CHAPTER 12

Challenges in Obtaining and Sharing Core Patient Information in Norwegian Nursing Homes and Home Care Services: A Qualitative Study of Nurses' and Doctors' Experiences

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Abstract: In Norwegian nursing homes and home care services, medication information and other core patient information (CPI) is usually registered and stored in separate digital systems not connected to each other. This may pose a threat to medication safety and quality of care in municipal health and care services. This study explores how nurses and doctors in Norwegian nursing homes and home care services experience access to and exchange of CPI before two new national solutions, the Shared Medication List and the Summary Care Record, are implemented in Norway. We used a qualitative research design with semi-structured individual interviews with nurses (n = 17) and medical doctors (n = 6) from home care services and nursing homes in six Norwegian municipalities. Data were coded and analyzed following an approach based on grounded theory. Our participants reported having extensive experience of various challenges related to accessing and sharing CPI. Five main challenges emerged from our data: 1) excessive time consumption;

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2) frustration; 3) uncertainty; 4) dependence; and 5) complexity and risk. Our participants thought that these challenges posed a risk to patient safety and quality of care, and they were especially concerned about medication information in patient transitions between levels of care. Our study shows that nurses and medical doctors face substantial challenges, because they lack seamless, up-to-date digital solutions able to share CPI across healthcare services. The ongoing national implementation of the SML and SCR should address these challenges directly, and closely evaluate their impact on patient safety and quality of care.

Keywords: core patient information, health professionals, medication information, primary healthcare, shared medication list, summary care record

To ensure quality of care and patient safety, it is vital that core patient information is accurate and easily available (Eden et al., 2016). In this chapter we use "core patient information" (CPI hereafter) to denote all critical and important health and treatment related information about patients, such as medication lists, prescriptions, diagnoses, allergies, etc. (Dyb & Warth, 2018).

Medication errors are linked to substantial financial costs worldwide (Kierkegaard, 2013), and are considered the third leading cause of death in the US (Institute of Medicine Committee on Data Standards for Patient Safety, 2004). During the 5 years following the release of the WHO's Third Global Patient Safety Challenge, "Medication Without Harm", report in 2012, WHO aimed to reduce medication-related harm by 50% globally (Donaldson et al., 2017). Patient safety is the foundation on which all other aspects of quality of care are built, and is indistinguishable from the quality of healthcare services (Institute of Medicine Committee on Data Standards for Patient Safety, 2004; Institute of Medicine Committee on Quality of Health Care in America, 2001).

The everyday work of health professionals typically involves the use of many different digital and manual sources¹ to obtain CPI. CPI is normally stored in several digital systems within the different healthcare organizations and units (hospitals, nursing homes, home care services, pharmacies, GPs etc.), and a significant challenge is that the different

¹ Digital sources: electronic health records (EHR), summary care record (SCR). Manual sources: paper, medicine list, phone, fax, face-to-face.

units use different systems, unable to share data across the healthcare services (Frydenberg & Brekke, 2012; Kierkegaard, 2013). This causes poor communication and information flow within and between services, and can lead to potentially harmful medication errors (Remen & Grimsmo, 2011). The lack of interoperability can also lead to ineffective care coordination and transitions of care (Samal et al., 2016). Health professionals' perspectives on improving information exchange reveal several challenges, such as ineffective communication, poor medication management and technical factors (Bengtsson et al., 2021; Sarzynski et al., 2019).

Keeping in mind this context, Norwegian authorities are currently working to implement several large national eHealth solutions, two of which are the summary care record (SCR) and the shared medication list (SML) (Helsenett, 2018; The Norwegian Directorate of eHealth (NDE) 2018). The implementation of the SCR in primary healthcare (nursing homes and home care services) was initiated in the first municipalities in late 2019/early 2020 and a full national rollout is expected in 2022.² The implementation of the SCR is a necessary and important step towards a national SML (expected national implementation in 2023–2025³). The SML is currently being piloted in the Bergen municipality. Bergen is Norway's second largest city, with a population of 285,601 as of 1 January,

A recent Norwegian study explored doctors' use of and trust in the SCR, and reported that doctors used only the pharmaceutical summary (one of six functions in the SCR), and primarily for just a few subgroups of patients: unconscious patients, elderly with polypharmacy, and patients with substance conditions (Dyb & Warth, 2018). Studies from the UK on the functionality and impact of the SCR, reported that health personnel regarded it as supporting better quality of care with the potential to prevent medication errors (Greenhalgh et al., 2010; Jones et al., 2017).

² https://www.helsenorge.no/en/summary-care-record/kjernejournal-for-safer-healthcare/

³ https://www.ehelse.no/programmer/program-pasientens-legemiddelliste

⁴ https://www.bergen.kommune.no/omkommunen/fakta-om-bergen/befolkning/folkemengdeper-1-januar-2021

FACT BOX

The summary care record (SCR) is the first national digital solution in Norway for the exchange of updated core health information, accessible regardless of where treatment is provided.^a The SCR contains critical information, a pharmaceutical summary, appointment history (hospitals), patient data (relative, GP) and self-reported information. The SCR is expected to have a huge impact on patient safety and quality of care, especially in emergency situations or situations in which the patient (or relative) cannot provide this information. The SML and the SCR are interconnected, as nurses and nursing home MDs will be accessing the SML through the SCR interface.

The study underlying this chapter is part of the larger national longitudinal study "The Summary Care Record and a Shared Medication List in Norwegian Nursing Homes and Home Care Services" (2019–2025). In this chapter our aim is to present in-depth knowledge on how nurses and medical doctors (MDs) in nursing homes and home care services *experience* the access to and exchange of CPI in the context of current digital and manual sources, pre SCR and SML.

Methods

Research Design

We used a qualitative research design based on a stepwise-deductive-inductive (SDI) approach (Tjora, 2010). One of the core elements of SDI is that the researcher should be open-minded and unbiased, and let issues and themes "emerge" from the material. We used the SDI approach to explore how health professionals experience everyday access to and exchange of CPI in primary healthcare *before* the implementation of the SCR and the SML. In line with our methodological orientation, we tried to approach the material without any fixed ideas or expectations, and we were determined to allow findings to emerge freely from the material. We conducted semi-structured interviews, using an interview

 $[^]a\ https://www.helsenorge.no/en/summary-care-record/kjernejournal-for-safer-healthcare/$

guide⁵ covering the following themes: 1) access to critical and relevant patient information; 2) access to medication information; 3) collaboration with other parties; 4) decision support; and 5) expectations for the SCR and SML. Participants were encouraged to talk freely about their experiences, thoughts and perspectives, and were able to influence the direction of the conversation. As interviewers, our job was to make sure that all themes in our interview guide were covered.

In this chapter we focus exclusively on access and exchange of CPI in nursing homes and home care services, and therefore only discuss findings from interviews with nurses and nursing home MDs, and cover only these themes: 1) access to critical and relevant patient information, and 2) access to medication information (see Table 1).

Table 1. Excerpt from Interview Guide

Theme 1: Access to critical and relevant patient information

How do you proceed to obtain critical and relevant information about the patients?

How do you consider the quality of the different information sources?

How do you experience the process related to obtaining critical and relevant patient information?

Theme 2: Experiences with current access to an overview of the patients' medications

How do you go about getting an overview of which medicines a patient is using?

What are the challenges today in relation to the limited opportunity to share medication lists, seen from your role and perspective?

How do you register and communicate changes in the medicines a patient uses?

Recruitment, Research Sites and Participants

For recruitment, we contacted the heads of health and care services in nine different Norwegian municipalities by email and phone, and provided them with information about the national study and an invitation to participate. The selection of municipalities was based on the following criteria:

⁵ Prior to the study, the interview guide was piloted on two colleagues (one nurse and one MD) with relevant clinical experience.

- Municipalities had to be in the process of implementing the SCR and SML
- All three main suppliers of EHR systems in Norway should be represented
- A spread of small, medium and large municipalities
- Different parts of Norway should be represented (geographical spread)

Seven out of nine municipalities agreed to take part in the study, and two declined due to lack of available resources at that time. For one of the seven included municipalities, planned interviews were postponed due to unexpected circumstances. After careful consideration, we concluded that data saturation was achieved through the six included municipalities. To secure experiences from different sites within the primary healthcare services who had not yet implemented the SCR, we chose to include nurses from both home care services and different nursing home contexts (long-term, short-term, and intermediate). We also recruited MDs working in nursing homes to obtain their experiences as well, as both nurses and MDs in these organizations lack access to the SCR. A contact person within each of the six municipalities helped to coordinate and recruit participants of both genders working at the sites mentioned above, having two or more years of experience as a nurse or MD at the site, and having experience using EHR systems for obtaining CPI. All participants received information on the study aims, funding and roles before the interviews. We hereby present findings from interviews with nurses (n = 9) and MDs (n = 6) employed in nursing homes (longterm, short-term, and intermediate⁶) and nurses from home care services (n = 8), a total of 23 participants.

⁶ Intermediate departments are organized through the municipal health services in Norway. Intermediate means between the specialist (hospitals) and municipal health service. Patients admitted to intermediate departments require more advanced treatment than the municipal health services are able to offer before returning to their own home or home care services, such as medical treatment or physical rehabilitation.

Data Generation and Analysis

The authors (USM, TTK) conducted all interviews with the participants at their workplaces from November 2019 to March 2020. Most participants were interviewed individually, with the exception of four, which we interviewed in pairs for practical reasons. The interviews lasted between 30 to 60 minutes, were digitally recorded and transcribed by a professional transcription service. Written informed consent was collected from all included participants.

Analysis and data coding were performed by both authors, in line with the SDI approach (Tjora, 2010), oriented towards identifying emergent issues and themes through an open inductive reading of the material. All transcripts were first coded in detail using NVivo 12 software. For the present study, we created 283 individual nodes covering access to and exchange of CPI. In the second step, the nodes were grouped into a coding tree consisting of five recurring themes: excessive time consumption, frustration, uncertainty, dependency, and complexity. In order to ensure rigour and continuity surrounding the empirical data, our open inductive reading, coding and grouping, we maintained a constant focus and dialogue to ensure that all of the themes we created both faithfully represented what was actually being said by the participants, and were general enough to cover all of the included nodes (Manskow & Kristiansen, 2021; Tjora, 2010; Trondsen et al., 2014). In line with the logic of the SDI approach, we constructed our categories, themes and concepts based on patterns that emerged from the empirical data.

Ethical Considerations

The study was conducted according to the guidelines of the Declaration of Helsinki and approved by the Data Protection Officer at the University Hospital of North Norway (Project no. 02417, ref.: 2020/2856). Ethical considerations, such as information on anonymity and confidentiality, voluntary participation, informed written consent, and information about publication were explained to all participants, and all participants signed a written consent before the interviews. The data material was anonymized and handled securely according to the recommendations of

the local data protection officer. All methods were carried out in accordance with relevant guidelines and regulations.

Results

Nurses and MDs in primary healthcare generally experienced the task of obtaining and sharing CPI as a significant challenge, especially related to patients' medication information. One main pattern that emerged from our material was that the participants regularly experienced situations where access to CPI was limited, and where professional tasks had to be performed without having all relevant information at hand. When analyzing the material, we found that the participants typically described experiences of five sorts: 1) excessive time consumption, 2) frustration, 3) uncertainty, 4) dependency, and 5) complexity and risk. In the following sections, we explore these experiences in more detail.

Excessive Time Consumption

The participants reported that when access to CPI was limited, excessive time consumption was a common consequence: "I spend 40% of my workday getting information" (Nurse). In terms of both losing time designated to core tasks as well as "stealing" time from other health professionals, one MD stated, "Not only does it cost me time, but it costs the specialist and GP time as well". One of the main reasons for excessive time consumption was said to be the lack of adequate digital solutions for sharing CPI across health services, which hindered information access.

[It is] difficult with systems that do not communicate and retrieve all the information. It is not easy. It does not come automatically, and we have to search for the information. (MD)

Some participants also reported that pre-existing time shortages could result in new problems, for example when nurses lack the time to obtain medical records with an updated medication list for new patients:

We have a busy time schedule, and you may not be able to do things as fast as you should. The patient arrives and then it may take a week before you realize that you need to obtain a medical record. (Nurse)

Also, most participants mentioned that they spend a lot of extra time gathering core information about new patients:

I spend a lot of unnecessary time calling around to find the right person and the right department in the hospital for information about a patient. (Nurse)

As illustrated above, the participants reported considerable time consumption, that is time spent searching for CPI, and that this was viewed as "excessive" by the participants.

Frustration Over Systems That Do Not Communicate

The participating nurses and MDs reported several types of situations that caused frustration. Frustration was often directed towards "systems that do not communicate" across sections and levels of the healthcare system, obstructing information flow. Frustration was also triggered partly by excessive time consumption and by difficulties in meeting the expectations of patients and relatives.

Yes, it is time consuming, so you simply get frustrated, over and over again. And the patients ask what is going on, so you feel that you are in a pinch, really, with both patients and relatives. I feel that I have to chase after information. (Nurse)

Lacking or incomplete discharge summaries⁷ from hospitals were one of the primary causes of frustration, especially among nurses. According to our participants, discharge summaries were often not fully approved at the time of discharge from the hospital. Many patients therefore arrive at primary care services before updated CPI about them is available to the responsible health professionals.

A discharge summary is the main source of standardized clinical information between healtheare services, and a vital information source for health professionals involved in a patient's treatment and care.

We are kind of helpless when we receive a new patient without any information available. (Nurse)

It is very stressful to receive a patient without having the necessary papers If you have not received the discharge summary by electronic message before the patient arrives, you may have no idea what kind of medication the patient should have So, if vital examinations need to be performed and at certain times, you need to have control. (MD)

The participants in our study reported that hospitals are aware of the problem, and that there is a formal agreement in place between the hospitals and primary healthcare services that the discharge summary must be approved and available before a patient is transferred, in order to avoid situations like the one mentioned above. However, as one nurse put it, "These agreements are constantly broken", and this was perceived as a source of frustration.

Uncertainty Caused by Lack of Information

Many participants reported that limited access to necessary CPI tended to make them feel uncertain. One type of situation where our participants reported this was when they had to handle a multitude of different information sources to obtain sufficient CPI.

We had to call around and were sent to different people for [core patient] information. So, we felt that when we finally did receive information, we were a bit in doubt as to whether we had received everything. (Nurse)

Health professionals also feared that their own uncertainty would affect the patients and possibly even cause harm, especially within psychiatric care. A psychiatric nurse explained how she feared that her own uncertainty could affect the patients:

I don't know whether it's bad for the patient. But, within the psychiatric services, it creates uncertainty, which is not good for patients. It is better that we know everything and can tell them, "This is how it is, and this is what we are going to do". (Nurse)

Both nurses and MDs reported that when they received an incomplete discharge summary from the hospital, their work with the patient would be characterized by an unhealthy combination of feelings of increased responsibility and constant uncertainty until the final summary arrived. They would not know whether important corrections had been added to the final summary before the hospital doctor actually signed and approved it:

Yes, it happens that they have written "not approved", and we are completely dependent as recipients to follow up and wait until we receive the final [approved and complete] discharge summary. And then we have to check whether there are any corrections from the pre-approved version. So, it puts a very heavy responsibility on the nurses in the ward. (Nurse)

As mentioned in the "time consumption" section, our participants reported delays ranging from one day to over a week before receiving a final and approved discharge summary from the hospital. In the meantime, considerable time and resources were devoted to obtaining updated CPI about the patient through other sources (phone, e-messages, patient). The patient's relatives also served as an important source of CPI, as one nurse said, "We have very little critical patient information in fact. So, you have to ask the relatives and, well, more or less interview them".

Dependency on Others

Both nurses and doctors reported that they often depended on GPs, hospital doctors, the patient or caregivers to confirm or provide access to correct CPI before they could proceed with their own tasks. This was challenging for nurses in home care services as well as in intermediate departments when receiving newly discharged patients from the hospital. As one MD stated:

So, we do not have an overview of this: blood tests, medication lists, and things like that. Then we send an e-message to the GP, and then we have to wait too. And sometimes we need an answer right away. (MD)

One intermediate care nurse stated:

And then, if the patients have not had previous healthcare services from the municipality, we have much less information, and are even more dependent on information from the hospital. Then there are the patients who are admitted for emergency care, where we depend on information from the GPs. (Nurse)

Our participants often needed to contact either the GP or treating doctor at the hospital for supplementary CPI about a new patient. In many cases, however, these GPs or specialists did not have the time to provide feedback during working hours, and the responsible nurse or MD had to spend a lot of time waiting for the information needed for the treatment and care of patients.

Complexity and Risk to Patient Safety

Complexity and risk in the information flow between primary healthcare and the hospital were seen as major challenges in everyday work, and were reported as posing a risk to patient safety. One doctor stated that "the information flow is highly vulnerable and critical between healthcare levels". As the available digital solutions did not allow sharing patient information across services, patient information often had to be obtained manually by phone or digitally through e-messages. Obtaining CPI thus became a more complex and riskier task.

Another challenge for some participants was the huge amount of information in the EHR and discharge summaries, which they experienced as "information overload" to some degree. They perceived an increase in complexity and risk in cases where they were unable to identify and retrieve necessary CPI. One nurse stated the following: "[The discharge summary] is often four or five pages, so it is a challenge to determine which information is relevant for us".

Another nurse stated the following:

The discharge summary needs to be thoroughly read by the nurses, because we can't expect the MDs to read 25 different patient summaries in detail, since there is a high turnover of patients in our short-term department. If we don't

catch the most important information, there is a risk that something will happen to the patient and their condition might get worse. (Nurse)

Our participants desired a more readily available, structured and easier system, both in terms of the local EHR systems and the ability to share CPL

Discussion

Our results indicate that nurses and MDs in Norwegian nursing homes and home care services have extensive experience of situations where inadequate access to CPI affected patient safety and quality of care. Our participants regularly linked these challenges to absent or inadequate digital solutions for accessing and sharing CPI across healthcare services. This complements a qualitative study of clinicians' perspectives, that revealed multiple areas in which the lack of interoperability led to ineffective processes and a lack of data in care coordination and transitions (Samal et al., 2016).

Another main challenge was excessive time consumption. This finding complements a 2020 review of nurses' time use *after* the implementation of health technology, that shows how nurses, after implementation, use more time documenting but less time administering medications, and that this in sum enables more time with the patient (Moore et al., 2020). Our findings complement this review by documenting how actual health professionals in Norwegian nursing homes and home care services experience their time use *before* the implementation of the SCR and SML.

Another finding was that limited access to CPI caused uncertainty about the correctness of the information at hand. This finding complements a cross-sectional study from the U.S. that evaluated the completeness and timeliness of information transfer and communication between a hospital and a post-acute care facility (PAC). The study reported that nurses and clinicians at the PAC experienced substantial deficits in content and timeliness of health information exchange (Jones et al., 2017). Another study from Sweden reported that both human limitations and technical deficiencies could lead to medication errors and patient harm (Bengtsson et al., 2021). Our findings complement both these studies, by

documenting how problems concerning information timeliness and correctness are experienced by actual health professionals in a Norwegian nursing home and home care setting before the implementation of the SCR and SML.

A similar problem was the frequent incomplete or delayed approval of discharge summaries from hospitals. As with the abovementioned limited access to CPI, this was also perceived as a major source of uncertainty. In addition, it was linked to frustration, and dependency. This finding complements Samal et al., who claim that the completion of structured discharge summaries before discharge from hospital should be one of the main targets for quality improvement (Samal et al., 2016). We complement Samal's point about discharge summaries and quality improvement, by showing different ways in which incomplete discharge summaries are experienced by actual health professionals in a Norwegian nursing home and home care setting before the implementation of the SCR and SML.

E-messages were commonly used in communication between nurses, MDs and general practitioners (GPs) in our study, to clarify a patient's medications and/or the need for observation. Some participants experienced quick answers from the GPs, although many reported that it could take days or even weeks to receive an answer to a question or clarification. Two Norwegian studies explored the impact of electronic messaging on patients in patient transition, and concluded that the introduction of e-messages, as well as information and communication technology, can support the work of nurses in the transition situation and benefit patients (Hellesø et al., 2016; Melby et al., 2015). Our study provides important nuances to these previous studies, as e-messages have certainly eased communication challenges, especially between GPs and nurses in home care, but limitations concerning CPI access and exchange is still a main issue and source of frustration and uncertainty among nurses and MDs.

In our study, both nurses and doctors reported that they often had to handle unnecessarily complex situations resulting from limitations in the access to and exchange of CPI, and that they considered this complexity as a threat to patient safety. This finding is in accordance with previous Norwegian studies reporting how inadequate information exchange poses a threat to patient safety, since fragmented patient information and

poor communication with and between services can lead to potentially harmful medical/medication errors (Frydenberg & Brekke, 2012; Remen & Grimsmo, 2011). Our results also complement a qualitative study from the US, which explored nurses' perspectives on improving information exchange between hospitals and home healthcare, and revealed the following challenges: ineffective communication, technological factors, poor medication management, and different patient factors (Sarzynski et al., 2019). Our findings complement these studies by documenting how challenges are experienced as an increase in complexity by actual health professionals in Norwegian nursing home and home care settings.

Considerations of Methodology and Design

We used a qualitative research design to obtain in-depth knowledge on the experiences of nurses and MDs in relation to obtaining and sharing CPI in their everyday work. This approach was chosen in consideration of our aims for the main study. We did not aim to provide a final and conclusive answer to our research question, but to explore the research topic in depth (Malterud, 2001a, 2001b). A recent review of factors for the success and failure of eHealth interventions supports our approach to perform in-depth studies of the workflow(s) that an intervention is intended to support, and to evaluate the clinical processes involved (Granja et al., 2018). By providing in-depth knowledge on health professionals experiences before SCR and SML implementation, we provide a context for our planned follow-up studies after implementation. Our research also contributes to the realization of the Norwegian eHealth strategy, which states that research-based knowledge on the intersection of health, technology, organization and society is a key tool for decision making and shedding light on the effect of eHealth interventions (The Norwegian Directorate of eHealth (NDE), 2018).

Our study is limited in terms of a relatively small number of participants and only six municipalities, meaning that we are not able to state how *widespread* the identified perceptions are among health professionals in Norwegian nursing homes and home care services. However, the research design enabled in-depth mapping and understanding *actual*

nurse and MD experiences of the challenges in obtaining and sharing CPI. By aiming for balance among large, medium and small municipalities from both urban and rural parts of Norway, we have also tried to secure breadth in our findings. As such, our included participants and municipalities may serve as a cross section of the Norwegian primary care services. The identified challenges may be similar and transferrable to other countries planning new national eHealth implementations, especially those with a health and social care system similar to that in Norway.

To comply with research ethics rules concerning personal information and the privacy of participants, we were not directly involved in the recruitment process. We contacted each municipality through its healthcare authorities to establish a good and solid relationship for the main national study, and had a local contact person handle the initial recruitment in each municipality. All participants were able to withdraw from the study with no explanation needed, and recruitment was voluntary. All in all, we assess the risk of participation bias to be low in this study.

Conclusion and Future Research

Equipped with accurate and updated CPI, health professionals can act with precision and confidence as participants in complex and fine-tuned co-operation, oriented towards the delivery of health services tailored to a patient's needs. Our results show that having access to accurate and updated CPI is not always the case in primary healthcare in Norway. The current digital solutions limit an effective utilization of health sector resources, and digital interaction is not fully prevalent. In Norway, most nursing homes and home care services do not yet have access to a summary care record (SCR), although the implementation process and the use of SCR have now started in some municipalities. The shared medications list (SML) is at present being piloted in one municipality in Norway, and a full national rollout is planned in 2023–2025. In this situation, our chapter provides important new insights into how the present challenges are experienced by nurses and MDs in nursing homes and home care services in six municipalities in Norway. We found that accessing CPI was

widely experienced as challenging among the participants. It was linked to frustration, uncertainty, unnecessary time-consumption and complexity, and was perceived as a threat to patient safety and to quality of care. Based on our findings, we contend that future eHealth initiatives aimed at improving quality and safety in healthcare must address these challenges in accessing CPI directly, especially in the critical phase of patient transition between levels of care. The knowledge presented in this chapter will serve as a baseline for the longitudinal main study on the implementation of SCR and SML in Norway. Our findings will enable monitoring the effects, limitations and possibilities of ongoing and planned national eHealth initiatives. The next steps following this pre-study of SCR and SML implementation will be to investigate the experiences of nurses and MDs *during* and *after* the implementation of the SCR and SML in the same six municipalities.

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