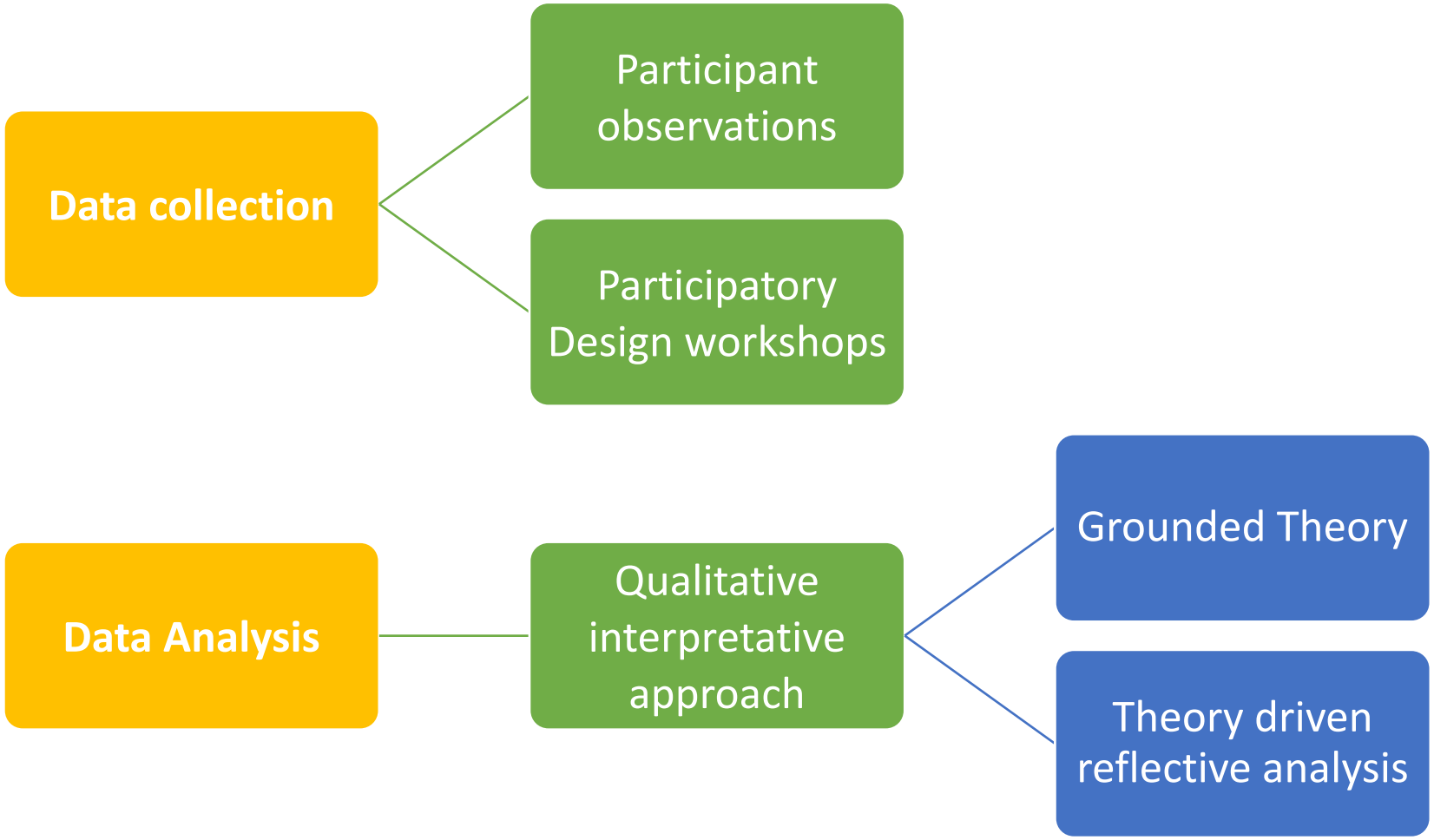
Coordination mechanisms

A specific organizational construct, consisting of a coordinative protocol imprinted upon a distinct artifact, which, in the context of a certain cooperative work arrangement, stipulates and mediates the articulation of cooperative work to reduce the complexity of articulation work of that arrangement

The case of cognitive rehabilitation

- A special rehabilitation program that is offered to people that suffer from cognitive impairments after an Acquired Brain Injury (ABI). ABI is brain damage acquired after birth.
- The cognitive rehabilitation aims to support the patients in therapeutic manners, thus, either improving his/her functions in daily life or helping the patients to find alternative ways for compensating the lost functions through additional aids.
- Multidisciplinary team working together with the patient
- Goal-setting approach
- The use of artefacts such as weekly plan and goal plan as common artefacts between patients and healthcare practitioners to manage the rehabilitation process

Methods


Data collection
Participant observations
Participatory Design workshops
Data Analysis
Qualitative interpretative approach
Grounded Theory
Theory driven reflective analysis

Implications for design for a PHR in rehabilitation

Enhance the existing shared artifacts

Implement elements of coordination

Support different representations

Integrate elements that can support enhanced interactions

Facilitating for personal spaces and having the possibility to negotiate boundaries for cooperation and coordination

Support continuity after the hospitalization period

A conceptual understanding of a PHR in Cognitive Rehabilitation

PHR in cognitive rehabilitation as a CIS - Cognitive rehabilitation involves several actors from different disciplines working together with the patient in an interdependent cooperative relationship and using a series of artifacts to facilitate their collaboration and interpretations.

PHR in cognitive rehabilitation as a Personal Information Space - The rehabilitation process is individual and closely related to the specifics of the patients. A patient receives personalized information regarding his/her rehabilitation. One of the most important requirements is that patients are able to construct personal interpretations of this information that they can use on their own to continue rehabilitation.

PHR in cognitive rehabilitation as a coordination mechanism

Designing a PHR in cognitive rehabilitation accounts for a coordination mechanism between the patient and his/her multidisciplinary team. This will contribute to making explicit the patient contribution in his/her rehabilitation, increase the level of awareness regarding the activities that happen as part of his/her treatment, and as well influence patient’s health literacy, involvement, participation in decision-making, and self-management.

We conclude that a PHR in cognitive rehabilitation can be conceptualized as a hybrid information space. However, within the hybrid information space, our findings also show that the PHR should also work as a coordination mechanism that recognizes the patient's position as part of the division of labor, supports the process of rehabilitation, and empowers the patient

Conclusion

We presented a set of implication for design for PHR is rehabilitation

We contributed in expanding the conceptualisation of PHRs also as coordination mechanisms

We discussed the case of designing a PHR to be used in hospital settings

For questions and comments please contact

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