Engaged Scholarship as Research Method: a Best Practice for evidence based IT-innovations for People with Severe Dementia

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Abstract— **Providing evidence for the added value of IT-innovations in health care for people with dementia is most challenging. Questions on relevant outcome criteria, methods of measurement, qualitative methods and quantitative, and correct stakeholder management are some of the issues coming to the fore. This short paper shares the best practices and challenges met on two short-term studies on IT-innovations for people with severe dementia. The paper also includes the topics and questions to discuss in the workshop EviDem: Evidence based IT-innovations for People with Dementia, during the eTelemed, the Ninth International Conference on eHealth, Telemedicine, and Social Medicine, 2017.**

Keywords: engaged scholarship; IT-innovations in health care; dementia; research method; evidence.

I. INTRODUCTION

In 2015 and 2016 I conducted two studies on IT innovation in intramural care for people with severe dementia. The first study was on the effects of a remote sensor system as regards to 1. the quality of life and care of the client and 2. the efficiency of care by the care providers. The second study was on the effects of a social media application as regards to 1. the quality of life of the client and 2. the relationship between client and care provider. Both studies were small-scale, involving 12 to 24 clients with severe dementia and lasted six months. This short paper focusses on the methods used and the challenges met.

II. ENGAGED SCHOLARSHIP AND ETHNOGRAPHY AS RESEARCH METHODOLOGY

The study on IT innovation for people with dementia in an intramural setting focuses on a series of complex issues in a social setting. The IT innovation is supposed to generate different results for various stakeholders in the arena of care, and all stakeholders have different interests. Clients with dementia are mostly hoping the IT innovation will improve their quality of life and care. Formal care providers often want to be able to give better care with the IT innovation. Boards of management of care providers direct their attention to efficiency in care while IT innovators and also financers of the IT innovation have commercial stakes when it comes to innovation in care practices.

At the same time the study on IT innovations is also supposed to contribute to the body of scientific knowledge on design and implementation of IT innovation in care. So the research method used has to serve multiple stakeholders in both the practice and the science of care. To increase the capabilities to study complex problems and to create the kind of knowledge that advances both practice and science in care, I propose the method of engaged scholarship by Van de Ven [1]. Engaged scholarship is a participative form of research for obtaining the views of key stakeholders to understand a complex problem. By exploiting differences between the viewpoints of the stakeholders, I found that engaged scholarship produces knowledge that is more penetrating and insightful than when researchers work alone.

Depending on the research purpose Van de Ven proposes 2 possible research perspectives: the 'detached outsider' and the 'attached insider' [1]. The purpose of my research was two-fold, namely to gain knowledge about the effects and the adaption of the IT innovation interventions together with the stakeholders and to gain knowledge about the complexity of intramural setting in which the IT innovation is launched. Therefore I chose the 'attached insider' view.

The first aim of studying the effects and adaption of the IT innovation demanded an action/intervention research. Developed by Kurt Lewin in 1944 action research is a reflective process of problem solving whereby researchers and stakeholders work together to improve the community's strategy, practices and knowledge of the settings in which they practice. The basis of this process is the participation of stakeholders in problem solving, using systematic methods of data collection, feedback, reflection and action [1]. By taking the perspective of the 'attached insider', I worked together with the key stakeholders to design and execute the research to ensure that all stakeholder's interests were served the best possible way.

The second aim, to gain insight in the complexity of the situation and to contribute to the body of scientific knowledge, required a collaborative basic research, another form of engaged scholarship [1]. This form of research entails sharing of power and joint activities among the researcher and stakeholders in order to co-produce knowledge about a complex problem or phenomenon. Taking again the perspective of the 'attached insider', I shared the daily life with the clients and care providers in

the intramural setting for a period of time, discussing our experiences and our viewpoints, their perceived obstacles and analyzing our findings together. I gathered the experiences and knowledge of the diverse stakeholders involved through interviews, conversation, participation and observation. To get a close and intimate familiarity with the stakeholders and their practices the key in the research strategy used here was participant observation, observing while playing a role within the group observed.

III. CHALLENGES MET

As Van de Ven notes, practicing engaged scholarship raises a number of challenges, two of which I also encountered while doing research in the intramural setting: divergent viewpoints and building relationships with stakeholders. Firstly, engagement generates divergent viewpoints that can be juxtaposing. In my research I incorporated the stakeholders' viewpoints and I gathered data from all the stakeholders involved: the clients, their care providers – formal and informal -, the board of management, the IT innovation developers and the financers of the IT innovation. The viewpoints generated showed different stances – not only on the IT innovation itself as intervention but also on the results this IT innovation generated by the client with dementia.

I found that reconciling these divergent viewpoints is not the point in this research. The point is to study and understand when and why these viewpoints are different. I tried to explain these differences by seeing the interconnectedness and webs of entanglement between the different dimensions of the processes in the daily lives of the clients and their care providers – formal and informal. I came to a holistic understanding from engaging all the stakeholders and analyzing their constantly evolving relationships.

The second challenge was negotiating the research relationship by establishing and building relationships with stakeholders. My research was undertaken with all stakeholders but especially I needed to build a good relationship with the clients and their formal care providers with whom I would be working. I experienced that building this relationship takes time, mutual understanding and a subordinate position of the researcher. The clients and care providers in my research were never involved in any sort of research before. When I suggested this research to them I made sure that they understood what it entailed from both sides, coming to work with them, talking and sharing, explaining, reflecting and exposing personal details.

The majority of the clients involved could not communicate and understand the implications of being involved in research. Their interests were represented by the care providers – formal and informal. The board, informal and the formal care providers had outlined their priorities as regards the clients: the wellbeing of the client at all stages of the research. This meant no intrusion, no upheaval, no insecurities in the clients' environment. As soon as it became clear that the client had a negative reaction or was obstructed in his or her daily life, the research and IT intervention would be stopped. Keeping the daily routine as regular as possible was key to the wellbeing of the clients. We made the agreement that the clients' wellbeing would always have precedent over any other issue that could in the study. All decisions made during the research were always guided by these principles. This way we made sure that all parties were contributors in working towards the development of the IT innovation and partners in the study.

Taking the time to build the relationship, mutual understanding and a complete subordinate position from the researcher to the wellbeing of the client made all stakeholders feel secure and safe, contributing as much as what was within their reach and therefore ensuring the best results within the study. It also meant however that the length of the study and the schedule set was determined by the clients from day to day. For me as a researcher this imposed a definite time challenge in the research frame that was dictated by strict delivery dates and deadlines.

IV. TOPICS AND QUESTIONS TO DISCUSS

The other challenges that I experienced in my studies on IT innovations and people with severe dementia are: 1. how to include the persons with severe dementia in the IT development and 2. how to take the constantly changing needs and abilities for persons with severe dementia into account while ensuring reliable research data.

It is proven that including the persons with dementia in the development of IT innovations ensures a better product/service and a higher adaptation of the innovation [2]. However, people with severe dementia are often not able to participate in research due to the fact that dementia in a severe stage restricts their interaction with their environment. To ensure the best results, what is the best practice to include the persons with severe dementia in the IT development?

During the research I experienced that the ability to interact with people with severe dementia can vary from hour to hour. One moment the person with severe dementia is able to interact and use the IT innovation provided, the next moment he or she is not able to due to the effects of the illness or the effects of the medication administered. This is an incredible challenge to both the client and the researcher. What is the best practice to take the constantly changing needs and abilities for persons with severe dementia into account while ensuring reliable research data?

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