

Keeping the loop going: representations and data practices in remote care

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Abstract. Data-driven remote care involves more than just monitoring patients' health values through digital means. It requires a two ways interaction between health professionals and patients where reciprocal trust and personalized care develop over time. For this to happen, continuity in interaction is crucial. In this study, we focus on the work of nurses to achieve continuity in data-driven remote care. Specifically, we focus on how nurses work on digital representations. This paper examines this issue through a case study of nurses work in a remote care center in primary care for patients with chronic conditions. We found that nurses work by enriching, tailoring and improving digital representations, and through these practices they support continuous interactions. Our findings show that the work on digital representations is highly iterative and show how the nurses work to keep the iterations going.

Introduction

In remote care health providers and patients interact at a distance. This form of care has increasingly become data-driven as digital personal devices and apps on mobile devices for measuring various vital signs are developed and adopted (Lupton, 2017). Data-driven remote care is, however, more than a monitoring activity for health providers. The use of digital personal devices in healthcare has shown to create health benefits when patients are motivated and involved. Benefits depend on patient compliance and on behavioral changes that take place on a daily basis outside of the formal care system (Brennan and Casper, 2015). This is not easily achieved as it requires, for instance, patients to develop analytical skills (Grisot et al, 2018), and health providers to interpret data with 'absent' patients (Andersen et al. 2010).

In this paper, we examine this issue from the perspective of health professionals, and their work through data in remote care. Data work in healthcare has recently been defined as that portion of work whose execution, articulation and appraisal deeply and intensively rely on data (Bossen et al 2019). The datafication of healthcare is changing the required competences, tasks, and functions of existing

occupations and professions. In our study we specifically focus on the work of nurses with digital representations resulting from combining patients' data, and on how they are created and used and what is their role in the interactions between nurses and patients. Research on telecare workers has foregrounded the complexity of their tasks (Procter et al 2016) and the additional 'emotional labour' carried out (Roberts et al. 2012). Also, it has pointed out that telecare often is not used in situations requiring immediate medical help, but it is rather part of long-term care services (Farshchian et al, 2017). Farshchian et al, argue that support to continuous care processes is crucial. However, they also point out that we lack understanding of how continuous long-term care processes should be supported both in relation to tools, documentation and practices (Farshchian et al, 2017).

In our study we are interested in understanding the role of digital representations for continuity in interaction between health professionals and patients in remote care. We study this in the context of a pilot for a novel remote care service in chronic care. The service is designed to support a continuous and personalized relation between nurses and patients. The work practices of the nurses are focused on the data and framed by their constituting digital representations of patients. While this might be considered an extreme case, as it is designed as a pilot for data-driven remote care, it provides an occasion to study in detail the work of nurses with digital representations. In this setting, patients remotely (at home) generate data by using personal digital devices. The development of this type of service is still in its early stages and there is a limited understanding of how patients' health data shape how digital representations are formed and used, and how they affect remote care practices. In particular we are interested in understanding what is the role of digital representation in 'keeping the loop going' by which we mean the work of supporting the iterative and continuous nurse-patient interaction the service requires for care delivery.

As argued by Burton-Jones and Grange representations are fundamental to understand the use of digital technology (Burton-Jones and Grange, 2012). Thus, attention should be directed towards understanding how data are collected, processed, and structured into representations, and how these representations are used and manipulated. In addition, research has shown that these processes are not smooth and technology-driven but require tuned configurations of practices and technologies to be carried out (Jones, 2018; Monteiro and Parmiggiani, 2019). Thus, we focus on how digital representations used in remote care to support continuity of interaction. Our findings show three practices by which nurses engage with digital representations: enriching, tailoring and improving. We describe each practice and show how they support continuity in interaction. We contribute to the understanding of data work in remote care.

Methodology

The research reported in this paper is based on an empirical case study of nurses' remote care practices at Digicare. Digicare is a Norwegian company that has developed ProAct, a system supporting the collection and analysis of personal device data and supporting patient-nurse communication through messages and personalized questionnaires. Between 2016 and 2018, Digicare has run in-house a remote care center staffed with four nurses and a medical doctor. As part of a government funded pilot, the center provided remote care to a group of chronic patients in a small municipality. The patients were selected by the municipal care services and had chronic conditions such as diabetes, COPD and heart diseases. The pilot aimed to try out a new service model for remote care in Norway where the remote care service is outsourced by the municipality to a private company. In addition, the pilot tested a data-driven mode of remote care. In this mode, patients generate data by using a set of measuring devices in their homes and the data are then sent to a remote care system (ProAct) accessed by nurses. Previously, patients with chronic conditions were monitored at a distance by use of alarms (e.g. fall alarms, GPS tracking, door alarms). Thus, the new mode introduces a focus on data-driven care.

In this study we have focused on the practices of the nurses working at the center. We primarily used three methods to collect data: interviews, observations, and document analysis (Yin 2017). We conducted a total of 23 semi-interviews with the nurses, other staff at Digicare, as well as municipal, regional and national stakeholders involved in the pilots. Interviews were recorded and later transcribed verbatim. We conducted 47 hours of observation of the work practices of the nurses. We observed the nurses during their daily tasks: while using the system, informally discussing among them, during the lunch breaks and during their weekly internal meetings, and other meetings (for instance in discussions of how to improve their care plan). In the center there was one head nurse and three operational nurses sharing the same office on three separate pc desks. We sat next to them, looking at their screen to observe their use of the system. To grasp what the nurses were doing we asked questions and listened to their conversations. We also participated in informal conversations with both nurses, developers, management and technical staff. During each visit, we took extensive field notes to document how the staff interacted in the office. Following the observation sessions, we immediately (on the way back, ca 1 hour on train) spent time to reflect on our observations, to write analytical memos, and to note down questions for later clarification. We also analysed various document including project reports, Digicare documentation, the care plan, and strategic documents.

Case background

Remote care at Digicare's center is organized as follows. When patients are assigned to the remote center by the municipal care coordinator, nurses are informed about the patients' diagnosis, health conditions, treatment plan and other details (e.g. to what extent the patient is expected to self-manage, what type of support s/he has from family and from municipal home services). Once enrolled, the patient receives a home visit from Digicare, where a nurse collects additional information about behavior, autonomy, cognitive capability, and more generally about the home environment, and the patient is provided with a set of digital devices (e.g. digital thermometer, digital scale) according to their needs and including a tablet with the ProAct application. The nurse instructs about how to use the devices and the app on the tablet.

The care plan structures the interaction between nurses and patients for the first year. In the first weeks, patients are followed up closely to make sure they learn how to use the devices properly, and acceptable ranges are set for each type of measurement (e.g. the range that is considered normal for each patient). Overall, patients are expected to use the devices to take regular measurements (e.g. temperature, weight, blood pressure), heed to directions given by the nurses via messages, on a daily basis answer personalized questions, and reply to messages in the ProAct application at least once a week. Following the enrollment period, there are a number of check-points. Both nurses and patients have access to the patient record including graphical visualizations of the measurements from each device (also listed with time of measurement), the message log between nurses and patients, and the personalized questionnaire. Nurses have additional access to each patient profile (e.g. personal information, diagnosis, medicines, comments) and to individual alert settings for each type of measurement.

Nurses attend to each patient at least once a week examining measurements, messages, and questionnaire answers received in ProAct. Based on these data, nurses compose a text message comprising an analysis of the weekly trend, responses to questions from patients, and general advices. Nurses communicate with patients mainly with text messages, less frequently with phone calls and via SMS, but the style of communication varies with patient preferences.

Findings

Our analysis focuses on how the nurses work with digital representations in their interactions with patients. In ProAct various type of data are collected from the personal measuring devices, from the messages, and the answers to the questionnaires. The data are displayed in form of chronological lists of events (e.g. measurements, text messages), of graphs (based on the measurements), of scores

(according to the answers to the questionnaire). The various ways data are displayed, and their combination form digital representations. Data about the patient are at first based on information nurses receive from the municipal care coordinator, and on information collected during the home visit. These are about the medical history, diagnosis, and overall health status, as well as family and housing situation. This baseline is over time enriched by data from devices, answers and messages generated by patients. Digital representations are updated many times per day as patients take measurements, reply to messages and answer the questionnaire.

In the following text we highlight the work of nurses to achieve continuity through digital representations, specifically we describe the practices of *enriching*, *tailoring* and *improving* digital representations as core practices to ‘keep the loop going’.

Enriching digital representations. Digital representations are not fixed representations of the patient’s health status. They are sensemaking device that work as long as they are updated to the current health status. When nurses attend to patients, they consider and triangulate the various data received in ProAct to assess the patient’s condition. For instance, they observe the values from the devices and the trend that is forming in the graph. They check if the new values are below or above the set threshold, and how they relate to the values of the previous week or weeks. They do this by zooming in an out of the graphs. Also, they read the text messages from the patient, and they check if the patient has answered to specific questions they have formulated in a previous message, or if they have taken measurements regularly. If they have not, nurses follow up and remind patients to do so. For instance in the case of a patient with diabetes who has not measured as expected, the nurse comments: “I am sure here it was in the evening and she had eaten and had been without insulin because you maybe have chosen the wrong food to eat, and so she has not checked her glucose level afterwards, which is not good because we have reminded her to do that, because when you have a so high value then we tell that you should try to correct it and then take another measurement, but she has taken it until the day after in the morning and then the value was 5,5 which is ok”. Nurses follow up on a missing data by reminding patient to take measurements. It is important that the flow of data does not stop. Nurses work with digital representations by enriching them by developing and building up a narrative over time, making sense of the new data in relation to the past data.

Tailoring digital representations. Digital representations can be manipulated and tailored to the needs of each patient. ProAct is a flexible technology where the different features can be tailored to the characteristics and needs of each patient. For instance, the text messages between nurses and patients are not standardized in terms of length, content or frequency of interaction. This supports nurses to develop a personalized interaction with patients. Personalization is important, because each chronic patient experiences his/her illness differently and has specific illness

trajectories. In addition, as patients' own behaviors and habits affect their health conditions, nurses need to understand their overall life style and situation. For instance, some patients not very comfortable with reading and writing text messages and prefer short messages, while others are very active. The nurse says: "here you have access to health personnel so you can ask any question, so depends on the person, some are very interested and ask a lot of questions, other are not, and you have to repeat and repeat." The questionnaire is also flexible and can be personalized in content, formulation and scoring. For instance, in a case a patient with COPD has questions that track his use of painkillers. The notes from the observation report the following: "the nurse looks at the answers from the questionnaire: the patient has answered that 'yes' she has taken some extra painkillers this week. She had answered 'yes' also the previous week. The nurse comments on this in the text by saying that she sees from the answers that she 'is struggling with pain everyday' because she says that she takes pills every day". Nurses work with digital representations by tailoring them to each patient as over time they get to know the patient preferences and adapt their interaction accordingly.

Improving digital representations. Digital representations guide nurses' interpretation of the health status of patients. By combining various data, nurses, in a continuous interaction with patients, reflect on how well the collected data and the digital representations they form actually represent the patient health status. For instance, they often revise and reformulate the questions in the questionnaire to match the changing needs and concerns of patients. In addition, nurses also reflect on the use of digital representation. For instance, one concern they have is that if a patient has all her measurements within the appropriate value range, the system would not display any alert. This would risk the patient to go 'unnoticed'. As one nurse commented: "we started by saying ok I think they should have a feedback once a week, what we were afraid of in the beginning is that some of the patients that were doing well, they will slip through our fingers and we wouldn't see them, you know, they are not alerted". Thus, they decided to interact with patients every week with a feedback text message, in addition to replying to messages patients sent. As the nurse explains: "we are doing both, and we still do it, if one of (nurse)'s patient is having an alarm on Monday and she gives him a feedback on that one, she gives him also a weekly feedback the next day as a weekly message, and that was not the thought when we started". Thus, working with digital representation means also to understand if the way they are formed and used is in line with the purpose of the care activities. In this case, a patient that has good routines 'slips through the fingers,' showing that the use of alerts can also contribute to unreliable digital representations.

Conclusion

In this paper we have examined a case of data-driven remote care which requires a continuous flow of information between health practitioners and patients. While chronic care has traditionally been delivered episodically, digital tools enable novel forms of remote patient care that support continuity of care (Lupton and Maslen 2016). Continuity is critical in remote care, yet we lack understanding of how it should be supported (Farshchian et al, 2017). In this paper we have approached this issue from the perspective of the health professionals providing remote care, and we have focused on the data work of nurses with digital representations. Specifically, we have examined the work of supporting continuity as work of ‘keeping the loop going’, thus proposing to understand continuity of care as an interaction loop between health providers and patients which needs ‘to keep going’. We have identified three ways nurses work with digital representations, which we have called enriching, tailoring and improving. By doing so, we have foregrounded the data work of nurses in keeping continuity in their interactions with patients and in care.

A crucial aspect of chronic care is that it takes time and work to cope with a chronic disease. Through the care process we have described, the aim is that patients become partners in a continuous conversation that iteratively builds up their knowledge of their disease and how to manage it. Patients learn how their habits affect their condition (e.g. how alcohol affects glucose), how medicines work (e.g. should insulin be taken before or after a meal?), how their condition can be acted upon (e.g. what a headache or insomnia may mean and what to do). For both nurses and patients this is a continuous learning process, as chronic conditions can develop and interact in unexpected ways over time. The nurses need to learn which methods are most effective in providing remote care for chronic conditions, what works in some cases (e.g. to a depressed patient they would write bold statements), and what does not work (e.g. an overweight patient that stops using the digital scale because her weight is increasing).

Responding to the call for research by Farshchian et al (2017), our findings show that the interaction between nurses and patients, needs to be iterative and continuous to support continuity of care. We propose to understand the challenge of supporting continuity as a challenge of keeping digital representations as active working tools for both nurses and patients. Our findings are relevant for the design of systems supporting patient-health provider interactions in remote care, and our future research will contribute to the definition of design principles for supporting iterations in remote care.

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References

- Andersen, T., Bjørn, P., Kensing, F., & Moll, J., 2011. Designing for collaborative interpretation in telemonitoring: Re-introducing patients as diagnostic agents. *International journal of medical informatics*, 80(8), e112-e126
- Andreassen, H.K., Dyb, K., May, C.R., Pope, C.J., Warth, L.L., 2018. Digitized patient-provider interaction: How does it matter? A qualitative meta-synthesis. *Social Science & Medicine* 215, 36–44.
- Bossen, C., Cabitza, F., Ellingsen, G., Pine, K., Piras, E., 2019. Data work in healthcare. Special issue of *Health Informatics Journal*.
- Brennan, P.F. and Casper, G., 2015. Observing health in everyday living: ODLs and the care-between-the-care. *Personal and Ubiquitous Computing*, 19(1), pp.3-8.
- Burton-Jones, A., Grange, C., 2012. From Use to Effective Use: A Representation Theory Perspective. *Information Systems Research* 24, 632–658.
- Farshchian, B.A., Vilarinho, T. and Mikalsen, M., 2017. From episodes to continuity of care: A study of a call center for supporting independent living. *Computer Supported Cooperative Work (CSCW)*, 26(3), pp.309-343.
- Grisot, M., Moltubakk, A. K., Hagen, L., & Aanestad, M., 2018. Supporting Patient Self-Care: Examining Nurses' Practices in a Remote Care Setting. *Studies in health technology and informatics*, 247, 601-605.
- Jones, M., 2018. What we talk about when we talk about (big) data. *The Journal of Strategic Information Systems*.
- Jonsson, K., Mathiassen, L., Holmström, J., 2018. Representation and mediation in digitalized work: evidence from maintenance of mining machinery. *J Inf Technol* 33, 216–232.
- Lupton, D., 2017. *Digital health: critical and cross-disciplinary perspectives*. Routledge.
- Lupton, D., & Maslen, S., 2017. Telemedicine and the senses: a review. *Sociology of health & illness*, 39(8), 1557-1571.
- Monteiro, E., & Parmiggiani, E., 2019. Synthetic Knowing: The Politics Of The Internet Of Things. *MIS Quarterly*, 43(1).
- Procter, R., Wherton, J., Greenhalgh, T., Sugarhood, P., Rouncefield, M. and Hinder, S., 2016. Telecare call centre work and ageing in place. *Computer Supported Cooperative Work (CSCW)*, 25(1), pp.79-105.