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“It is not the fading candle that one expects”: general practitioners’ perspectives on life-preserving versus “letting go” decision-making in end-of-life home care

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ABSTRACT

Background Many general practitioners (GPs) are willing to provide end-of-life (EoL) home care for their patients. International research on GPs’ approach to care in patients’ final weeks of life showed a combination of palliative measures with life-preserving actions.

Aim To explore the GP’s perspective on life-preserving versus “letting go” decision-making in EoL home care.

Design Qualitative analysis of semi-structured interviews with 52 Belgian GPs involved in EoL home care.

Results Nearly all GPs adopted a palliative approach and an accepting attitude towards death. The erratic course of terminal illness can challenge this approach. Disruptive medical events threaten the prospect of a peaceful end-phase and death at home and force the GP either to maintain the patient’s (quality of) life for the time being or to recognize the event as a step to life closure and “letting the patient go”. Making the “right” decision was very difficult. Influencing factors included: the nature and time of the crisis, a patient’s clinical condition at the event itself, a GP’s level of determination in deciding and negotiating “letting go” and the patient’s/family’s wishes and preparedness regarding this death. Hospitalization was often a way out.

Conclusions GPs regard alternation between palliation and life-preservation as part of palliative care. They feel uncertain about their mandate in deciding and negotiating the final step to life closure. A shortage of knowledge of (acute) palliative medicine as one cause of difficulties in letting-go decisions may be underestimated. Sharing all these professional responsibilities with the specialist palliative home care teams would lighten a GP’s burden considerably.

KEY POINTS

- A late transition from a life-preserving mindset to one of “letting go” has been reported as a reason why physicians resort to life-preserving actions in an end-of-life (EoL) context. We investigated GPs’ perspectives on this matter.
- Not all GPs involved in EoL home care adopt a “letting go” mindset. For those who do, this mindset is challenged by the erratic course of terminal illness.
- GPs prioritize the quality of the remaining life and the serenity of the dying process, which is threatened by disruptive medical events.
- Making the “right” decision is difficult. GPs feel uncertain about their own role and responsibility in deciding and negotiating the final step to life closure.

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Introduction

Most terminally ill patients prefer to spend their last months at home and also to die there [1]. General practitioners (GPs) are well placed to accompany them in this choice. Most perceive end-of-life (EoL) home care as a typical task for GPs and find it both satisfactory and burdensome [2,3]. In Western countries, one-third to two-thirds of home-care patients are hospitalized in the

final weeks of life and die there [4,5]. However, home deaths substantially increase if the GP is aware in advance of the patient’s wish to die at home [6], if she/he pursues a palliative approach from the start [6], and when she/he cooperates with home care nurses and specialist palliative home care teams [7]. Yet, international research on GPs’ approach to care in the patient’s final months/weeks of life shows a combination

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of palliative measures with life-preserving actions (principally antibiotics and parenteral fluid) [8,9], even when the care setting has been labelled palliative [10]. The reasons why GPs resort to this combination have not yet been explored. It might be that GPs' transition from a mindset of life-preservation to one of palliation and "letting go" occurs (very) late in the terminal illness process [8]. Alternatively, the combination might also be triggered by the erratic course of terminal illnesses [9].

The concept of palliative care for the terminally ill and the dying (which we refer to as "hospice care" [11]) encompasses various aspects. In the EoL care continuum, it comprises two meaningful episodes: the patient's last months/weeks of life and the actual transition from life to death, the latter being a critical period of hours up to a week. As a philosophy, it prioritizes the quality of the remaining life, helps patients live as actively as possible until death, regards and accepts dying as a normal process, and intends neither to hasten nor postpone death [12]. As a service, it is a 24/7 delivery of skilled comfort care that acknowledges and plans for the patient's deteriorating trajectory and inevitable death [13]. Regarding environment, it stresses the home as the primary setting of care [14].

In Belgium, GPs involved in palliative home care can rely on specialist palliative home care nurses and reference physicians (SPHC Teams [SPHCTs]). SPHCTs mainly advise and support patients/family and professional home care providers. Yet they are available to deliver domiciliary assistance and technical sustenance for patients who have high-level medical needs near death.

This study aims to explore the perspectives of GPs who are involved in EoL home care on the issue of life-preserving versus "letting go" decision-making.

Material and methods

This study is part of a large qualitative study in Flanders, the Dutch-speaking part of Belgium, exploring interaction and decision processes in EoL home settings. Fifty patients plus their primary carers (61) and GPs involved (53) were enlisted. Recruitment was based on the GP's registration of the patient as terminally ill with the health insurance agency in order to apply for financial support for EoL home care. Interviews were conducted between February 2007 and November 2008.

Sampling strategy

The first inclusion step was undertaken by the health insurance's physician who informed the applying GP of the study and requested him/her to communicate

any objections regarding the patient's inclusion. Patients sampling was consecutive; inclusion criteria were adulthood and a granted palliative allowance; the aim was to include 50 patients, which was reached in July 2007. If no objections were registered, the health insurance's physician sent a request to the patient to participate. Upon agreement to participate, the identity of patient and applying GP were passed on to the research team. Due to the Ethics Committee's obligations, the research team had no contact with the patients and GPs at this inclusion stage. As a result no data are available on missing or excluded patients. Next, participating patients were contacted by the research team and GPs were invited for an interview. In three cases a second GP was involved in the EoL home care. These three GPs were equally invited to participate.

Interviews with the GPs

The interviews took place between January and August 2008. The GPs were interviewed in their office by the first author SM, who is a GP herself and is working part-time as a researcher. The interviews were semi-structured and lasted 80 minutes on average (35 to 120 minutes). After receiving the GP's informed consent, diverse topics surrounding EoL practice were broached, including: the GP's approach to care and EoL decision-making; estimated knowledge on palliative care; collaboration with other home care providers; communication styles with EoL patients and their family; view on palliative sedation and euthanasia. EoL was defined as the situation in which chronic life-limiting disease has reached a final stage, disease-modifying practice has come to an end and the patient's life expectancy is at most three months. The topic guide questions concerning the current study are shown in Table 1.

Data analysis

Due to the amount of interviews with patients, the bereaved, and GPs in a short time, data analysis started after all interviews had been executed. As the study comprised interviews with a previously determined group of 52 GPs, data saturation was not an issue.

Table 1. Interview topics.

How do GPs experience EoL home care?
What is their view of EoL diagnostic technology?
How do they respond to disruptive events?
What is their opinion on life-preserving interventions such as artificial nutrition and hydration, antibiotics, oxygen, blood transfusions and cardiotonics?
How do they experience the tension between "holding on" and "letting go"?
What are GPs' motives for hospitalizing a patient near death?

All interviews were audiotaped, transcribed verbatim, re-heard and re-read. Analysis was performed by SM and the second author VRV, who is also a GP. Both SM and VRV coded and analysed all interviews. Analysis was guided by the qualitative research methodology of HERG [15] and the Qualitative Analysis Guide of Leuven (QUAGOL) [16]. By using one writing board, we first generated a non-hierarchical frame of both anticipated themes from the topic guide and themes that emerged from the first 10 interviews. Subsequently we read all interviews with the preliminary framework at hand. Through constant comparison, we (re-)categorized GPs' statements and added new (sub-)themes on the writing board, along with the GP IDs and their particular perspectives. Thereafter, the actual coding process started with the actual thematic framework at hand and using QRS NVivo 8™ (QRS International (UK) Ltd, Daresbury, UK). The aim was to find more particular nuances, linked to suitable quotes. With each step we discussed and agreed on meaning and interpretation. To ensure interpretive validity, the process of analysis was supervised at serial meetings by the research team (two psychologists AK and DM; two GPs PP and DA).

This study was approved by the Ethics Committee of Ghent University Hospital (EC Project No: 2007/084; Belgian Registration No: B6702007190).

Results

After analysis one core theme transpired, namely GPs' basic attitude towards death: life-preserving vs. "letting go". Five major themes were identified that influence a GP's letting-go mindset: GPs' aim to achieve a decent EoL phase and serene death; the erratic course of terminal illness; GPs' intervention options; GP's determination in deciding and negotiating life-preserving vs. "letting go"; the patient's/family's wishes and preparedness for demise.

Characteristics of GPs

Of the 53 GPs who were invited to participate one refused the interview. Of the 52 interviewees, 71% were male. The mean age was 51. On average, the GPs had been practising for 26 years. This group fairly represents the Belgian GPs when it comes to age and sex (78% are male; mean age is 51.4) [17]. All interviewees were prepared to take on EoL home care for their patients. They treated an average of 3.2 EoL patients this way per year. Most provided out-of-hours home care, especially during patients' final weeks of life. Half of the GPs assessed their palliative care competencies as "just

enough", 25% as "insufficient", and 25% as "good". All interviewees had little or no palliative care education as undergraduates, yet had postgraduate training to a greater or lesser degree. All interviewees were used to working with home care nurses and nearly all had worked with the SPHCTs at least once. GPs' level of cooperation with the SPHCTs differed from minimal/superficial (25%) to good/intense(75%).

GPs' palliative home-care mission and basic attitude towards death

All interviewees were prepared to set up palliative service delivery and to enable the patient to die at home. For this, almost all GPs adopted a basic mindset of "letting go". They felt permitted to opt for comfort care and to allow the person to die:

... Well, I am not pro life-preserving [at this stage], absolutely not. Ensuring maximal comfort for the patient, increasing pain relief and sleep medication, the gentle way of [letting him] die, that, yes. (GP51, male, aged 38)

Their view on the use of diagnostics mirrored this letting-go attitude. In spite of the need to objectify a clinical deterioration or complication, hospice-oriented arguments for refraining from technical diagnostics were given priority: there was no disease-directed goal, the process might be too demanding for the patient and the results might only bring more bad news:

... in case of an acute event, honestly, I often have the feeling of "leave it as it stands". Because often you cannot diagnose without a hospital admission. Then I try to explain that transportation is too difficult, that nobody would blame them if they were to say "leave it". (GP21, female, aged 40)

Some GPs, however, were more inclined to order diagnostics, sometimes to justify their hospice approach, sometimes when the patient and family put pressure on them or, as in the example below, out of a sense of insecurity:

... At certain moments you are in quicksand, "What's happening now?" And now and then we do that, very limited, a thorax X-ray. Of course, the patient must be able to be transported to the local radiologist. ... Or lab tests so that we can see how it evolves ... because speculating on the nature and treatment of any complication is always a bit with sweaty palms. (GP14, male, aged 54)

A few GPs did not adopt a letting-go mindset. They could only accept death if it was immediately imminent. One GP considered each extra day a victory and would always blame herself for not having done enough to

hold off death. Another based his holding-on mindset on recognition of his inability to crush the myth of hope of survival:

Then you're not going to say: "Well, now I'm taking all hope away." So, however absurd it may be, you continue: "We are going to gain time." Only if you see the whole family is at the end of their tether and the patient is also at the end, finally, then you will stop too. (GP37, male, aged 54)

The meandering path of the "letting-go" approach and GPs' intervention options

GPs' letting-go mindset was not an "all-or-nothing" attitude. The erratic course of terminal illness could challenge this approach. Acute events might undermine the quality of the patient's last weeks, unwantedly hasten death or cause an undignified ending and force the GP to act:

... a sudden event, it can always happen ... then you have to decide ... and I find that hard; all the more because nobody can be prepared enough for that, myself included. It is not the fading candle that one expects. (GP55, female, aged 36)

Of the events that GPs listed in this context, palliative emergencies (e.g. acute haemorrhage) did not occur that often. More frequently they cited severe deteriorations and complications (e.g. respiratory failure, pneumonia, dehydration) that are potentially remediable. Finding the right thing to do in these acute situations was often hard and difficult. GPs experienced two areas of tension: (1) (acute) life-preserving versus (acute) palliative measures which did not interrupt the dying process and (2) persevering with home care versus hospitalization.

The GPs clearly perceived the very few life-preserving interventions that they considered applicable at home (antibiotics, cardiotonics and other organ-specific medication, oxygen and, rarely, artificial nutrition and hydration) to be non-invasive and compatible with the overall goal of palliative care in that they reduce the symptom burden and improve the patient's level of comfort:

If a patient is still able to swallow tablets and the lung infection can get treated, and we ease the breathing this way, why not [use antibiotics]? I see it partly as comfort care. We meander between life-prolonging actions and pure comfort care, I think. (GP54, male, aged 29)

Regarding interviewees' opinions on symptomatic "letting go" interventions, several GPs questioned the value of a bitter dying process and of having to fully endure it. One GP was able to let death take its course and even let the patient pine away while ensuring the necessary comfort. Another GP would facilitate the

dying process by generously intensifying symptom medication. Half of the interviewees, however, lacked ready knowledge of palliative sedation:

[I'm letting them go] by generously increasing morphine or by not rendering life-prolonging care, i.e. not hydrating. Everyone says: "Drying out, that's the worst thing there is." It is untrue. A patient died of multiple sclerosis. By taking away that enteral tube and letting her dehydrate, she has suffered far less than when she still had the tube. (GP15, male, aged 57)

Notwithstanding the GPs' letting-go mindset, letting-go decision-making in the midst of a disruptive event was a wrench. All GPs felt this struggle, but on different levels and for different reasons. For one GP it was "to let someone go when you can still patch him up". For another it was the acuteness of the decision. The nearer to the end of life, the clearer it became for the GP to deliberately choose to let go. Apart from that, GPs felt that there was no fixed scenario. Several GPs described the decision-making process as an intuitive one:

(Regarding an elderly person with dementia who had explicitly expressed the wish to die at home but who had serious swallowing problems and recurrently became dehydrated in the final months of life)

And the last time, I was thinking: "Should I let her go? Can we let her dehydrate? OK, we'll wait a day and see how it evolves." In the long run I say: "if we don't do anything now, it is most likely fatal." So then she was in the hospital again [and died there]. The question is: "Wouldn't she have been better off at home?" (GP35, male, aged 46)

(Regarding a patient with an acute bowel obstruction with immense pain)

I discussed it with the family, "Look, we had promised to care for him at home. But this is catastrophic. We want to [grant his wish], but then we have to make a tough decision [acute palliative sedation] right now." And the family hasn't hesitated one single minute: "go ahead". But you have to imagine! I could have called the emergency services and he would have been admitted. (GP55, female, aged 36)

Hospitalization was, among other major reasons such as a carer's breakdown or a patient's situation that required invasive (life-preserving vs. palliative) procedures, often a way to hand over the decision. Yet GPs strongly diverged in the ease with which they hospitalized. Several were determined to avoid hospitalization. For others it was less of a barrier, because they felt indecisive or unable to tackle the situation:

... if [the patient] chooses to die at home, then you have to do everything to enable him to die at home; then hospital admissions are out of the question, even if the patient has severe dyspnoea. And if you can't get him

through it, well, you know that you're working palliatively. (GP39, male, aged 57)

I, myself, I feel the need to have the patient admitted in stressful situations. (GP5, female, aged 54)

Factors that contribute to life-preserving vs. letting-go decision-making

GPs' aim to achieve a decent EoL phase and serene death

Firstly, GPs strove to maintain the patient's (quality of) life for the time being, if appropriate. In the case of a disruptive event, going for life-preserving versus letting go depended on the estimation of the clinical parameters at that moment: the severity and remediability of the current event, patient's age, comorbidity and overall life expectancy, the patient's present quality of life and that to be expected after the intervention. If those parameters were favourable, then the goal was to recover the patient's (quality of) life. If they were unfavourable, then simply ensuring comfort recognized the event as a step to life closure and letting the dying process run its course:

For example someone who gets pneumonia: if at that moment his quality of life is reasonable, and if he still wants to "stick around" in a manner of speaking, then I would give him antibiotics; and then he perks up for a couple of weeks! It's worth one's while. But if something serious happens, like a heart attack, then I wouldn't do that. (GP18, male, aged 47)

Second, GPs strove for a serene dying process: the expected death must be a good one, the road to it peaceful and the patient, relatives, and GP should be prepared for it. If a disruptive event hampers these goals, then postponing death might be appropriate to reset the goal of ensuring a serene death later on:

Such events always bring stress. Suddenly the situation changes from reasonably serene to pain, fever, and I don't like it at all, having to let someone die like that. While perhaps objectively it is a very good moment! (GP31, female, aged 54)

... in order to decide whether to start or stop meds, you also have to take into account: "are the people ready for it yet?" They know "our father is dying", but are they ready for it? (GP39, male, aged 57)

Inversely, a letting-go decision should not induce a long, drawn-out dying process. Several GPs found this irreconcilable with the concept of a serene death and mentioned that, paradoxically, they used life-preserving interventions in such cases to soothe the family and thus avoid hospital admission:

For instance, he gets severe bronchitis and you say: "I'm not going to give antibiotics, nothing any more to stop

death." But then it can linger on. And the family must be able to bear it too. That's why I sometimes take life-sustaining measures. Because if you let it linger on, people get exhausted! After a few days, because the family can't take it any more, a hospital admission is considered after all! (GP14, male, aged 53)

GPs' determination in deciding and negotiating "letting go"

GPs strongly differed in the way they viewed their mandate in the decision-making. Some GPs shied away from the moral responsibility "to decide on life and death" while others felt entitled to do so:

It's not easy if you don't have an [advance directive]. Then you think: "I'm deciding on life and death here. Am I allowed to do that?" (GP35, male, aged 46)

GPs also differed in the determination with which they intervened. Some GPs felt entitled to steer the decision towards "letting go"; others felt they had only an advisory role. Some would adopt a clear and encouraging style while others would recommend "letting go" in a suggestive manner and counted on patients/relatives to make the decision themselves:

(Regarding two patients who caught pneumonia at the end)

I told the family: "You can give antibiotics, but it doesn't make much sense. Maybe you'll gain a day, but she will die anyway." And generally, they listen! At one point you have, well, not to intimidate, but to steer a little, of course while taking a number of things into account. (GP26, male, aged 59)

Then I say that antibiotics will have little consequence; most people understand that and say: "no, better not"... With a cold you can say: "I would do this or I wouldn't do anything", but in an EoL context? You try not to influence them, you see. (GP28, male, aged 34)

Other GPs described an overwhelming saviour reflex, or felt incapable of taking a swift decision, or feared that their letting-go opinion might be interpreted as abandoning the patient:

Who am I to tell the family: "I think that your mum has the right to die now!" It is difficult. I will bring it up, but I don't want those children to say: "Doctor, you don't want to let my mother live any more!" (GP6, male, aged 47)

A long-standing relationship with the patient and family was for some GPs facilitating, but for others decision-hindering:

It is pleasant that you have known the family and the patient for years. That you can talk it over calmly and say: "Look, now it's enough, you see?" (GP8, male, aged 38)

I: Does it stress you, making decisions in acute situations? GP: Definitely! These are all people that you've known for 20 years, seen the children born and grow up; these are more than purely medical cases. (GP50, male, aged 53)

For several GPs, the application for financial support for EoL home care with the patient's health insurance agency functioned as a moral aid:

... if you really are in the terminal phase and you have applied for an allowance for EoL home care, then that's a "Comfort Measures Only" situation to me. (GP40, female, aged 39)

Deliberation with the other EoL care providers could also ratify a letting-go decision. Some GPs felt supported when the home nurses or SPHCT shared their opinion:

Having to balance between comfort and life-prolonging actions, I feel insecure sometimes: "Am I doing the right thing?" But I always try to stay in contact with a palliative doctor or anybody who can lend me some support. (GP21, female, aged 40)

The patient's/family's wishes and preparedness for the demise

Whatever the decision, GPs took the patient's and the family's wishes, strength, and preparedness into serious consideration. Any advance agreement with them on EoL policy and preferred place of death strengthened the GPs' mandate to comply with a letting-go approach:

With a palliative crisis, if it is not extremely terminal, then it's difficult! Except if the explicit request of the patient was already known: "I don't want to leave, not to the hospital any more." Then I would say: "OK, let go then." (GP30, male, aged 69)

Nevertheless GPs indicated that EoL talks were delicate and, therefore, often reached effective EoL care planning only late in the terminal process when the demand or necessity to address it became imperative. Some GPs stressed that continuous consultation was essential, as patient and family might change their minds at any critical moment. GPs also felt it extremely difficult to object to external life-preserving viewpoints. When the patient's/family's view differed from the GP's opinion or when the patient/family appeared not to be ready for the approaching loss, the GP would succumb. Not wanting to give the impression of "giving up" and to sustain the bond with the family were the two most mentioned reasons for doing so:

To a big extent you are influenced by the environment. You explain to the family that it would be best to handle things in a certain way, but if they have a different view, then I will take on their view, I think. You think about it afterwards, well, after the

demise you want to be able to look the family in the eye. (GP3, male, aged 59)

If the end was near and no advance agreements or "ad hoc" EoL preferences of the patient and entourage were known, as could be the case with an on-call intervention, GPs' opinions differed. Most GPs would choose the life-preserving option. A few older GPs felt they could unilaterally decide that "this patient had had enough".

Discussion

Within an EoL context, the term "letting go" has been used to refer to a state of emotional preparedness that recognizes the impending death and approaching loss of a person. It validates the decision to go for comfort care only and to allow the person to die. This death is supposed to be good and peaceful [18]. In this study, we have explored the perspectives of 52 GPs who are involved in EoL home care on the issue of life-preserving versus "letting go" decision-making.

We found that not all GPs adopted a letting-go mindset and that for the majority who did, this mindset was not an "all or nothing" attitude. Disruptive medical events threatened the prospect of a peaceful end-phase and death at home and forced the GP either to maintain the patient's (quality of) life for the time being or to recognize the event as a step to life closure and "letting the patient go". Making the right in-the-moment decision was very difficult. Influencing factors included: the nature of the crisis, a patient's clinical condition and overall prognosis at the time of the event itself, a GP's level of determination in deciding and negotiating "letting go" and the patient's/family's advance and "ad hoc" wishes and preparedness regarding this death. Hospitalization was often a way out of the dilemma.

Although the burden of medical decision-making in palliative crises has been reported, mainly via case reports, in the palliative and emergency care literature [19,20], this study is as far as we know the first to investigate GPs' thoughts and dilemmas on this matter.

Life-preserving interventions "for the time being"

In supporting a home death, GPs feel that both the patient's last months/weeks of life and death itself are important, as is the transition from the one to the other. First, GPs prioritize the quality of the remaining life and help patients live as actively as possible until death, if appropriate. This aspect of EoL care is clearly mentioned in the WHO definition of palliative care [21]. GPs perceive the few life-preserving interventions that are applicable at home as non-invasive actions given equally/mainly to

control symptoms and improve patients' comfort. Furthermore, GPs strive for a serene transition from life to death, for which patient and relatives are prepared. This aspect of EoL care is not defined as such in the WHO definition of palliative care. If any remediable event might cause an undignified ending or unwantedly hasten death, then postponing death may be appropriate to ensure a more controlled death later on.

However, the literature has stressed the pitfalls of escalation of these life-preserving interventions and of losing sight of the rationale of hospice care to guide patient and family towards nearing death [22,23]. Wright et al. showed that terminally ill cancer patients receiving palliative chemotherapy were more likely than other such patients to undergo cardiopulmonary resuscitation and mechanical ventilation and to die in hospital [24]. Persevering with palliative home care is a protection against this danger: the limited access to technical diagnostics and invasive life-preserving remedies constitutes on the one hand a most vulnerable side of EoL home care, but on the other hand functions as the best protection against an aggressively medicalized death.

Making explicit letting-go choices

Despite GPs' letting-go mindset we found that they find it hard to accept a palliative event as a momentum for the dying process to start, and letting the patient go. We have come across ambivalences concerning (1) deciding and (2) putting forward the "letting go", and (3) executing the decision.

Uncertainty about moral responsibility and mandate in deciding on "letting go"

In dealing with decisions in the midst of a sub-acute/acute event, the GP has to make both fast and accurate judgements on the intervention's focus. Circumstances might be uncertain: it is not easy to accurately predict a short-term death [25] and rarely is there nothing more to do "to buy one some time". GPs can be overwhelmed by a pang of doubt even if a letting-go choice feels right to them in a moral sense. Normative ambivalence is incorporated in a physician's professional role. Physicians are supposed to learn (by medical education, experience) how to blend seeming or actual incompatible values into morally acceptable and flexible professional behaviour [26]. However, a letting-go decision seems to create a situation in which GPs risk failing to meet these requirements.

One hypothesis is that a GP's EoL mandate is less clear than that of a palliative care physician. Admission to the American home hospice care services [27] and Belgian

inpatient hospice care [28] presupposes a "comfort measures only" management. In Belgium, a patient's registration as terminally ill with the National Health Insurance Fund is intended as an application for an EoL home care allowance, but is not a commitment to a strict hospice approach, although for several GPs the registration functions as a moral aid [29].

Furthermore, swift and intuitive decision-making can be a valuable judgement aid in uncertain circumstances without prescribed solutions, as long as the necessary domain knowledge and experience is present [30]. In EoL home situations the GP judges, but lacks palliative competencies and routine [31]. Although the GP can use the SPHCTs' expertise and several interviewees feel supported by them, only a few GPs cited the ratification of a letting-go decision through multidisciplinary deliberation. Sharing this professional responsibility, however, would lighten the moral burden considerably [32].

Negotiating the "letting go"

In the philosophy of hospice care, management of death relies on the ideals of shared decision-making and, thus, on awareness of dying from all parties [33]. However, not all patients/relatives want to be aware of or do accept the impending death. Or they accept death but cannot anticipate it [33]. Wanting to sustain the bond with the patient/family, GPs struggle with how to bridge their letting-go opinion with the patients'/family's wishes and preparedness for death. One GP feels entitled to steer, while another GP feels he only has an advisory role. In this respect, we refer to Blackhall: "End-stage Patients do not ought to know that they are terminally ill so that they can 'refuse' futile life-preserving therapy. Instead, they need to understand why it should not be advised, exactly because they are terminally ill" [34]. Several authors plead that it is a physician's responsibility as a professional to guide patient and family towards nearing death and – within the spirit of shared decision making – clearly recommend "letting go" [22,34].

Executing the letting-go decision

A symptomatic "letting go" treatment of an EoL patient who suffers badly from an acute episode is challenging. It requires a lot of coolheadedness to keep the patient comfortable and permit the dying process to take its course [36]. Ready knowledge and expertise in (acute) palliative care and medicine is key to meeting these goals [36,37]. Many GPs, however, are unaccustomed to palliative devices and techniques such as a syringe driver and palliative sedation [38,39]. Yet a remarkable, and highly significant, absence from our interviewees'

responses is that, while acknowledging this lack of ready knowledge of acute palliative medicine, they do not relate it to letting-go decision difficulties. However, surveys on the reasons for EoL hospitalizations confirm the need for (acute) comfort sustenance in the hospital due to an “uncontrollable” acute episode at home. Yet, besides patient/carer/home related factors, home care provider-related factors are also manifest: Hjermsstadt et al. showed that a great part of the EoL comfort sustenance delivered in hospital could have taken place in the patient’s home [40]. In another study GPs indicated that some patients could have been managed at home if they had conducted more forceful palliative treatment [41]. This is a further reason why the GP should use the SPHCTs’ expertise. Surveys show that home deaths substantially increase when the GP cooperates with the SPHCT [7]. Yet in Belgium, GPs still underuse the SPHCT to an important degree [3].

Developing a “letting-go” attitude

In undergraduate medical education the predominant discourse still focuses on cure and prolonging life worldwide [42,43]. Acquiring an accepting attitude towards death and dying and knowledge of comfort care is still mainly left to the physician’s personal postgraduate development and initiative. Research confirms that many GPs are acquiring a letting-go mindset alongside their professional career [3]. Our study, however, shows that a proportion of GPs caring for terminal people at home do not adopt this. The causes of a physician’s life-preserving attitude and therapeutic tenacity are multiple and interdependent, yet sensitizing physicians to the finiteness of life seems acquirable [44]. Although it is internationally well recognized that teaching about terminal decline and death and palliative care should begin at the undergraduate level, its incorporation into teaching programmes in medical schools is still substandard worldwide [43,45]. Acceptance of dying is, however, considered as a precondition for effective palliative practice [33] and acquiring this attitude should not be left to a physician’s own resources.

Limitations

As we limited participation to GPs who were involved in EoL home care, this study does not present a representative sample of Belgian GPs. We interviewed a previously determined group of 52 GPs. Yet we can assume that by interviewing a broad sample of GPs of different ages, sex, life views, locations, and experiences of EoL decisions a wide range of experiences and relevant perspectives surrounding life-preserving versus letting-go have been covered. We showed only GPs’

perspectives on life-preserving/letting-go without studying the patients’/family’s perspectives.

Conclusion

The rationale of (home) hospice care is to guide patient and family towards impending death. Yet, implementing a letting-go attitude in real home EoL practice may be extremely difficult. The hypothesis that a GP’s EoL mandate is less clear than that of a palliative care physician needs further research. A shortage of knowledge of acute palliative medicine as one cause of difficulties in letting-go decisions may be underestimated. The expertise of the SPHCTs represents an excellent yet underutilized resource to better equip the GP in this professional responsibility.

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Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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