Karine Lan Hing Ting, Dimitri Voilmy, Abéline Moreau, Antoine Malone, Guillaume Pradalié, Michel Van Rechem, David Laplanche, Stéphane Sanchez (2019): Population-based responsibility: a participatory approach to care networks efficiency*. In: Proceedings of the 16th European Conference on Computer-Supported Cooperative Work: The International Venue on Practice-centred Computing an the Design of Cooperation Technologies - Exploratory Papers, Reports of the European Society for Socially Embedded Technologies (ISSN XXX-XXXX), DOI: 10.18420/ecscw2019-to-be-added*

Population-based responsibility: a participatory approach to care pathway efficiency

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Abstract. In order to improve coordination in the care pathway, an experimental project called “population-based responsibility” is being run in 5 regions in France. The project has a triple objective: better health for the population, better patient experience, and a lower cost for society. It is based on an integrated approach to health, a more holistic approach to the patient and on the commitment of all the actors involved, so that they can collectively work in the same direction to serve the population. One of the challenges is a better cooperation between primary care and hospital care. What is envisaged is a better understanding and considering of the needs of general practitioners and their patients, and to give GPs more capacity of action, including the one of organizing the care pathway around the patient within the ecosystem of healthcare actors. This position paper describes the first participatory workshop held in Aube and Sézannais experimental area, which brought together professionals of different types and stakeholders from civil society , to co-create the ideal care pathway scenario. This workshop allowed to trigger participation (hopefully leading to coordination) in a positive and optimistic spirit, and to gather the first insights concerning expectations and needs of different stakeholders.

Introduction

All indicators show that chronic diseases constitute a challenge, having a considerable cost from a health (morbidity and mortality), societal and financial perspective. The estimation is that 12 to 20 million people in France suffer from a chronic disease, which represent 65% of total health expenditure, with an upward trend due to the ageing of the population and to medical progress. By far, the most important chronic disease is diabetes, representing 18.4% of LTCs in 2015, followed by Coronary insufficiency with 6.8%. (Présentation de la Cartographie médicalisée des dépenses de santé, 2017).

The population-based responsibility approach (PBR) – initiated by the French Hospital Federation (Fédération Hospitalière de France) – was initially built around these two chronic diseases, diabetes and coronary insufficiency. The Aube and Sézannais experimental area, whose participatory research is presented in this paper, is one of the five experimental areas in France (selected because already engaged in innovative clinical integration projects at different levels). In this area, the PBR approach has been extended to three other categories of patients: elderly and handicapped persons, Chronic Obstructive Pulmonary Disease, and vulnerable/precarious persons, aiming at an even greater clinical integration.

Population-based responsibility: a paradigm change

Clinical integration has been described as a situation where care by professionals and providers to patients is integrated into a single or coherent process within and/or across professions, such as through use of shared guidelines and protocols (Curry & Ham, 2010). Originally developed in Quebec (INSPQ, Roy & al. 2010), PBR is the shared responsibility and commitment of all actors in this clinical integration approach, with characteristics like: an integrated approach to health, a more holistic approach to the patient, aiming at proposing to the population a quality of service offer that is comprehensible, accessible, and continuous, thus empowering the patient. It thus has a triple objective: better health for the population, a better patient experience, and a lower cost for society (Berwick & al. 2008, Institute for Healthcare Improvement). The approach also implies overcoming the city-hospital dichotomy, through a better cooperation between primary care and hospital care, a better focus on prevention (v.s hospital's curative care), and more capacity of action to general practitioners. Interestingly, the challenges of PBR share common characteristics with care networks literature, including richness of care networks (multiple actors involved), complexity of care scenarios, importance of communication and information sharing, empowerment of the patient and his entourage.

Coordination and Care networks

Care networks in CSCW have mainly been researched in terms of elderly living independently at home. The knowledge in terms of what we consider the ecosystem of actors involved, communication practices and coordination issues (presented below), appear relevant to the case of PBR approach.

Consolvo & al (2004) described how elders who live at home generally have rich care networks – support networks of people who provide the elder with care. These care networks include people who provide assistance ranging from day-to-day activities to social support. They consist of family members, friends, and often neighbors. Paid help such as professional caregivers, pharmacists, house cleaners, and doctors might also be involved (Consolvo & al, 2004).

Focusing on informal care, Tellioglu & al (2014) note the need for the identification of complex scenarios, including other stakeholders like formal caregivers or health care professionals, and of (common) patterns occurring in care giving processes by informal caregivers. The paper describes how, along the disease trajectory, informal caregivers have to *make sense* and *work* with a wide range of organizations and actors like health professionals, psychologists, social workers, external housework and home care services, health institutions and insurance services, professional carers. Communication and information sharing on the care receiver situation is identified as a problematic area for cooperation between informal and formal caregivers.

Though technology may improve this coordination (Berg, 2004), Weerakkody & Ray (2004) discuss how, although telemedicine applications and Electronic patient record (EPR) contribute to the improvement of healthcare services, poor communication mechanisms and practices negatively impact on quality of service (QoS) in teamwork environments of patient care. Based on the same observation, an impressive number of articles have argued about the necessity of adopting a sociotechnical approach.

More recently, in their research on multimorbidity self-management, co-designing the tool *with* older adults and their care network, Doyle et al. (2018) show how improving best practice around the provision of well-coordinated, person-centred care for individuals with multimorbidity, requires empowering the individual and their primary informal caregivers to play an active role in self-management of their health.

(Tellioglu & al, 2014) and (Doyle et al. 2018) both stress the importance of participation of stakeholders in understanding the needs and in co-designing an appropriate tool. Following this approach (Voilmy, 2017; Lan Hing Ting & al., 2018), a first participatory workshop – bringing together stakeholders from the civil society and different Health Care Professionals (HCPs) – was held on March 7th 2019, as part of a one-day workshop bringing together the network of professionals in the area. The workshop aimed at revealing the discrepancy between the actual practice and the ideal/aimed one, the values associated to care pathway coordination, the identification of the complexity of actors ("who does what?) – in a needs identification objective – around a main research question: how can a more horizontal/participatory approach contribute to coordination rather than overlapping.

Participatory scenario Co-design and insights

The workshop was about co-designing the ideal scenario of care pathway, in a positive/optimistic, collaborative and horizontal spirit. There were three tables, of 8 participants each. Each table was hosted by a facilitator (including 2 co-authors) and proposed a specific scenario: Diabetes, Coronary insufficiency, an elderly going to the Emergency following a fall. E.g in the diabetes scenario, a persona and short guideline invited participants to creative story writing: "Jean-Marie, 50 years old, overweight, good-natured. He meets a diabetes association at a fair. The test reveals abnormal blood sugar levels. What will happen to him next?".

The insights gained can be categorized as: realization of the richness of care networks and scenarios, important values that need to be respected in the ideal scenario and by extension in the population-based approach, and more reflexive insights about the methodology. First, imagining the ideal scenario made participants realize to what extent a lot of different actors were involved at different levels: medical, dietary, socio-economic, relational etc. The values that emerged as being essential for the population-based approach are: patient-centredness, education and information. The Diabetes scenario, for example, stresses the overall care management of the patient and the necessary adaptation of the treatment taking into account the patient's lifestyle, the education of the patient *and* his entourage, the patient's position as an actor in his trajectory. Therefore, the patient is active and cooperates with the doctor so that *together*, they co-create the patient's care path, which will be comprehensible to him, adapted to his needs, and to which he will adhere (patient compliance) since he was actively involved in collaboratively elaborating it with his doctor. Patient empowerment appears as both a necessary condition and an objective to attain, both from a pragmatic and political perspective, with the final aim of more horizontal cooperation and mutual trust in the doctor-patient relationship, and more efficient coordination of all HCP actors involved *for* and *around* the patient.

In addition to the insights in terms of values of patient-centred cooperation and prevention, the workshop revealed the unanimous satisfaction of the participants to work collectively and positively to imagine the ideal scenario: "*it feels good to be optimistic. We doctors are used to always envisaging the worst*" (E.R, doctor), as well as their willingness to continue working with the Living Lab/participatory approach in order to collaboratively co-construct a first action plan.

Future work

The next sessions will be held in May and will take the form of participatory working groups, involving all the HCPs engaged in the project. To complement the participatory approach, ethnographic fieldwork (Randall & al, 2007) focusing on analyzing current practices (Schmidt, 2018) of care network are planned.

Acknowledgments

The authors warmly thank the Resp'Aube association, our colleagues from the Centre Hospitalier de Troyes, and the participants to this research project, including the members of the Amis du Living Lab community and HCPs for their participation in this workshop.

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