

272

### ASSESSING PATIENTS' CARE TRAJECTORIES AND THEIR EXPERIENCES, NEEDS AND ISSUES

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**Introduction** The aim of this study was to assess patients' experiences, needs and issues regarding treatment decision making in oncology.

**Methods** A longitudinal study was conducted in which patients from four hospitals in the Netherlands were shadowed through their journey in the care pathway until a treatment decision had been reached. We visualized patient journeys using metrolines. Consultations between patients and healthcare professionals were observed and audiotaped. We further conducted informal conversations after consultations and a semi-structured interview once a decision had been reached. Transcripts of audiotaped data were analyzed both deductively and inductively using thematic analysis.

**Preliminary Results** Five patients per hospital were included in four pathways (hematology, neuro-oncology, gynecology, upper gastro-intestinal): 79 observed consultations, 40 informal conversations and 20 interviews and questionnaires. Although patients' experiences with the decision process varied, it was fragmented over time in all care pathways with treatment decisions being made in more than one consultation. Three main themes emerged. First, factors influencing the decision process (e.g. time). Secondly, the different roles of stakeholders in the decision-making process (patient, professional, nurse specialist, informal caregiver). The perceived role of the professionals varied, from a purely 'disease-centred' role of the specialist to a 'patient-centred' role of the nurse specialist. Finally, the importance of a patient-centered approach (e.g. shared decision-making).

**Preliminary Discussion** Our triangulated data collection uncovered important themes for further research. In a next study we will assess the viewpoints from different healthcare professionals.

**Preliminary Conclusion(s)** Knowledge and awareness of the fragmented decision-making process over time is crucial for advancing research on treatment decision-making in oncology. Furthermore, it is essential to acknowledge and address; factors that influence the decision-making process, the roles of the different stakeholders and adopt a patient-centered approach.

273

### STRATEGIES FOR TREATMENT DECISION-MAKING AMONG ESOPHAGOGASTRIC CANCER PATIENTS WITH LIMITED HEALTH LITERACY: FINDINGS FROM A QUALITATIVE STUDY

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**Introduction** Patients with limited health literacy and/or numeracy (HL) can face challenges in utilizing key numerical risk and benefit information throughout their decision-making process. Previous research has focused on understanding this numerical information but has often not examined different aspects involved in decision-making strategies. We investigated the strategies used by patients with limited HL in treatment decision-making for esophagogastric cancer, while taking into account their use of numerical outcome-information.

**Methods** Patients with limited HL were recruited in six Dutch hospitals. We interviewed patients (n=10 thus far) during their decision-making process. Consultations about treatment options (n=10 thus far) were audio-recorded and used to enhance interpretation of interview data. Audio-recordings were transcribed verbatim and analyzed thematically.

**Results** The analyses revealed three preliminary categories. (1) *Use of medical information*: Patients tended to avoid (additional) medical information, opting for less rather than more information and focusing on positive information. During consultations, patients seemed overwhelmed by information and confused by ambiguous terminology used by clinicians; (2) *Choosing treatment options*: Patients expressed a lack of perceived choice, emphasizing that the selected treatment was their only option. In the interviews, they remembered some numerical outcome-information about chosen treatment, but less about alternatives discussed; (3) *Social/cultural influences*: Most patients reported limited social support. Cultural and religious beliefs seemed to influence decision-making, as some patients emphasized their trust in advice from their relatives or in God.

**Discussion** Our initial findings suggest that patients with limited HL were overwhelmed and averse to excessive and negative information, in a larger extent than found in previous research for patients without limited HL. This may result more frequently in suboptimal decision-making strategies for patients with limited HL.

**Conclusion** Preliminary findings highlight the need to develop novel communication strategies and help patients with limited HL navigating the complex landscape of available treatment modalities.