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Are specialist-provided end-of-life scenarios key to initiation of advance care planning in primary care? A mixed-methods study

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Abstract

Objectives. Specialist-provided end-of-life scenarios (SP-EOLS) may improve advance care planning (ACP) implementation in primary care by helping overcome barriers such as uncertain prognosis and poor interprofessional collaboration. We aimed to explore the current use and potential impact of SP-EOLS on ACP in Dutch primary care.

Methods. We performed a mixed-methods study. From patients discussed in a hospital-based academic palliative care multidisciplinary team meeting between 2016 and 2019 and died, we collected primary care electronic medical records data on SP-EOLS, actual EOLS, and ACP initiation and applied descriptive and comparative analyses. Subsequently, we interviewed general practitioners (GPs) and thematically analyzed the transcripts.

Results. In 69.7% of 66 reviewed patient files, SP-EOLS were found. In patients whose GP had received SP-EOLS, ACP conversations were more often reported (92.0 vs. 61.0%, $p = 0.006$). From 11 GP interviews, we identified 4 themes: (1) SP-EOLS guide GPs, patients, and relatives when dealing with an uncertain future perspective; (2) SP-EOLS provide continuity of care between primary and secondary/tertiary care; (3) SP-EOLS should be tailored to the individual patient; and (4) SP-EOLS need to be personalized and uniformly transferred to GPs.

Significance of results. SP-EOLS may facilitate ACP conversations by GPs. They have the potential to help overcome existing barriers to ACP implementation by providing guidance and supporting interprofessional collaboration. Future research should focus on improving SP-EOLS and tailor them to the needs of all end users, focusing on improving their effect on ACP conversations.

Introduction

Patients with incurable diseases benefit from advance care planning (ACP) (Brinkman-Stoppelenburg et al. 2014; Houben et al. 2014; Rietjens et al. 2017). ACP increases the quality of end-of-life care and aligns personal preferences for care and delivered care (Brinkman-Stoppelenburg et al. 2014; Houben et al. 2014). In addition, end-of-life discussions are associated with more appropriate care and lower healthcare costs (Mack et al. 2012; Starr et al. 2019; Wright et al. 2008).

General practitioners (GPs) play a pivotal role in providing and monitoring end-of-life care in primary care. In the Netherlands, for example, 72% of deaths occur in a primary care setting (Council of Europe 2003; Evans et al. 2014; Forrest and Barclay 2007; Oosterveld et al. 2020). GPs' long-term relationships with patients, their knowledge of the social and psychological context, and their easy accessibility facilitate this key role (Kearley et al. 2001; Wichmann et al. 2018).

Despite the advantages of ACP and the important role of GPs, ACP conversations in general practice are still limited (Ermers et al. 2021, 2019; van der Plas et al. 2017), and if applied, ACP is initiated late in the disease trajectory (Wichmann et al. 2018). Several GP barriers to initiating ACP conversations have been identified, such as insufficient knowledge of the disease course, including its unpredictability, determining the right timing, and lack of structural collaboration between the GP and specialist (Blackwood et al. 2019; De Vleminck et al. 2013, 2014; Tilburgs et al. 2018). GPs have suggested that ACP implementation may improve by combining specialist and GP knowledge on their patient's life trajectory (Wichmann et al. 2018).

Discussing the expected course of disease with the patient, including hypothetical "disease- and end-of-life scenarios" (EOLS), is recommended in several ACP guidelines

(Conroy et al. 2009; Davidson et al. 2016; NICE Guideline Advance Care Planning 2017; Guldemond et al. 2017; Schreiber et al. 2017; Schrijvers and Cherny 2014; Selecky et al. 2005) and found to be an effective way of talking about sensitive subjects, such as the end-of-life (Parry et al. 2014). However, the aforementioned guidelines and scientific literature lack concrete recommendations on the expected course of the disease and EOLS (Conroy et al. 2009; Myers et al. 2018; Rietjens et al. 2017; Schrijvers and Cherny 2014).

Our hospital-based expert palliative care team (PCT) systematically explores possible EOLS during their consultations for each patient. Such EOLS can be generic (e.g., loss of general condition), disease-specific (e.g., pulmonary hemorrhage for lung cancer), or patient-specific (e.g., relapse of pre-existing anxiety disorder).

When these EOLS are communicated to GPs, this practice can help overcome 2 important barriers to ACP initiation in primary care: it may provide GPs with specialist knowledge regarding the prognosis of the disease and possible end-of-life course, thus overcoming the barrier of prognostic uncertainty, and facilitate collaboration between healthcare professionals in primary care and hospitals.

It is unclear if and how GPs use the EOLS of the PCT and how they perceive the impact on their daily practice and patient outcomes. Our study, therefore, aimed to explore the use and impact of such specialist-provided EOLS (SP-EOLS) on ACP in primary care.

Methods

We conducted an exploratory mixed-methods study, combining a retrospective quantitative case file study with interviews with GPs. We used a convergent study design in which data collection occurred parallel. Data were integrated at a methodological level, as the study sample for the interview study was based on the patient selection of the case file study (Fetters et al. 2013).

Case file study

Study design, setting, and participants

The PCT of the Radboudumc Nijmegen, the Netherlands, is a multidisciplinary team of GPs, medical oncologists, anesthesiologists, pain and palliative care specialists, nurse practitioners, and spiritual caregivers. The PCT discusses cases in their weekly multidisciplinary team meeting (MDTM) and can be consulted by hospital specialists and GPs. During these meetings, EOLS per case are jointly defined, reported in the hospital's electronic health record (EHR), and subsequently communicated to the consulting specialist or GP in discharge letters. Patients were eligible for inclusion in the case file study if they were: 1) discussed in the PCT between 2016 and 2019, 2) died before September 2021, and 3) had a GP who was connected to the Practice-Based Research Network affiliated with the academic hospital (Box 1). Patients were excluded from the study if they had opted out of using their routinely collected practice data for research purposes.

Box 1. The academic hospital had a practice-based research network of 16 general practices (88 GPs) collaborating with the Department of Primary Health Care. Its goal is to improve primary care through inspiring collaboration and development of academic knowledge of research and innovation in primary care.

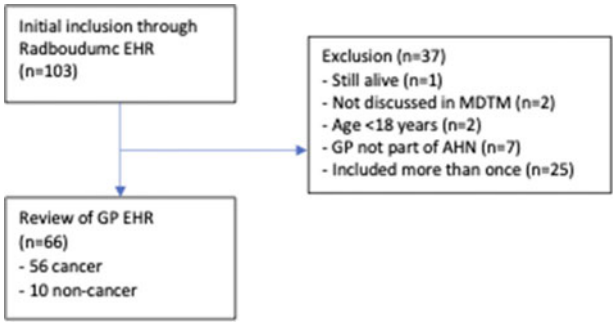

Figure 1. Study flowchart case file study.

Study procedure and data collection

A list of eligible patients was retrieved from Radboudumc's EHR, from which we manually selected the patients based on the inclusion criteria. We then used this information to access the patients' GP EHR (Fig. 1).

One researcher (S.P., junior researcher and medical doctor) pseudo-anonymized the data by extracting them from the GP's EHR via a case report form (CRF), which was developed with the research team based on previous research (Ermers et al. 2019), which only contained the study number. A second researcher (D.E., PhD student with experience in qualitative research and GP in training) checked 11 CRFs. In case of disagreement, one of 2 specialists (M.P., GP and senior researcher with expertise in qualitative research, and E.K., medical oncologist and senior researcher with experience in qualitative research) were consulted to reach consensus.

Outcomes

We defined 2 primary outcomes: the percentage of cases in which GPs discussed SP-EOLS with the patient and the concordance between SP-EHR EOLS and actual EOLS. All outcomes and baseline characteristics are listed in Table 1.

Data analysis

Quantitative data analysis was performed using IBM® SPSS® Statistics (Version 25). Descriptive statistics were applied to all variables. The Shapiro–Wilk test for normality was performed on continuous variables.

We compared outcomes between patients for whom SP-EOLS were communicated in the letter to the GP and patients for whom they were not. Chi-squared tests were used in categorical variables. In continuous variables, independent *t*-tests and independent-samples median tests were used for normally and not normally distributed variables, respectively.

Because of the explorative character of this study, we did not correct for multiple testing to minimize the chance of a type-II error.

Interview study

Study design, context, and participants

We approached the GPs of patients included in our case file study to participate in a semi-structured interview by e-mail. We did not apply other selection criteria to select GPs for the study sample (convenience sampling). When GPs agreed to participate, the researcher (S.P.) provided them with study information and scheduled the interview. Interviewees gave verbal and written consent for their participation.

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Table 1. Outcomes and data collection

Outcomes	Data collection
Primary	
Indicators that GPs discussed SP-EOLS with the patient.	This information was taken from the free-text part of the GP EHR. Any indication that the SP-EOLS were discussed (e.g., "discussed SP-EOLS with patient" or "talked about possible ways of dying").
Actual EOLS matches the EOLS predicted during the MDTM.	Described in the EHR. This was done by consensus between S.P. and E.K.
Secondary	
Information regarding the death of a patient.	From the EHR: - Date of death; - Place of death; - Cause of death; - Whether euthanasia or palliative sedation was performed; - Time from MDTM to death.
Information regarding PCT MDTM.	From the EHR: - Date of MDTM; - Possible EOLS described; - Other relevant information from the MDTM letter.
Information regarding health-care use from MDTM until death.	From the EHR: - Number of ER visits; - Number of hospital admissions; - Number of consultations with the GP (in and out of office hours); - Involvement of home care.
Information regarding ACP by the GP.	From the EHR: - ACP conversation documented by GP from MDTM letter until the death of the patient; - Date of first ACP conversation; - Content of ACP conversation; - ACP items: do not resuscitate policy, intensive care policy, ventilation policy, policy for referral and hospitalization, limitations regarding medical treatment, preferred place of death and treatment, euthanasia directive, declaration of will, and discussing palliative sedation.
Baseline characteristics	
Patient characteristics	From the EHR: - Sex; - Age; - Type of cancer according to the Integral Centre for Cancer of the Netherlands (IKNL)[a]; - Date of diagnosis and incurable disease (i.e., treatment not directed at curation, e.g., metastasized or local progression). Consensus was reached between S.P. and E.K. First of the month was taken; - Whether still receiving tumor-directed treatment; - Religion; - Marital status; - Children: number and whether or not deceased or no contact with; - Country of origin; - Treatment place at the time of MDTM; - Referral to MDTM by which doctor.
GP characteristics	From the GP questionnaire: - Experience as a GP in years; - Age; - Sex; - Extra training: GP specialist palliative care or geriatrics, palliative care differentiation during GP training, or physician consulted for euthanasia).

[a]See list of abbreviations.
GP = general practitioner; SP-EOLS = specialist-provided end-of-life scenarios; MDTM = multidisciplinary team meeting; EHR = electronic health record; PCT = palliative care team; ER = emergency room.

Study procedure and data collection

Semi-structured interviews of approximately 30 minutes using an interview guide were conducted, which took place face-to-face or via video call (interviewee preference) to stimulate an open conversation. The interview guide was adapted during data collection and analysis. To base the interview on experience rather than opinions alone, we prepared a case from the quantitative study in which the GP was involved. Interviews were conducted in Dutch, audiotaped, transcribed verbatim, and anonymized. When relevant interview topics arose, previous interviewees were approached again to give their opinion on those topics.

The interviewer (S.P.) had no relationship with the interviewees prior to the study. Before the interview, baseline characteristics were collected (Table 1). In addition, interviewees were asked to rate their perceived ACP skills and the frequency of ACP conversations with patients with cancer on a five-point Likert scale.

Data analysis

The iterative data collection and analysis process was subject to continuous reflection and changes based on new themes and views. ATLAS.ti (version 9.1.6) was used to support this process. Each interview was coded by 2 researchers independently (S.P. and D.E.). Codes were discussed until consensus was reached.

The codebook was updated and changed where necessary after each interview. Already coded interviews were re-coded when new codes arose. Open codes were combined into axial codes, categories, and themes and discussed in research meetings by S.P., D.E., M.P., and E.K. until consensus was reached. The study was reported according to the consolidated criteria for reporting qualitative research (COREQ-criteria).

Results

Case file study

Baseline characteristics

Files of 66 patients were reviewed (Fig. 1). The patients were 67.6 years on average, and 53% were female. Patients mainly had cancer (84.8%) and were referred to the PCT by a medical specialist (93.9%). Approximately half were inpatient (51.5%) (Tables 2 and 3). About 31 GPs were involved in the care of the included patients. The GPs had a mean age and experience of 49.3 and 16.6 years, respectively. The male-female ratio was roughly 1:1.

Primary outcomes

In 46 of the 66 cases reviewed (69.7%), SP-EOLS were made during the PCT MDTM. In 25 of these 46 cases (54.3%) SP-EOLS were included in the discharge letter to the GP. When GPs received SP-EOLS, they registered discussion of SP-EOLS in approximately one-third of the patients. GPs received a median of 7 SP-EOLS per patient, of which on average 43.1% occurred. In 91.3% of the cases, at least one provided SP-EOLS occurred (Table 4).

Secondary outcomes

Patients for whom GPs received SP-EOLS, more often had an ACP conversation recorded (92.0 vs. 61.0%, $p = 0.006$). In these ACP conversations, emergency room (ER) admission was more often discussed ($p = 0.030$). Circumstances of death did not differ between the groups (Table 5).

Interview study

Of the 18 GPs invited, 11 GPs participated. Five GPs did not specify their reason for nonparticipation, and 2 indicated a lack of time.

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Table 2. Patient baseline characteristics

Patient characteristics $N = 66$ unless stated otherwise			
Sex, *N* (%)	Male		31 (47.0)
	Female		35 (53.0)
Age in years (mean) [95% CI]			67.6 [41.9–93.3]
Disease, *N* (%)	Cancer		56 (84.8)
	Type of cancer, *N* (%)*	Hepato Pancreatic Biliary cancer	10 (15.2)
		Lung cancer	10 (15.2)
		Prostate cancer	6 (9.1)
		Colorectal cancer	8 (12.1)
		Bladder cancer	3 (4.5)
		Hematological cancer	3 (4.5)
		Ovarian cancer	3 (4.5)
		Other	13 (19.7)
	Non–cancer		10 (15.2)
Tumor-directed treatment, *N* (%)	Yes		18 (27.3)
	No		48 (72.7)
Time from diagnose until MDTM in months, median [range]*			13.0 [0–376]
Time from incurable cancer until MDTM in months, median [range]+			6.5 [0–148]
Religion, *N* (%)	Unknown		39 (59.1)
	Catholic		9 (13.6)
	Not religious		7 (10.6)
	Non-practicing		6 (9.1)
	Other		5 (7.6)
Marital status, *N* (%)	In a relationship		52 (78.7)
	Divorced		6 (9.1)
	Widow/widower		7 (10.6)
	Single		1 (1.5)
Children, *N* (%)	No		10 (15.2)
	Yes		56 (84.8)
	Any children deceased		2 (3.0)
	Any children no contact		3 (4.5)
Country of origin, *N* (%)	The Netherlands		58 (87.9)
	Other		8 (12.1)
Treatment place, *N* (%)	Inpatient		34 (51.5)
	Outpatient		32 (48.5)
Referred by, *N* (%)	Specialist		62 (93.9)
	GP		4 (6.1)

*$N = 56$.
+$N = 52$.

Table 3. GP baseline characteristics

GP characteristics $N = 31$		
Experience as a GP in years (at MDTM) (mean [95% CI])		16.6 [−0.3–33.4]
Age in years (at MDTM) (mean [95% CI])		49.3 [29.5–69.0]
Sex, *N* (%)	Male	17 (54.8)
	Female	14 (45.2)
Extra training, *N* (%)	GP specialist palliative care	1 (3.2)
	GP specialist geriatrics	1 (3.2)
	Palliative care differentiation	1 (3.2)
	None	28 (90.3)

Table 4. Primary outcomes

The GP discussed SP-EOLS with the patient, *N* (%)*	Yes	8 (32.0)
	No	17 (68.0)
At least 1 of the SP-EOLS occurred, *N* (%)+	Yes	42 (91.3)
	No	4 (8.7)
Number of SP-EOLS made in MDTM, median [range]+		7 [1–21]
Percentage of SP-EOLS that occurred per patient, mean [95% CI]□		43.1 [36.5–49.6]

*$N = 25$.
+$N = 46$.
□$N = 45$.

GPs interviewed were on average 53 years old (48–59) and had a mean of 21 years of working experience (17–26). All GPs classified the quality of their ACP conversations as "good" or "very good."

We identified 93 codes, 29 axial codes, 9 categories, and 4 themes, see Table 6.

Theme 1: SP-EOLS guide GPs, patients, and relatives when dealing with an uncertain future perspective

First, SP-EOLS give guidance to GPs, who identify prognostic uncertainty as a significant barrier to implementing ACP: "Well, to paint a picture of different scenarios, informing the patient, because it is not only asking what the patient wants, but looking with the patient at different possibilities and scenarios that exist, and thát, that is where I sometimes lack knowledge and could use more knowledge." (GP2, male, GP for 12 years). Prognostic uncertainty is considered to be enhanced by advanced medical developments. "…in my first year as a GP, when you heard 'lung cancer,' someone really was a dead man and passed very quickly. And all of a sudden, the treatment options have improved quite a lot (…)" (GP4, female, GP for 9 years).

SP-EOLS can transfer specialist medical knowledge to the GP: "I think that is helpful because you have the experts who say something about that [SP-EOLS]." (GP5, female, GP for 26 years), which can also explain the etiology of symptoms: "Hypercalcaemia [in colon carcinoma] also leads to obstipation, (…) I'd have thought it was due to obstruction. (…)" (GP1, female, GP for 18 years).

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Table 5. Secondary outcomes

		Total ($N = 66$)	SP-EOLS in GP letter ($N = 25$)	No SP-EOLS in GP letter ($N = 41$)	*p*-value
Patient's death					
Place of death, *N* (%)	Home	44 (66.7)	20 (80.0)	24 (58.5)	0.073
	Hospital	11 (16.7)	2 (8.0)	9 (22.0)	0.140
	Hospice	11 (16.7)	3 (12.0)	8 (19.5)	0.427
Cause of death, *N* (%)	Related to main disease (cancer or other)	61 (92.4)	24 (96.0)	5 (12.2)	0.261
	Other	5 (7.6)	1 (4.0)	36 (87.8)	
Palliative sedation or euthanasia, *N* (%)	Palliative sedation	17 (25.8)	8 (32.0)	9 (22.0)	0.365
	Euthanasia	10 (15.2)	3 (12.0)	7 (17.1)	0.577
Time from MDTM to death in months, median [range]		0 [0–37]	1 [0–10]	0 [0–37]	0.086
Healthcare use from MDTM until death					
Number of ER visits, median [range]		0 [0–3]	0 [0–2]	0 [0–3]	0.474
Number of hospital admissions, median [range]		0 [0–3]	0 [0–3]	0 [0–2]	0.288
Number of consultations with the GP, median [range]	In office hours	11 [0–83]	16 [0–52]	6 [0–83]	0.700
	Out of office hours	0 [0–8]	2 [0–8]	0 [0–3]	**0.001**
Involvement of home care, *N* (%)	Palliative home care	36 (54.5)	15 (60.0)	21 (51.2)	0.487
	Regular home care	7 (10.6)	3 (12.0)	4 (9.8)	0.774
Advance care planning (ACP) reported in GP EHR from MDTM until death					
ACP conversation by GP, *N* (%)		48 (72.7)	23 (92.0)	25 (61.0)	**0.006**
Time first ACP conversation until death (days) (median [range])		34.5 [0–364]	53 [0–364]	23 [1–298]	0.248
Content of ACP conversation (if applicable) NB: more aspects could be applicable to one patient		$N = 48$	$N = 23$	$N = 25$	
Resuscitation		15 (31.3)	8 (34.8)	7 (28.0)	0.613
Ventilation		4 (8.3)	3 (13.0)	1 (4.0)	0.257
ICU		4 (8.3)	3 (13.0)	1 (4.0)	0.257
Hospital admission		18 (37.5)	9 (39.1)	9 (36.0)	0.823
ER admission		12 (25)	9 (39.1)	3 (12.0)	**0.030**
Antibiotics		6 (12.5)	5 (21.7)	1 (4.0)	0.063
IV fluid or tube feeding		5 (10.4)	2 (8.7)	3 (12.0)	0.708
Other treatment preferences(e.g., palliative chemo therapy, dialysis, influenza-vaccination)		10 (20.8)	5 (21.7)	5 (20.0)	0.882
Treatment place of preference		17 (35.4)	10 (43.5)	7 (28.0)	0.263
Death place of preference		16 (33.3)	7 (30.4)	9 (36.0)	0.683
Palliative sedation		24 (50.0)	11 (47.8)	13 (52.0)	0.773
Euthanasia		32 (66.7)	3 (13.0)	6 (24.0)	0.331
Personal wishes/goals		16 (33.3)	7 (30.4)	9 (36.0)	0.683
Official representative		3 (6.3)	2 (8.7)	1 (4.0)	0.502
Official will		6 (12.5)	5 (21.7)	1 (4.0)	0.063
Official euthanasia request		6 (12.5)	3 (13.0)	3 (12.0)	0.913

GPs indicate that SP-EOLS facilitate better preparation for ACP conversations: "Well, if you don't know what's coming, you can kind of paint a picture like 'oh yes, I should pay attention to that.' (…)" (GP8, male, GP for 16 years).

Second, GPs feel that discussing SP-EOLS makes patients and relatives well-informed, which gives them a sense of security and confidence. "I think that patients often want to know where they stand, what they can expect…" (GP5, female, GP for 26 years).

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Table 6. Code book

Theme	Category	Axial code
1. SP-EOLS guide GPs, patients, and relatives when dealing with an uncertain future perspective.	The transfer of medical-specialist knowledge through SP-EOLS offers more prognostic certainty to GPs.	Prognostic uncertainty is a barrier to ACP for GPs.
		Advanced medical developments, a more uncommon and complicated clinical picture, and a lack of experience as a GP increase prognostic uncertainty.
		Medical specialists have substantive medical knowledge (e.g., about SP-EOLS) that GPs generally need to gain.
	Being prepared gives guidance to the GP.	Through SP-EOLS, the GP is better prepared for high-impact acute situations.
		Through SP-EOLS, the GP is better prepared for different scenarios.
	Discussing SP-EOLS gives a sense of security and confidence to patients and relatives.	SP-EOLS help inform patients and relatives.
		Discussing SP-EOLS can often reduce anxiety and distress in patients and relatives.
		Continuity of care through SP-EOLS gives the patient confidence.
		Complete prognostic certainty of SP-EOLS is not the most feasible: discussing them gives the patient peace of mind.
2. SP-EOLS provide continuity of care between primary and secondary/tertiary care.	GPs are well-equipped for ACP conversations.	GPs have good insight into the context of a patient.
		GPs are good at having ACP conversations with patients.
		GPs are motivated to have ACP conversations.
	There is a lack of continuity of care between primary and secondary/tertiary care regarding ACP.	There is a lack of communication regarding ACP between primary and secondary/tertiary care.
		A patient's stage of disease and whether active treatment is still offered are unclear to the GP.
		There is insufficient involvement of the GP regarding treatment decisions in secondary/tertiary care.
		GPs want to be involved in the PCT MDTM.
	SP-EOLS facilitate continuity of care regarding ACP between primary and secondary/tertiary care.	SP-EOLS of the PCT ensure continuity in terms of content between primary and secondary/tertiary care.
		SP-EOLS of the PCT could provide collaboration between primary and secondary/tertiary care.
3. SP-EOLS conversations should be tailored to the individual patient.	Acceptance influences needs in an SP-EOLS conversation.	Needs in an SP-EOLS-conversation vary between patients.
		A patient's acceptance of their fate facilitates discussing SP-EOLS.
	Sometimes, discussing SP-EOLS is not advised.	Some SP-EOLS are unfit to discuss.
		GPs indicate that some patients experience anxiety or distress due to discussing SP-EOLS.
4. SP-EOLS need to be personalized and uniformly transferred.	Needs of GPs regarding the content of the SP-EOLS.	GPs need case-specific, realistic SP-EOLS.
		GPs need a complete list of SP-EOLS.
		GPs want a broad view on multiple axes on SP-EOLS.
		Treatment advice on SP-EOLS could be helpful.
		GPs need information regarding communication between medical specialists and patients on SP-EOLS.
	Needs of GPs regarding the model of the transfer of SP-EOLS.	GPs need a structured and uniform practice regarding SP-EOLS.
		There are various preferences among GPs regarding the manner of transfer of SP-EOLS.

Being informed also reduces anxiety and distress: "…I think that much anxiety comes from… from the unknown. (…)" (GP10, male, GP for 25 years). Moreover, consistency in information between primary and secondary/tertiary care gives patients confidence: "Patients appreciate it if the same thing is said by the doctor in the hospital, because often it [SP-EOLS] is already discussed, so it gives a sense of confidence…" (GP5, female, GP for 26 years).

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Theme 2: SP-EOLS provide continuity of care between primary and secondary/tertiary care

GPs indicate that continuity of care between primary and secondary/tertiary care regarding ACP is lacking. "In very old people, that sometimes really… while I'm having conversations about the end of life and how to continue and maybe am quite conservative, and then suddenly in the hospital they pull out all the stops…" (GP4, female, GP for 9 years). Also, it is often not clear if the treatment goal is still curation. "…often you get very medical-technical letters that I think really do not say anything about what might happen with someone. (…) Truly what you need is to talk to the specialist for a minute to hear how they judge the situation. (…)" (GP4, female, GP for 9 years). Another GP said: "For example, right now I have a man of 45 years old with advanced cancer with liver metastasis; but is that viewed as 'can be brought to remission for a long time'? (…) Should I see that as disease control or should I see it as palliative? That's what I need from a specialist…" (GP6, female, GP for 27 years). GPs experience barriers to ACP if the patient is still treated in the hospital. "(…) I often notice that people are completely focussed on the hospital, which makes it hard to keep in touch sometimes; (…) and then SUDDENLY they come back, or they come to you all of a sudden while you lost them out of your sight. (…)" (GP4, female, GP for 9 years).

According to the GPs, SP-EOLS can facilitate continuity of care between primary and secondary/tertiary care regarding content and collaboration. SP-EOLS may align the messages from the GP and the medical specialist: "…as a GP, it is pleasant to have a somatic scenario as well, through which you can convey the same message. (…)" (GP6, female, GP for 27 years). SP-EOLS facilitate collaboration between GP and medical specialist: "…I think then [SP: when SP-EOLS are applicated] it will become the same treatment continuum because otherwise the hospital and the GP do different things." (GP6, female, GP for 27 years).

Theme 3: SP-EOLS should be tailored to the individual patient

According to most GPs, discussing SP-EOLS is appropriate for most patients: "…most patients are fit to discuss this [SP-EOLS] with; I think that 10% are not fit and 90% are." (GP6, female, GP for 27 years).

However, some GPs say that some patients experience anxiety when SP-EOLS are discussed: "…some patients just get very anxious because of that [discussing SP-EOLS]." (GP3, female, GP for 20 years).

Most GPs feel that discussing SP-EOLS in ACP conversations should be tailored to the individual patient. To start, GPs indicate that patients have different preferences in ACP conversations, which also vary depending on the level of acceptance. "Some patients want to prepare themselves and have use for it [SP-EOLS], and others can't talk and don't want to know all that. Some don't even want to know they're dying and can't talk about that. And some can deal with it well and accept it… so that is very different between patients… (…)" (GP7, female, GP for 27 years).

Theme 4: SP-EOLS need to be personalized and uniformly transferred

Regarding SP-EOLS content, GPs indicate that they need SP-EOLS that are realistic and patient-specific. They feel that SP-EOLS that are too general run the risk of being overlooked. "Yes, but it should be written in a way so that you don't get the feeling of reading the patient leaflet of medication in all options that could happen are described; if you get that, then you'll think 'never mind.'" (GP8, male, GP for 16 years). Concurrently, some GPs expressed the need for a complete list of SP-EOLS: "I think the letter should contain all SP-EOLS. You [the PCT] can't know which SP-EOLS is obvious to which GP. So, I'd prefer a complete letter, which partly consists of SP-EOLS which are obvious to me, to it being estimated beforehand what GPs generally find obvious." (GP5, female, GP for 26 years). In addition, GPs prefer SP-EOLS to have a broader approach instead of just focusing on the physical aspects of care. The letter, in their view, should also contain information on what has been communicated to the patient. As for treatment advice to go with the described SP-EOLS, GPs have various opinions. Some GPs appreciate treatment advice, especially in more complex cases; others do not need it.

Regarding the transfer for SP-EOLS, GPs mention the need for a uniform and structured practice: "Yes, it would be nice if it [making SP-EOLS] happens in the same way everywhere, because the [name of academic hospital] is of course for most patients not the preferred hospital, so if there would be some kind of uniformity that would be very great (…)" (GP5, female, GP for 26 years). GPs have different opinions, varying from a telephone call to letter to app-message, on the best way for SP-EOLS communication.

Discussion

Main findings

This exploratory mixed-methods study illustrated the potential of SP-EOLS in implementing ACP in primary care. SP-EOLS were made for 69.7% ($n = 46$) of the patients discussed in the PCT, according to the hospital EHR. Only 54.3% ($n = 25$) of these SP-EOLS were included in the discharge letter to the GP. GPs received a median of 7 SP-EOLS per patient, of which on average 43.1% occurred. In 91.3% of the cases, at least one provided SP-EOLS occurred.

In primary care EHRs, we found more ACP conversations documented for patients whose GP had received SP-EOLS (92.0 vs. 61.0%, $p = 0.006$). Semi-structured interviews with GPs revealed how SP-EOLS might contribute to ACP implementation. They were reported to decrease prognostic uncertainty and make GPs better prepared for various (acute) scenarios. GPs felt SP-EOLS make patients well-informed and less anxious and stressed. Furthermore, SP-EOLS were suggested to help bridge the gap between primary and secondary/tertiary care, as they facilitate better continuity of care in terms of content of ACP and collaboration on ACP. For broader implementation, GPs needed SP-EOLS to be realistic and uniformly transferred.

Comparison to existing literature

Similar to earlier findings (Wichmann et al. 2018), we found that GPs are well-equipped to have ACP conversations. Our study confirmed previously studied barriers to ACP implementation (De Vleminck et al. 2013, 2014), such as the "lack of GP knowledge regarding illness trajectories," and "the ability to foresee health problems in the future" to facilitate GPs to initiate ACP, and a lack of structural communication and collaboration between primary and secondary/tertiary care (Wichmann et al. 2018).

Earlier studies and guidelines (Conroy et al. 2009; Davidson et al. 2016; Wichmann et al. 2018) recommend care incorporate collaboration between GP and hospital specialist. Our study revealed the potential of SP-EOLS to achieve this.

Some GPs interviewed in our study questioned the appropriateness of discussing SP-EOLS with every patient; they feared

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that engaging in ACP too early "makes patients give up hope." However, previous studies have shown that hope is not decreased and may even be increased when engaging in ACP (Cohen et al. 2022). We have, therefore, no reason to believe that discussing SP-EOLS, guided by a healthcare professional, will decrease hope.

Strengths and limitations

One of the main strengths of our explorative study is its mixed-methods study design. By collecting quantitative and qualitative data, we have created a rich dataset in which our interview study gives meaning and explains the outcomes of our case file study. In the interview study, we also discussed cases of actual patients from GP's practices instead of hypothetical scenarios, making the outcomes transferable to a real-life care setting. Also, adding to this relevance and transferability to a real-life care setting, we included a diverse population of patients in the case file study and GPs in the interview study. Moreover, we combined data from both primary and secondary/tertiary care, thus creating an even more diverse dataset. The interview analysis was performed by researchers with various clinical backgrounds from both primary and secondary care (investigator triangulation).

Our study had several limitations. We measured the reporting of ACP conversations of GPs, which does not necessarily correspond with actual ACP practice (Hemkens et al. 2016). This might have led to an underestimation of the effect of SP-EOLS on having ACP conversations. The patient perspective is lacking in our study, which limits the study's practical applicability. In the quantitative part of our study, only a small number of patients could be included. Therefore, confirmative conclusions could not be made. We found that in only half (54.3%) of the cases, SP-EOLS were included in the discharge letter, which may have caused selection bias.

Practice implications and recommendations for future research

Our explorative study shows a promising role for SP-EOLS in ACP, as they guide GPs, patients, and relatives and continuity of care.

However, to improve SP-EOLS to implement in daily practice, future research should include (further) exploration of all stakeholders involved. Patients' perspectives could inform us on the personalization of SP-EOLS content and wishes regarding the discussion. The needs of GPs in SP-EOLS regarding the preferred level of SP-EOLS accuracy should be investigated. Developing an SP-EOLS network model that includes views of patients, informal caregivers, GPs, and hospital specialists on preferred collaboration, communication, and transfer of information could facilitate implementation.

Data availability statement. Data are available upon reasonable request up until 3 years after publication. All data relevant to the study can be attained through reasonable request from the principal investigator (s.w.poelman@gmail.com).

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