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CONFERENCE ABSTRACT

On track on the care pathway: Care coordination, information, and communication needs among Norwegian cancer patients.

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Background: Cancer patients may have long-lasting and complex care pathways. These typically involve a wide range of care providers who must coordinate their actions, so that treatment and follow up is experienced as seamless and integrated. Good communication with patients and providing them with the 'right amount' of information is crucial to ensure that patients feel engaged and empowered along the pathway.

The study: This paper reports from an ongoing research study ('Pathway') on the management of patient pathways in Norway, exemplified with cancer pathways. The project aims to give detailed descriptions of the unfolding of pathways, with an emphasis on patients' experiences and needs. These form the basis for the development of a theoretical pathway model and a visual multi-layered modeling language. This paper addresses the research question: What are cancer patients' information- and communication needs from care providers during their patient pathway?

Methods: We conducted three workshops with cancer patients and next of kin (n=35), supplemented with individual interviews (n=6) in June 2022. Participants had various cancer diagnoses. Data collection was conducted on a digital platform. Study participants were asked i.e., about communication with the services, their information needs, and how they keep overview of their appointments and contacts with the services, as well as how they would like to stay informed and engaged.

Results: A 'regular' cancer pathway was described to involve a wide range of providers, like regional and local public hospitals, private medical imaging centers, general practitioners, municipal care providers (i.e., physiotherapy, home care services), as well as the labour and welfare office. For the most complex cancers, and for multimorbid patients, the pathways could be even more complex. Study participants unanimously agreed that knowing as much as possible about the disease, its treatment, and follow up is critical to feel in control. Even though the participants mostly were satisfied with the cancer pathway, they all had experienced breakdowns in care coordination, missing and contradictory information, and providers lacking overview of their situation. Most participants had experience with taking on the task of collecting and aligning information and taking responsibility for coordinating their own follow up and care. Specifically, this was true when patients were discharged from hospital and from the standardized cancer patient pathway (CPP). The participants had invented various creative ways of keeping track of all the information they were given, and they frequently acted as messengers between providers.

Learning and next steps: The study underscores the challenge of ensuring integrated care for patients. Cancer is among the diseases that has evidence-based treatment protocols, and in

Norway diagnostics and treatment is organized in standardized care pathways. Nevertheless, also these patients struggled with keeping track of their 'simple' pathways. Such findings remind us about the need to keep on working for improving integration across disease specific pathways, and that good communication and access to information for all the involved actors are means for achieving this. The next step in our study is to map patients' touchpoints with the services over time, in detail.