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Oncological palliative care   MENTOR Study

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Appendix 2: Focus Group Results and Delphi Survey Statements

DELPHI SURVEY (E-MAIL)

First of all, thank you very much for your willingness to participate in this important project as a focus group participant in autumn 2015. After the data collection of three focus groups and data analysis with qualitative methodology, we have now drawn conclusions from the focus groups. We are grateful for your cooperation. We want to check whether we are on the right track.

Attached is the abstract of the summary. If you are interested in a more in-depth document, please contact Franzisca Domeisen (franzisca.domeisenbenedetti@kssg.ch).

In a next step, we ask you to assess the main results of the focus groups in the form of a Delphi survey. For this purpose, we have prepared a Survey Monkey survey. In a few weeks, the shorter second Delphi survey will come with consolidated results. In March 2016 we will present the results.

Thank you very much for participating in this important effort to integrate palliative interventions into our routine care for the benefit of our patients.

Sincerely,

Florian and team

Summary of the MENTOR study

Early integrated, specialized palliative care can improve patient outcomes (quality of life, symptoms, etc. for patients and caregivers). Key interventions of palliative care (KIPCC) can be provided by non-specialists (oncologists, family doctors, nurses, home health, etc.) and specialists in palliative care. However, it remains unclear how the palliative needs of patients can be monitored and palliative interventions integrated in routine clinical care.

In summer/autumn 2015, three focus groups (90-120 minutes) were held at the KSSG, in which 17 doctors, 9 nurses and 1 psychologist from oncology, palliative care and emergency medicine from the outpatient and inpatient sector participated. The discussion guide addressed three main categories: characteristics of patients and HCPs, components of a clinical practice tool and embedding in the clinical care process. The Focus groups were digitally recorded and transcribed verbatim.

The data analysis was carried out with the inductive content analysis.
1) The full interview transcripts were wrapped in codes and subcategories formed by open coding. These were then assigned to the main categories.
2) Codes from the second FG were compared with the first FG. Each code was discussed in the research team and assigned to a main category when consensus was reached.
3) The newly formed subcategories from the transcripts of the second and third FG were examined and differences in terms of content and further subcategories were formed.
4) The open codes were continuously assigned to the subcategories and then to the main categories.
5) A reorganization, the analysis of subcategories and the synthesis of data including visualization were discussed by two researchers until a consensus was reached.

The results of the focus groups are shown in **4 graphics including legends** on the following pages. **We kindly ask you to take** a quick look at these results. If you are interested, the comprehensive study report (12 pages) can also be viewed.

The next step is to check how well the main findings are supported by you as a focus group participant.

We invite you to assess the following **statements** regarding **consent** with the given scale, we also ask for use of the comment **fields.**
(8-category Likert scale: fully agree, agree, tend to agree, narrowly agree, narrowly disagree, tend not to agree, disagree, disagree at all)

Figure 1
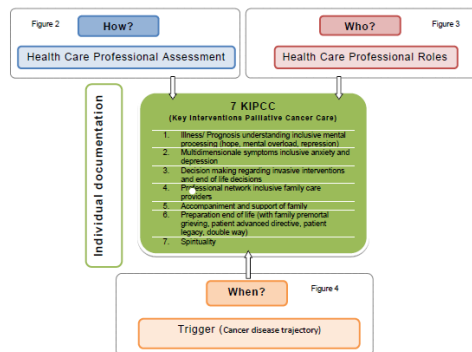
All Health Care Professionals (HCPs) participating in the focus groups agreed that all seven KIPCC (Key Interventions Palliative Cancer Care) are important in the routine of oncology care, but KIPCCs are still insufficiently documented.

Delphi Statements
- All seven KIPCC are important in patients with advanced cancer.
- All seven KIPCC are important in clinical practice.
- They are important **for all HCPs** in clinical practice.
- The recording of the KIPCC is individually adapted to the needs of the individual patients.
- The registration of the KIPCC is voluntary.
- The recording of the KIPCC is embedded in the routine processes of the clinic.
- The KIPCC are documented uniformly and centrally.

- In routine clinical care, HCPs use an instrument to record KIPCC.
- Existing tools are used.
  - Nursing history
  - Symptom assessment
  - Medical history
  - Advance directive
  - PMS Medfolio
- The tool is easy to find.
- All professions must have access.
- The tool is easy to use.

- Patients and relatives need in-depth information (e.g. in the form of a brochure) about KIPCC.
- Patients and relatives need a document to record their individual needs.

A tool variant is...
- Checklist for patients
- Booklet for patients (e.g. like ESMO booklet)

☐ Checklist for Health Care Professionals
☐ Conversation Guide for Health Care Professionals
☐ Document on preparation for patients at home

Figure 2
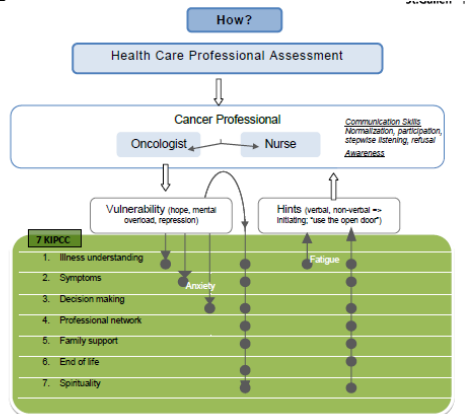
Recording and documentation of the KIPCC requires competencies, including awareness of the vulnerability of the patients and relatives cared for and the ability to respond to indications or hints from patients.
To recognize the vulnerability of patients in the routine care of HCPs, it is important that they understand their disease and that psychological symptoms are monitored. The understanding of the disease includes the principle of hope, fears of patients and the assessment of the possibilities and ability to make decisions. A possible, psychic overload of patients must be considered.

Delphi Statements
☐ HCPs have basic competencies on a verbal or non-verbal level so that they can react accordingly in the current situation to indications or statements of the patients (hints) in conversation.
☐ They can recognize emotional reactions, reporting of fears, recognition of complex situations and the level of suffering.
☐ They can respond to emotional reactions, reporting fears, recognizing complex situations, and the level of suffering accordingly.

Figure 3

Examples of KIPCC allocation under several professionals.
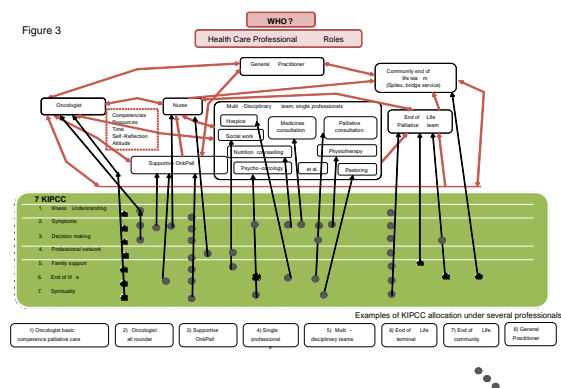
The needs assessment can take place by individual HCPs, by several HCPs together, or successively or multidisciplinary. The attitude of HCPs to the collection and monitoring of palliative needs, HCP's influences their actions and interactions. This can lead to different interaction patterns.

Delphi Statements

☐ All health care professionals (individuals or teams) record palliative needs of patients.

☐ Oncologists with basic competencies in palliative care
☐ Oncologists who are all-rounders
☐ HCPs of Supportive Oncology Palliative Care
☐ Individual professionals
☐ A multidisciplinary team
☐ Team for end-of-life care (terminal phase), inpatient
☐ Team for end-of-life care (terminal phase) at home

Figure 4
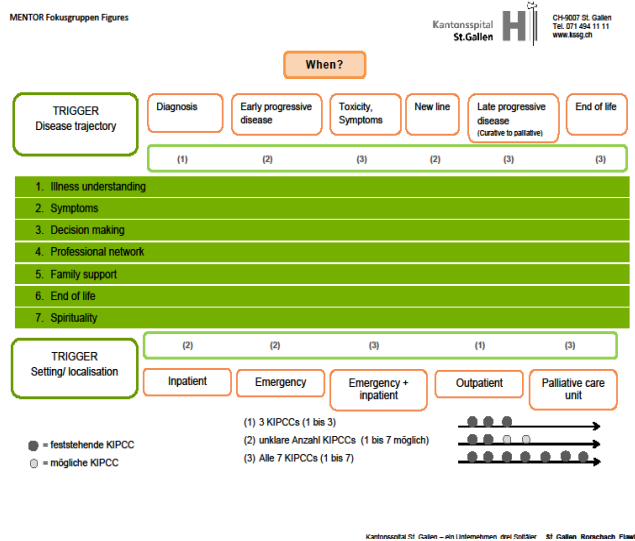
The setting/treatment location (such as Emergency Department, outpatient and inpatient treatment, palliative care unit), as well as triggers (such as progressive disease, complications) can influence the recording and monitoring of needs.
Typical triggers in the course of advanced cancer are diagnosis, early progression, late progression of the disease (curative to palliative), symptom toxicity, a new line of chemotherapy, as well as the end of life

Delphi Statements

A trigger for needs assessment is the course of the disease.

☐ In patients with advanced cancer, a needs assessment is tailored to the setting/location of treatment.

☐ A routine needs survey is more complex than the definition of triggers.

☐ Needs assessment (KIPCCs 1 to 3.3) is carried out when diagnosed with advanced cancer.

☐ Needs assessment (KIPCC 1 to 7) is successful in early progression of advanced cancer.

☐ Needs assessment (all 7 KIPCCs) occurs when toxicity, symptoms occur due to cancer treatment.

☐ The needs assessment (KIPCC 1 to 7) takes place with a new line of cancer treatment.

☐ Needs assessment (all 7 KIPCCs) occurs in late progression of advanced cancer.

☐ The needs assessment (all 7 KIPCCs) takes place at the end of life.

A trigger for the needs recording is the setting/treatment location.

☐ Needs assessment (KIPCC 1 to 7) occurs in patients with advanced cancer if they are regularly hospitalized.

☐ Needs assessment (KIPCC 1 to 7) occurs in patients with advanced cancer when treated in the emergency department.

☐ Needs assessment (all 7 KIPCCs) occurs in patients with advanced cancer when they are treated in an emergency and subsequently hospitalized.

☐ Needs assessment (KIPCCs 1 to 3.3) occurs in patients with advanced cancer when they are treated on an outpatient basis.

☐ Needs assessment (all 7 KIPCCs) occurs in patients with advanced cancer when they are hospitalized in the palliative care unit.

☐ Weighing up treatment decisions in the treatment team is a trigger.

☐ Dissent regarding therapy decision in the treatment team is a trigger.

The prioritization of the needs should be carried out by the affected patients.

Delphi Statements
Characteristics (behaviors) of patients influence the recording of needs.

o Patients can take an active or passive role
o I wait until the patient addresses needs on his or her part
o I recognize when the patient makes a hint /hint regarding needs

Characteristics (behaviors) of health care professionals influence the recording of needs.
o I search for and record the needs of patients with advanced cancer in interaction (conversation, ward round, etc.).

Communication:
o Health Care Professionals should take an active role (inquire, inquire)
o Health Care Professionals should take on a passive role (Pat. takes the first step)
o Health Care Professionals recognize when a patient is vulnerable (hope, mental overload, repression)
  ▪ The communication is adapted accordingly.

Declarations of changes to Delphi Round 2

General
1.1 and all of the following: KIPCC (Key Interventions Palliative Cancer Care) has been replaced by *core palliative interventions.*
1.3 and 1.4 Adaptation/clarification of the wording:*"it is desirable that..."*
1.3 Supplement: simple and uniform documentation
1.4 Adaptation: routine clinical processes such as follow-up sheets and medfolio are used *for documentation.*

Section on WHO does the screening

2.1 Supplement: *in principle*

2.2 Summary of two statements and adaptation/clarification of the wording: "it *is desirable that* oncologists and oncology nurses discuss the recording of and implementation of palliative core interventions in routine everyday life *and* document them simply and *without duplication.*

2.3 Adaptation of the formulation: Oncologists and/or oncology nurses can carry out individual or all palliative core interventions themselves *according to their own competencies and preferences* or delegate them to appropriate specialists.

2.4 Adaptation of the formulation: *In principle,* all 7 palliative core interventions are important for all health care professionals (such as doctors, nurses, psychologists, chaplains, social workers, etc.) in clinical practice, with *different weightings according to profession and current patient situation.*