Cancer patients’ experiences with an early palliative care conversation: A qualitative study of an intervention based on the SENS-structure

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## Faculty Disclosure

<table>
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<tr>
<th>Company Name</th>
<th>Honoraria/Expenses</th>
<th>Consulting/Advisory Board</th>
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X No, nothing to disclose

Yes, please specify:
Background

Palliative Care should be incorporated early on in the disease trajectory of patients with advanced cancer


But...

• Does a structured approach fulfill their needs?
• How do cancer patients experience and perceive a structured ePC intervention?
• What impact has the ePC intervention on their life?
SENS-Trial (NCT01983956)

- Multicenter, two-arm, randomized-controlled trial
- Longitudinal study (6 months): distress level
- **Eligibility criteria:** Cancer not amendable to curative treatment \( N=150 \)
  - NSCLC
  - Colorectal cancer
  - Prostate cancer
  - Breast cancer
  - Urothelial cancer
  - Pancreatic cancer

**Nested qualitative study**
SENS-structure – PC Intervention

- Structured, pragmatic, problem-oriented conversation
  - Symptoms
  - End-of-life decisions & expectations
  - Network
  - Support of the carer
- Incl. suffering / resources
- Prompt sheet
- Intervention performed by PC physician & nurse

(Eychmüller, 2012, Fliedner et al 2018, to be submitted)
Nested qualitative study

• Aim
  • Experience and perception and the impact of the ePC intervention based on the SENS-structure

• Methods
  • Semi-structured interviews (N=20)
  • Qualitative content analysis (Mayring 2014)
### Characteristics of participants (N=20)

<table>
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<tr>
<th>Characteristic</th>
<th>Value</th>
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<tbody>
<tr>
<td><strong>Age</strong></td>
<td>years - mean 66</td>
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<tr>
<td><strong>Gender</strong></td>
<td>female / male 7 / 13</td>
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<tr>
<td><strong>Marital status</strong></td>
<td>married 15, widowed 3, single 1, divorced 1</td>
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<td><strong>Cancer</strong></td>
<td>lung 9, prostate 4, pancreatic 3, colorectal 3, breast 1, urothelial 0</td>
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<td><strong>Duration interview</strong></td>
<td>in minutes: median (min; max) 41 (19; 70)</td>
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Results

Experience with / perception of SENS intervention

Emotional experience

Cognitive experience

Impact from SENS

Change of understanding of PC

Actions triggered by SENS

PERSONAL BACKGROUND

TIMING OF INTERVENTION
“Oh yes, we have done that (advance directive prior to SENS), we really did that. We haven’t finished it at that time but we were discussing it … and we are registered … in a home for elderly where one can stay until the end...” (P9, 226)

“I informed myself about the whole thing, also from the internet...“ (P20, 189)

“… and to approach someone – I think that is individual – it is difficult to say either right at diagnosis or wait – I have the feeling that this differs really between the patients.” (P 20, 139)

“… for me the conversation would not have been necessary – or at least not at that timepoint. And especially ... if a patient is instable and then such a conversation is commenced I can imagine that it pulls that person down” (P6, 95)
## Results: Experience / Perception

### Experience with / perception of SENS intervention

#### Emotional experience
- Conversation based on trust & attentiveness
- No necessity to be too pessimistic
- Normal but emotional conversation
- Challenge talking honestly about death & dying and bemoaning difficult topics

#### Cognitive experience
- SENS makes sense
- SENS provides safety, support and affirmation
- Incorporation of PC into standard care
- Objective conversation

### Personal

#### Emotional experience

> “we talked intensively about my final phase of life and that was deeply emotional for me” (P17, 238)

#### Cognitive experience

> “… on the other hand I received confirmation that basically I already had done everything about these future issues” (P17, 136)

#### Personal

> “… so what shocked me a bit was how doctor X explained to me how it could develop, that it could go for some time well and then ‘Boom!’ and that is the end. To be honest that somehow shocked me” (P15, 101)
Results: Impact from SENS

“…yes, it gave an impulse, yes. But also – exactly, I wasn’t able to do it, the resume of my life and these things – these I still need to do… it is still on my mind” (P13, 161).

“… but it then it appeared to me that the next step is the dying” (P17, 94)

“… we went so far – an example: so far I did all the things in my family – the bank, ah bank transfers – all that I did for the family. Step by step I transferred it to my wife. These are small things but they also belong to that” (P17, 158).

Change of understanding of PC
- PC also for family
- Food for thoughts
- Encouraging impulse to reflect on future
- Knowing where to turn to
- Associations with end-of-life

Actions triggered by SENS
- Involving social network
- Actively planning future health care issues
- Self-determination of practical matters
Results

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PERSONAL BACKGROUND

TIMING OF INTERVENTION

MASCC 2018
Conclusions

• Intervention facilitated reflection and reduced stigmata
• Patients were well-informed, keen on this participatory approach
• Topic of “End of life” not addressed before
• Timing for the intervention: early <-> late?
• Limitation: only one conversation
• SENS-structure
  • is pragmatic and helpful for patients to prioritize care
  • should be incorporated into standard oncological care
• ePC intervention based on SENS
  • touched emotionally and cognitively by topics discussed
  • passive as well as active impact
Thank you very much for your attention!
For further discussion: monica.fliedner@insel.ch