Digital Health and Informatics Innovations for Sustainable Health Care Systems
J. Mantas et al. (Eds.)

doi:10.3233/SHTI240409

How Do Cancer Patients Keep Track of Their Patient Journeys?

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Abstract. Cancer patients undergo long periods of treatment and follow-up, and it is challenging to keep track of appointments, treatment plans etc. This paper report from a study involving 41 patients and next-of-kin focusing on their strategies for managing the patient journey. Most patients take an active role, employing a variety of tools. The national patient portal is seen as useful for accessing information and keeping an overview but does not alone meet their information needs.

Keywords. Cancer patients, overview of patient journey, patient strategies

1. Introduction

Cancer journeys require complex care coordination, appointment scheduling, and treatment and follow up may span multiple years. This necessitates sustained patient engagement, as well as involvement of next-of-kin. Despite an increase in studies on patient journey mapping [1], giving insight into how patient journeys are organized within and across healthcare organizations, there is limited information on how *patients* keep track of their own journeys. This topic was explored in a study conducted with cancer patients and their next-of-kin in Norway.

2. Methods

A total of 41 participants (28 patients and 13 next-of-kin) were recruited for the study. Out of these, 35 participated in workshops, while six were interviewed individually. Written consent was obtained from all participants. Data were collected in May-June 2022. The workshops alternated between plenary sessions and focus sessions with 3-4 participants, led by a facilitator. We explored critical incidents in cancer journeys (to be published elsewhere) and questions regarding patient involvement and management of care. This paper presents the results from the question "How do you keep an overview of your patient journey?". Participants were given 3 minutes for reflection, followed by 5 minutes to share their insights. The feedback was compiled in a spreadsheet for further analysis.

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3. Results

Study participants highlighted the necessity of patients' effort and self-management, stating: "*If the patient doesn't coordinate themselves, then no one else will. It is quite a paradox*". They kept an overview using various means (Table 1), including the national patient portal (Helsenorge.no), digital and paper-based calendars, notes, logbooks, and diaries, paper documents in binders, electronic spreadsheets, and online searches on the homepages of e.g., hospital departments and patient organizations. These were used for practical planning and preparations (e.g., keeping an overview of appointments), accessing and processing clinical information (e.g., preparing for consultations and getting knowledge about treatment options), and to document and systematize information (e.g., having an overview of the patient journey to ensure the information flow between healthcare actors). Patients gather and store information for several reasons: to recall future and past events, be mentally prepared for what is ahead, formulate questions and gain a better understanding during consultations, process their own thoughts, and receive better medical treatment. Many found the national patient portal useful for accessing information and keeping an overview, however, it did not meet all their information needs, and they therefore supplemented it with other means.

Table 1. Methods adopted by the participants to keep an overview of the patient journey.

Means to keep an overview	Count	More details
Patient portal	19	Appointments, patient record, test results
Notes, logbook, diary	17	Write down information, questions, thoughts
Calendar	8	Keep track of appointments
Paper documents in binders	6	Keep track of the full patient journey
Hospital, patient organization homepages	4	Get information on the disease and treatment
Spreadsheet	3	To keep track of the full patient journey

4. Discussion and Conclusions

Keeping track of the patient journey is demanding, adding pressure to already vulnerable patients. Health information systems (HIS) are often designed from a provider-specific perspective [2], causing fragmented care pathways [3]. The results show that while health portals can help patients manage their care journeys, they often lack a comprehensive overview. Additionally, a significant portion of patients' involvement results from inadequate communication and information flows between healthcare providers, highlighting the need for HIS presenting key patient information clearly.

Acknowledgement: This work was supported by the Research Council of Norway under the Pathway project (grant no. 316342).

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