

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

MC Fliedner^{1,3}, S Zambrano¹, C Lohrmann²,

JMGA Schols³, R Halfens³, S Eychmüller¹

¹University Center for Palliative Care, University Hospital Bern (CH)

²Department of Nursing Science, Medical University of Graz (A)

³Department of Health Services Research, University Maastricht (NL)



2018
28-30 JUNE
VIENNA

MASCC/ISOO
ANNUAL MEETING
SUPPORTIVE CARE IN CANCER



Faculty Disclosure

X	No, nothing to disclose
	Yes, please specify:

<i>Company Name</i>	<i>Honoraria/ Expenses</i>	<i>Consulting/ Advisory Board</i>	<i>Funded Research</i>	<i>Royalties/ Patent</i>	<i>Stock Options</i>	<i>Ownership/ Equity Position</i>	<i>Employee</i>	<i>Other (please specify)</i>

Background

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

Dans, M., et al., J Natl Compr Canc Netw, 2017. 15(8): p. 989-997;
Ferrell, B.R., et al., JCO, 2017. 35(1): p. 96-112.

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)



SWISS NATIONAL SCIENCE FOUNDATION

- Structured Palliative Care (PC) intervention for patients with advanced cancer (“SENS”) (2013 – 2017)
- Multicenter, two-arm, randomized-controlled trial
- Longitudinal study (6 months): distress level
- Eligibility criteria: Cancer not amendable to curative treatment (N=150)
 - NSCLC
 - Breast cancer
 - Colorectal cancer
 - Urothelial cancer
 - Prostate cancer
 - Pancreatic cancer

• Nested qualitative study

SENS-structure – PC Intervention

- Structured, pragmatic, problem-oriented conversation
- **S**ymptoms
- **E**nd-of-life decisions & expectations
- **N**etwork
- **S**upport of the carer
- Incl. suffering / resources
- Prompt sheet
- Intervention performed by PC physician & nurse



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

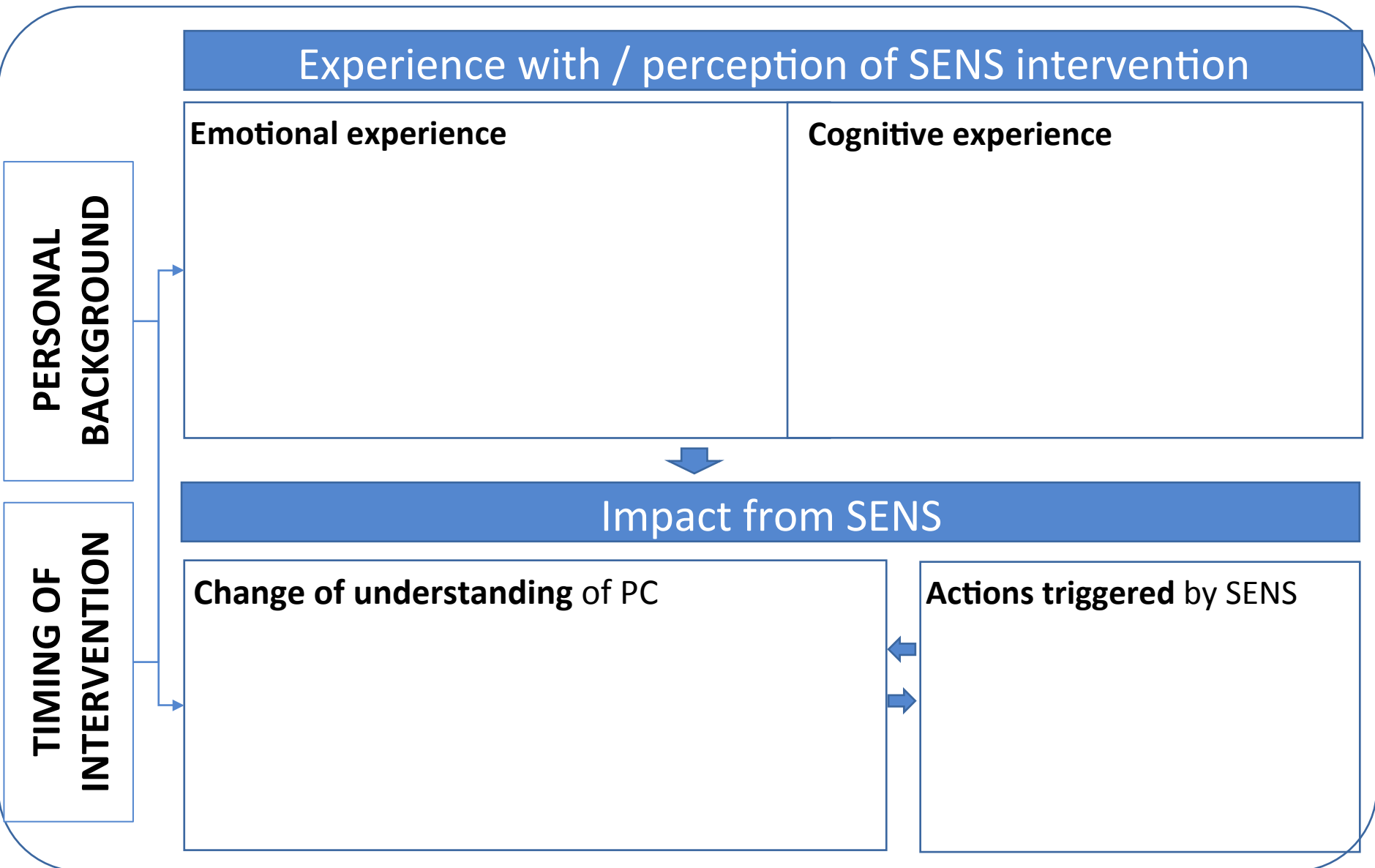
Nested qualitative study

- 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)

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

Results



Results: Background / Timing

PERSONAL BACKGROUND

“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)

TIMING OF INTERVENTION

“... 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

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



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



“... 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).



Impact from SENS

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

from



Actions triggered by SENS

- Involving social network
- Actively planning future health care issues
- Self-determination of practical matters

Results

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



Impact from SENS

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

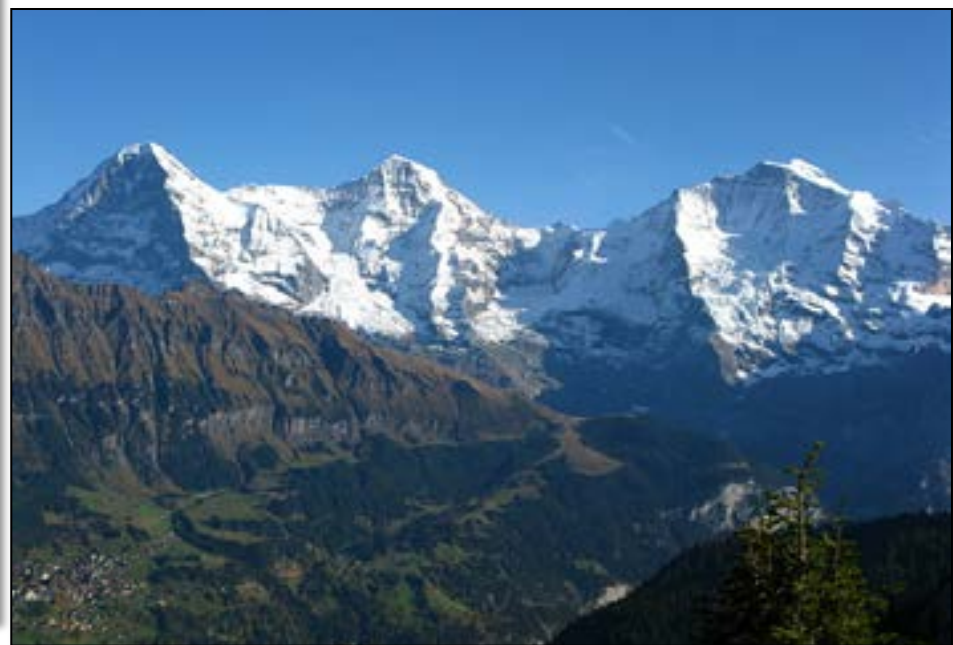
- Involving social network
- Actively planning future health care issues
- Self-determination of practical matters

PERSONAL
BACKGROUND

TIMING OF
INTERVENTION

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