Methods

An interactive, qualitative design is used. Experiences from patients/next-of-kin representatives in NSK working groups are explored using interviews. A deductive content analysis is used to analyze data where the findings are related to Carman’s model; describing patient involvement at different levels; organizational design and governance and policy making with a continuum of engagement (consultation, involvement and, partnership and shared leadership). Persons with own experience are included in the research group. We collaborate with patient organizations and different groups within the NSK.

Results

We present preliminary results since the study is ongoing. Patient and next-of-kin representatives experience that they have been fully accepted as participants in the national groups by the healthcare professionals. They express that their suggestions and lived experience have been appreciated and incorporated during the process of producing clinical pathways. Also, they express that they have been properly introduced to their assignment. Being more than one representative in a group is experienced as favorable. From the narratives, it is clear that different perspectives are presented depending on whether the representative come from a patient organization or not.

Discussion

The value of patient participation is still under debate. Some professionals doubt that the patient perspective will bring something new to the table and consider themselves as advocating the patient perspective.

We address the experience of participating in national groups connected to the NSK and the prerequisites for a successful patient participation.

REFERENCES

Method This study constitutes the qualitative part of a feasibility study which evaluates a digital information tool. A qualitative design was employed where individual interviews were undertaken. The semi-structured question guide focused on the participants experience of the active health information process prior commencing a course of radiation therapy. A deductive approach was used taking a stance in the three main domains of health literacy: functional, interactive, and critical health literacy.

The digital information tool

The tool consists of two separate but coherent applications: 1) virtual reality which offers a simulated visit to the high-tech environment at the radiation treatment clinic, 2) information application with a focus on cancer and radiation therapy.

Results To promote and maintain health applying apprehended health information requires a person-centred approach where mutual beneficial proficiency incorporate the individuals experience, characteristics, and cognitive abilities. Adequate patient information may not only promote improved HL and reduce distress but also foster a valuable relation between the individual and the healthcare professional. A relation valuable not only viewed from a person-centred approach but one which favour positive outcomes such as patient satisfaction, increased self-efficacy, and sense of preparedness before commencing radiation therapy.

Message A better understanding of women’s preferences to access, understand, appraise, and apply health information will facilitate improved development of health information resources to meet the specific needs of the individual person. Furthermore, an increased understanding of the use of digital technology can provide important guidance in the co-design of digital health interventions.

REFERENCES