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Qualitative Research

# General practitioners' practical approach to initiating end-of-life conversations: a qualitative study

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## Abstract

**Background.** As doctors who provide care across the life-course, general practitioners (GPs) play a key role in initiating timely end-of-life discussions. Nonetheless, these discussions are often not initiated until close to death. Given the ageing of the population, GPs will be confronted with end-of-life care more often, and this needs to become a core skill for all GPs.

**Objective.** To describe GPs' approach to initiating end-of-life discussions.

**Methods.** Fifteen GPs or GP trainees from South-East Queensland, Australia, were purposively recruited to participate in a semi-structured interview. We analysed transcripts using a thematic analysis.

**Results.** GPs' approach to initiating end-of-life discussions was summarized by four themes: (1) Preparing the ground; (2) finding an entry point; (3) tailoring communication and (4) involving the family.

**Conclusions.** Emphasis on the doctor–patient relationship; assessing patient readiness for end-of-life discussions; and sensitive information delivery is consistent with factors previously reported to be important to both GPs and patients in this context. Our findings provide a framework for GPs initiating end-of-life discussions, which must be tailored to patient and GP personality factors. Further research is required to evaluate its outcomes.

**Key Words:** Communication, family practice, general practice, palliative medicine, physician-patient relations, qualitative research

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## Background

Early end-of-life care planning is associated with improved patient and healthcare outcomes, and will be increasingly relevant with an ageing population and rising prevalence of chronic disease (1–5). End-of-life planning involves assessing patients' needs and preferences, and establishing a future care plan that is aligned with their preferences to meet their anticipated needs (6). An essential first step

prior to end-of-life planning is initiating discussions with patients concerning end-of-life. However, even in the presence of life-limiting illness or frailty, end-of-life discussions are often not initiated until close to death (1,7–11).

As doctors who provide care across the life-course, general practitioners (GPs) have an opportunity to initiate timely end-of-life discussions (12,13). However, our previous research showed that

### Key Messages

- GPs describe a staged approach to initiating end-of-life discussions.
- Preparation and finding an entry point precedes end-of-life conversations.
- GPs employ tailored communication and family involvement in these discussions.
- The communication style used depends on patients' and GPs' personalities.
- These findings provide a GP framework for initiating end-of-life discussions.

despite being aware of approaching death and changing the focus of treatment to comfort care, GPs described not always articulating to patients that end-of-life was approaching (14). Failure to initiate this discussion may limit patients' opportunity to plan (15).

We conducted a qualitative study to explore GP initiation of end-of-life discussions. We found that GPs consider it their responsibility to initiate end-of-life discussions with patients, however may be cautious to do so due to patient, family, cultural/societal and personal factors (FAMPR-170-19.R1, manuscript under review). In this paper, we describe GPs' practical approaches to initiating end-of-life discussions.

### Objectives

To describe GPs' practical approaches to initiating end-of-life conversations.

### Methods

We used a descriptive qualitative methodology. Researchers comprised an experienced GP academic (GM), an experienced social work and health services research academic (MF), a GP trainee (HT), an epidemiologist (LD), and a medical student (NS). All authors were involved in project development, data analysis and approving manuscripts. GM provided project oversight; LD was involved in recruitment and HT conducted interviews and drafted the final report. We used purposive and snowball sampling to recruit fifteen GPs or GP trainees from South-East Queensland, Australia, through the University of Queensland's Primary Care Clinical Unit practice networks, aiming for a range of age, gender and experience. We sent email or postal invitations to 122 practices, who distributed these to their GPs. Eleven GPs from eight practices initially agreed to participate. We recruited another four GPs from other practices through snowball sampling. Participants provided informed consent, and participated in one 20–45 minute semi-structured face-to-face or telephone interview regarding initiating discussions about end-of-life. The interview schedule (online supplementary file) was pilot tested. Interviews were conducted by one researcher (HT) to data saturation, transcribed and analysed inductively using thematic analysis, using a similar approach to Braun and Clarke (16). Two researchers (NS and either of LD or HT) independently coded transcripts and achieved consensus on initial codes; higher-order themes were determined by discussion among the research team. The analysis was assisted by NVivo 11 software (QSR International).

We obtained ethics approval from the University of Queensland's Human Research Ethics Committee (201800027).

### Results

Thirteen GPs and two GP trainees participated (Table 1). Four themes describe GPs' practical approach to initial end-of-life conversations: (1) preparing the ground; (2) finding an entry point;

**Table 1.** Participant characteristics ( $n = 15$  Australian general practitioners, 2018)

Code	Gender	Years since graduation (primary medical degree)	In-training <sup>a</sup>
GP1	Male	37	No
GP2	Male	32	No
GP3	Female	22	No
GP4	Female	30	No
GP5	Male	41	No
GP6	Male	49	No
GP7	Male	20	No
GP8	Male	37	No
GP9	Female	10	Yes
GP10	Female	7	Yes
GP11	Female	8	New fellow
GP12	Female	33	No
GP13	Male	8	New fellow
GP14	Male	10	No
GP15	Female	7	New fellow

<sup>a</sup>'In-training' refers to general practice registrars; 'New fellow' refers to participants who obtained their general practice specialization within the 5 years preceding the interview.

(3) tailoring communication; (4) involving the family. The first two themes directly concern initiating end-of-life conversations; the final two themes describe GPs' approach when engaging in these discussions.

### Initiating end-of-life discussions

#### Theme 1. Preparing the Ground

GPs described preparing prior to initiating end-of-life discussions. They described the value of a strong doctor-patient relationship, gauging patients' readiness for end-of-life discussions and managing time availability.

GPs described the value of drawing on a longstanding, strong doctor-patient relationship to facilitate end-of-life discussions. They described '*establishing a secure doctor-patient relationship that is hopefully patient centered*' [GP5] as the first step in initiating these discussions. The presence of rapport and trust made the conversation easier: '*... it's a patient rapport thing... the better relationship you have with a patient... the easier it is to have those conversations...*' [GP10]; '*it helps a lot if we've met them before... so they know who you are and trust you and the conversation is quite easy*' [GP7]. However, participants implied that while longstanding relationship was preferable, it was sometimes necessary to have end-of-life conversations without this: '*I have definitely been in situations where the first time I've met them... they're like, 'This is what happened.' I'm like, 'Great, [laughs] this is going to be a fun discussion ... definitely that relationship helps you*' [GP15]. Some less-experienced GPs reflected that their regular patient demographics did not include many patients approaching end-of-life, and that patients who they

saw in this demographic were often regular patients of a more experienced GP at the practice. One reflected that they would be reluctant to initiate the conversation in this circumstance: *'I do see older people from time to time but they're usually going back to see whoever it is they usually see ... so I don't often get involved ... it's probably not a conversation that I would suddenly bring up if I'm only seeing them once or twice'* [GP11].

Participants also consistently described gauging patients' readiness to discuss end-of-life before raising the topic. One explained that *'each patient goes through stages of readiness... to have that conversation so you've got to be aware of where they are in that process... and pick your time'* [GP4]. They considered patients' personalities when judging readiness: *'...everybody's fairly unique ... some people are fighters ... some people are very passive and you've got to encourage them to recognize there's a right time to get themselves ... ready... some people are terrified so you've got to... work on... the relationship you have with them and... very sensitively lead them to the point of preparing for their own death...'* [GP5]. They also considered patients' psychological state: *'of ... far greater impetus to have that conversation would be the patient's demeanor and their psychological presentation... compared to their baseline. [Prognosis is] sort of irrelevant if you think that it's going to impact the patient psychologically poorly'* [GP13]. Additionally, GPs asked: *'open-ended questions about how people are feeling about what they already know'* [GP11] and gauged their verbal and non-verbal responses: *'it's... a lot of non-verbal cues just knowing your patients... Listening to their verbal cues as well'* [GP13].

Finally, GPs described that managing time availability was important. End-of-life conversations were often time consuming. Participants frequently identified that time constraints could be a barrier to initiating end-of-life discussions in primary care, where funding rewards *'high-throughput medicine'* [GP13]. Participants with all levels of experience identified time pressure; however, less experienced GPs seemed more consistently concerned about this. One summarized: *'I'm always feeling pushed in my consults. I often think... there's so many more things I could cover but... you're usually running late anyway and... what can of worms you're opening with asking those kind of questions [about end-of-life]'* [GP11]. GPs described deliberately preplanning end-of-life discussions and managing time to facilitate them: *'...that appointment where that conversation does take place you... make sure that you've got adequate time... 30–45 minutes to do it all nice and slowly and clearly and answer any questions...'* [GP13]. However, depending on the patient, they could sometimes briefly flag the issue for future discussion. Some participants believed that GPs did not avoid end-of-life conversations due to time constraints, as having the discussions saved time in the long term: *'... end-of-life care is going to be time consuming whether you talk about or not. It actually saves you time if you put it out in the open'* [GP3].

By attending to these factors, GPs aimed to facilitate adequate preparation for sensitive end-of-life conversations.

## Theme 2. Finding an Entry Point

GPs described finding appropriate entry points for end-of-life conversations. Examples included responding to patient initiation; incorporating conversations into routine care; initiating direct discussions around prognosis; and indirect questioning or hypothetical planning.

Patient or family initiation was a simple entry point: *'all sorts of tricky conversations are much easier had when someone else initiates...'* [GP10]. However, this did not always occur.

GPs described routinely initiating end-of-life conversations in some consultation types. Many participants identified that GP

management plan and annual health assessment consultations provided an opportunity for these discussions. One described routinely initiating end-of-life discussions with new nursing home patients. Several initiated the conversation through discussing advance health directives or statements of choices. Participants had mixed views regarding whether a checklist approach to initiating these discussions might be helpful. All GPs in-training and new fellows agreed that checklists would be helpful: *'[Checklists] would definitely be something I would use just to cross check that I'd done everything that's available or done everything that requires discussion.'* [GP13]. Many experienced GPs agreed that checklists may benefit inexperienced GPs. A minority of experienced GPs felt that they would find checklists personally helpful, while others strongly opposed this approach: *'...you've got all these... tick boxes in your head... I really don't want to have... formal tick boxes on top of that.'* [GP03]

Some GPs described directly initiating conversations around prognosis: *'You would... put that out there with... patients and say... the evidence is that... your chances of living more than two years with this is very low... this is the evidence...'* [GP12].

In other situations, GPs used more indirect entry points. These could involve enquiring about patients' religiosity or views on death, though some GPs admitted that they rarely did this: *'...it doesn't hurt to ask them their views on death and if they have any religious beliefs that help them... cope with the thought of death... it's not difficult to ask those sorts of questions and probably I should...'* [GP12]. It could also involve planning for hypothetical deterioration: *'I'll... start to ask some probing questions... along the lines of... what do you see the future looking like and... what's your plan if your condition were to deteriorate? Not quite so bluntly as that but I just try and... weave it into the conversation...'* [GP13].

Initiating end-of-life conversations was not a one-time event; GPs consistently described that these often occurred across multiple consultations: *'... You can't do it in one [consultation]... it doesn't work'* [GP1]. This was important to avoid overwhelming patients: *'...obviously, you have to get them back for more consults... doing it slowly, not just lumping everything on them at once'* [GP15]. Many participants described repeatedly mentioning the issue until patients were ready to engage: *'...you just fertilize the seed and... one day they'll say, 'Yeah that's a good idea, I think you told me that before'...'* [GP1]. They described preparing patients by flagging the issue to discuss at a future consultation: *'...planning it ahead... telling them... "Look this is something I want to talk about... we're not going to talk about it today but... we'll talk about it the next time I come, so they've got... time to ... get used to the thought that I will be bringing up those questions..."'* [GP3].

GPs' chosen approaches to initiating end-of-life conversations depended on clinical and GP and patient personality factors.

## Engaging in initial end-of-life discussions

### Theme 3. Tailored Communication

Careful attention to communication characterized participants' descriptions of end-of-life conversations. Participants described a range of communication styles; these were tailored to the individual doctor and patient.

Some participants described a direct approach: *'...you call a spade a spade'* [GP5]. One described having: *'...very frank conversation[s]... 'you know this is going to kill you, it's just a matter of when...'* [GP4]. Direct communication techniques included: *'...using... straightforward terminology, like 'someone's... dying', not... being vague...'* [GP7].

Conversely, many participants described more gentle approaches: *'...you have to tiptoe around the topic... introduce it... very gently...'*

*the worst thing you can do is come in and say, "...you'll be dead in three months..."* [GP2]. Participants described several non-confrontational communication techniques. One of these was active listening: *'a slow and thorough approach to the conversation... you ask... open questions...'* [GP13]; *'listening to how they're feeling and not just steam rolling'* [GP15]. GPs described framing the conversation positively: *'... I would ... say to them everyone ... who has... this ... condition I like to ... take a long-term approach to it. See whether there's anything I can do to make your life better in the foreseeable future and try and phrase it positively'* [GP13]. Unlike participants who used direct language, some described using indirect euphemisms: *'I think the terminology that I used was... your heart and your kidneys are on borrowed time and I think he knew what I meant by that'* [GP14].

Direct and indirect approaches were not necessarily mutually exclusive; one participant described being: *'gentle but frank'* [GP10]. The approach taken depended on the personality of the GP and the patient. One GP who took a very direct approach explained that this reflected their personality and communication style: *'My patients know me as someone who's likely to call a spade a ... shovel ... and so they expect honesty from me'* [GP4].

This tailored communication, albeit in different styles, was central to GPs' approach to end-of-life discussions.

#### Theme 4. Involving the Family

Participants described involving patients' families when initiating end-of-life conversations. This could occur in several ways. Participants described giving patients the opportunity to have family members present for end-of-life discussions: *'I might ... forecast the plan to have the conversation with them so they can have... husband, wife, son, daughter, whoever around with them'* [GP13]. Multiple participants described the value of family meetings to facilitate information sharing and consensus about treatment: *'... I try to have as many conversations with everybody... at once as... possible'* [GP13]; *... having family discussions... making sure everybody's on board'* [GP15]. Where patients were reluctant to engage in end-of-life discussions, some GPs described that these sometimes occurred primarily with family members: *'I... find that you end up... talking with the kids over the top of the patient a little bit...'* [GP10]. However, they were conscious of maintaining confidentiality. Dementia was a special case in which GPs primarily engaged in end-of-life discussions with family members rather than the patient: *'...you might leave the [dementia] patient in peace [by withholding diagnostic information] but you will be clear and open to the relatives'* [GP8]. This family involvement commonly featured in GPs' approach to end-of-life discussions.

## Discussion

This study elucidated the GPs' practical approach to initiating and engaging in end-of-life discussions. Participants described a nuanced and discretionary approach embedded within each doctor-patient relationship dynamic. GPs described end-of-life conversations as a process. This involved initially preparing the ground for the discussion by establishing strong doctor-patient relationships; gauging patients' readiness to engage; and managing time availability. Entry points to the conversation varied and could include responding to patient initiation, incorporation into routine care, raising discussions around prognosis or less directly discussing hypothetical deterioration or enquiring about patients' views about death. When conversations occurred, these involved tailored communication, which

varied in style and directness depending on doctors' and patients' personalities, and often involved patients' families.

Our findings share similarities with previous research on skills that GPs consider important when initiating end-of-life discussions. Like our participants, Belgian GPs identified that assessing patients' readiness to participate in end-of-life discussions was important, listened for patient cues and were aware of trigger moments to initiate these conversations (15). Clinical practice guidelines recommend that end-of-life discussions should involve preparation, relating to the patient through rapport and empathy, and eliciting their preferences regarding information provision (17). This elicitation of preferences is similar to our participants' descriptions of judging patients' readiness to have the conversation, though perhaps involves a more direct approach.

Importantly, the approach that GPs in our study described largely aligns with previous research on patients' preferences for end-of-life discussions (18–20). Patients valued having these conversations with a trusted health professional who knew them, consistent with our participants' emphasis on the doctor-patient relationship (18,20,21). They wanted doctors to be candid, but this was conditional upon first assessing patients' readiness to have end-of-life discussions, giving an invitation to participate, and delivering information sensitively (18). Patient preferences for family involvement vary; while most patients in one study wanted someone present for end-of-life discussions, others wanted to have the conversation alone in order not to upset the family, or to deliver the news to family members themselves (21). Nonetheless, previous research suggests that the approach our GPs describe largely aligns with patient preferences for care.

Practically applying our findings presents challenges due to their nuanced nature and dependency on patient and GP personality factors. While some participants described gentle indirect communication approaches, others were very direct. Previous research suggests that patients prefer a style that is candid but not blunt, balancing realism and hope (18,20). Figurative or indirect approaches can result in miscommunication with some patients; however, explicit phrasing can distress others (22). This perhaps informs our participants' descriptions of tailoring their approach to individual patients, suggesting that this is necessary and appropriate. However, research also suggests that doctors do not accurately predict patients' readiness to have end-of-life discussions based on non-verbal cues, and may need to ask about this directly (23). Balancing these factors poses a challenge requiring well-developed communication skills and perhaps a degree of relational intuition. Perhaps in this situation, communicating genuine care may be more significant than the specific approach employed.

Another challenge to apply our findings involves the time required to engage in the complex and sensitive conversations that our participants described. Consistent with previous research, participants felt that time pressure poses a barrier to engaging in these conversations (24,25). They identified that in Australian primary healthcare, longer consultations are not as well remunerated as high-throughput medicine. Systematic changes to the structure and finding of primary care may be necessary to address this and facilitate end-of-life discussions.

Our findings suggest approaches to supporting less experienced GPs to conduct end-of-life discussions. These may include facilitating opportunities to regularly care for a patient demographic approaching end-of-life; support in managing time pressure; and perhaps checklist approaches to use before these become internalized with experience.

Our study has several strengths. We interviewed Australian GPs with a breadth of age, gender and experience. The qualitative approach enabled a rich exploration of their views and emerging themes. Interviews were conducted between colleagues (with a general practice trainee (HT) as interviewer) to facilitate participants' comfort and honesty. However, the research team conducting analysis had diverse backgrounds, which helped to minimize researcher bias.

Study limitations include relying on GPs' descriptions of their practice, without direct observation. Further research could evaluate the extent to which GPs practically employ the approach described, and its outcomes. GPs with an interest in end-of-life care may have chosen to participate in the study; their approach may not reflect that of GPs more broadly. Finally, our research does not explore the perspectives of patients and other stakeholders; information from research with these groups should be considered alongside our findings.

## Conclusion

Australian GPs describe a nuanced approach to initiating end-of-life conversations, involving skilful communication tailored to patient and GP personality factors. This provides a framework for approaching these discussions, whose outcomes require further evaluation.

## Declaration

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Ethical approval: This study was approved by the University of Queensland's Human Research Ethics Committee (201800027).

Conflict of interest: The authors report no conflict of interest.

## References

- Barclay S, Momen N, Case-Upton S, Kuhn I, Smith E. End-of-life care conversations with heart failure patients: a systematic literature review and narrative synthesis. *Br J Gen Pract* 2011; 61: e49–62.
- Howie L, Peppercorn J. Early palliative care in cancer treatment: rationale, evidence and clinical implications. *Ther Adv Med Oncol* 2013; 5: 318–23.
- MacMillan Cancer Support. *No Regrets: How Talking More Openly About Death could Help People Die Well*. 2017. [https://www.macmillan.org.uk/\\_images/no-regrets-talking-about-death-report\\_tcm9-311059.pdf](https://www.macmillan.org.uk/_images/no-regrets-talking-about-death-report_tcm9-311059.pdf) (accessed on 27 May 2019).
- Wright AA, Zhang B, Ray A *et al*. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008; 300: 1665–73.
- Etkind SN, Bone AE, Gomes B *et al*. How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Med* 2017; 15: 102.
- NHS Department of Health. *End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life*. 2008. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/136431/End\\_of\\_life\\_strategy.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf) (accessed on 28 August 2019).
- Abarshi E, Ehteldi E, Donker G, Van den Block L, Onwuteaka-Philipsen B, Deliens L. Discussing end-of-life issues in the last months of life: a nationwide study among general practitioners. *J Palliat Med* 2011; 14: 323–30.
- Evans N, Costantini M, Pasman HR *et al*. End-of-life communication: a retrospective survey of representative general practitioner networks in four countries. *J Pain Symptom Manage* 2014; 47: 604–619.e3.
- Houben CH, Spruit MA, Schols JM, Wouters EF, Janssen DJ. Patient–clinician Communication About End-of-Life Care in Patients With Advanced Chronic Organ Failure During One Year. *J Pain Symptom Manage* 2015; 49: 1109–15.
- Janssen DJ, Engelberg RA, Wouters EF, Curtis JR. Advance care planning for patients with COPD: past, present and future. *Patient Educ Couns* 2012; 86: 19–24.
- Momen N, Hadfield P, Kuhn I, Smith E, Barclay S. Discussing an uncertain future: end-of-life care conversations in chronic obstructive pulmonary disease. A systematic literature review and narrative synthesis. *Thorax* 2012; 67: 777–80.
- Australian Institute of Health and Welfare. *Palliative Care in General Practice*. 2017. <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-in-general-practice> (accessed on 27 May 2019).
- Royal Australian College of General Practitioners. *What is General Practice?* [Internet]. <http://www.racgp.org.au/becomingagp/what-is-a-gp/what-is-general-practice/> (accessed on 13 May 2019).
- Deckx L, Mitchell G, Rosenberg J, Kelly M, Carmont SA, Yates P. General practitioners' engagement in end-of-life care: a semi-structured interview study. *BMJ Support Palliat Care*. 2019. <https://spcare.bmj.com/content/bmjspcare/early/2019/09/03/bmjspcare-2019-001817.full.pdf> [Epub ahead of print].
- De Vleminck A, Pardon K, Beernaert K, Houtteker D, Vander Stichele R, Deliens L. How do general practitioners conceptualise advance care planning in their practice? A qualitative study. *PLoS One* 2016; 11: e0153747.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006; 3:77–101.
- Clayton JM, Hancock KM, Butow PN *et al*. Australian and New Zealand Expert Advisory Group; Australasian Society of HIV Medicine; Australian and New Zealand Society of Palliative Medicine; Australasian Chapter of Palliative Medicine; Royal Australasian College of Physicians; Australian College of Rural and Remote Medicine; Australian General Practice Network; Australian Society of Geriatric Medicine; Cancer Voices Australia; Cardiac Society of Australia and New Zealand; Clinical Oncological Society of Australia; Motor Neurone Disease Association of Australia; Palliative Care Australia; Palliative Care Nurses Australia; Royal Australian College of General Practitioners; Royal College of Nursing, Australia; Thoracic Society of Australia and New Zealand. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *Med J Aust* 2007; 186(S12): S77–S108.
- Abdul-Razzak A, You J, Sherifali D, Simon J, Brazil K. 'Conditional candour' and 'knowing me': an interpretive description study on patient preferences for physician behaviours during end-of-life communication. *BMJ Open* 2014; 4: e005653.
- Brighton LJ, Bristowe K. Communication in palliative care: talking about the end of life, before the end of life. *Postgrad Med J* 2016; 92: 466–70.
- Parker SM, Clayton JM, Hancock K *et al*. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. *J Pain Symptom Manage* 2007; 34: 81–93.
- Clayton JM, Butow PN, Tattersall MH. When and how to initiate discussion about prognosis and end-of-life issues with terminally ill patients. *J Pain Symptom Manage* 2005; 30: 132–44.
- Karlsson M, Milberg A, eds. *Abstract FC14.2: Pushing up Daises, Slipping Away or Dying - a Qualitative Study on the Expressions of Death and Dying Among Family Members of Palliative Patients*. In: 14th World Congress of the European Association for Palliative Care, Copenhagen, Denmark; 2015.
- Hudak PL, Frankel RM, Braddock C III *et al*. Do patients' communication behaviors provide insight into their preferences for participation in decision making? *Med Decis Making* 2008; 28: 385–93.
- Momen NC, Barclay SI. Addressing 'the elephant on the table': barriers to end of life care conversations in heart failure - a literature review and narrative synthesis. *Curr Opin Support Palliat Care* 2011; 5: 312–6.
- Trankle SA, Shanmugam S, Lewis E, Nicholson M, Hillman K, Cardona M. Are we making progress on communication with people who are near the end of life in the Australian Health System? A thematic analysis. *Health Commun* 2018;1–10. <https://www.ncbi.nlm.nih.gov/pubmed/30475078> [Epub ahead of print].