Interview guide – palliation in focus

Purpose: The project seeks to increase the quality of the basic palliative care provided in a surgical gastroenterology department. The purpose of the project is to investigate the patients' experience of the needs assessment and the treatment of palliative symptoms of a physical, psychological, social, and existential nature, in their treatment course for upper GI cancer. The project also seeks to investigate the patients' experience of involvement in the form of whether they have been included in decisions about the treatment of palliative symptoms.

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| Introduction: The interview deals with being seriously ill with cancer and the symptoms (e.g. pain, nausea, hopelessness, etc.) that are associated with this. I specifically want to talk to you about how you experience our interest in the symptoms and how they are taken care of. I know that these are sensitive topics that we must talk about, and it is of course entirely up to you how much or how little you want to share. There are no right or wrong answers - it is important that you tell it as you experience it.  Your participation is completely voluntary, and you can withdraw your consent to participate at any time.  Your participation is anonymous. This means that your name and other personally identifiable information will be anonymized.  The interview is recorded on tape so that important points are not missed.  Subsequently, it will be transcribed.  The interview takes a maximum of  1 hour and most likely around 40 minutes. |  |
| Theme | Interview questions |
| Diagnosis + background for current and possible previous admissions:  - Physiological complication as primary cause (e.g. sepsis or stenosis)?  - Palliative symptoms as primary cause (e.g. pain, vomiting, untenable home situation) | I would like to start by asking a little in general about your illness and your hospitalization here.   * Would you like to tell me a little about the course of your illness leading up to this admission? * What was the reason why you were admitted to this ward? * Have you been admitted to this ward before? * What was the reason for the previous admissions? * (If there is no answer to it in the open questions):   + - Which diagnosis?     - When diagnosed?     - Age? |
| The detection and treatment of physical symptoms associated with upper GI cancer | I would like to talk to you about the physical symptoms that can be associated with having cancer.  Would you like to tell me a little about the physical symptoms you experience and how they affect you during the day?   * The mentioned symptoms:   + How long have you had the symptom?   + Was the symptom contributing to the current or previous admissions?   + Are you receiving any medical treatment for the symptom?   + Have you talked to the doctor or nurses about all your symptoms?   + Have you been involved in the decision-making process regarding how the symptom should be treated?   + Did the treatment work? And if it didn't work, what happened?   + Do you have any physical symptoms that you have not spoken to a healthcare professional about? / have no treatment plan for? |
| The detection and treatment of psychological, social, and existential symptoms associated with upper GI cancer | Now I would like to jump away from the physical symptoms to ask a little more about the psychological, social, and existential symptoms that often accompany having a cancer.   * Would you like to tell me a little more about how the disease has affected you psychologically? How have you coped with it in everyday life? * Has the disease caused any social problems? * Has the illness caused thoughts/problems of an existential nature? (Here I mean such things as hope/hopelessness, the meaning of life, the relationship with death and religion). * The mentioned symptoms:   + Is the symptom something you have spoken to a healthcare professional about?   If yes:   * + Can you describe how that conversation took place?   + Has a treatment plan been put in place to treat the symptom? / has good advice been given on how to deal with the symptom?   + Have you been involved in the decision-making process regarding how the symptom should be treated? * How is your everyday life affected? (preferably concrete examples) * Was the symptom contributing to the current or previous admissions? * Do you expect the healthcare staff to inquire about your mental/emotional state during an admission? * Do you expect the healthcare staff to talk to you about the end of life? * Have you and your relatives received information about opportunities for you and your family? For example, carer's leave, offers from cancer counseling etc. * Did you and your relatives generally feel heard and included during the hospitalization? |
| Structured needs assessments | I would like to know if you have been presented with a needs assessment form in your treatment course ("Support for life with cancer" and EORTC form are shown for recognizability)?  - If yes:  o How did it happen?  o Did it result in any concrete treatment plans or advice?  o How was the experience?  - If no  o Do you think you would get something out of filling out such a form? |
| The perceived coherence of the palliative treatment in the course of treatment | Finally, I am interested in hearing about your overall impression of the treatment of the various symptoms we have talked about in the interview.   * Is there anything you wish we had done differently?   + - Greater or lesser involvement in decisions?     - Communication between you and the healthcare staff. Have you felt heard?     - Anything else you would like to add? |
| Wrap-up: Thank you so much for taking the time to talk to me. |  |