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Where do general practitioners find patients with possible palliative care needs? Cross-sectional descriptive study

Article category: Health services research

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Abstract

Background

For general practitioners (GPs) to implement early palliative care, the first step is to identify patients with palliative care needs, e.g. with a no-response to the Surprise Question (SQ) (not surprised if a patient would die within a year).

Aim

To describe setting-specific screening results of patients eligible for early palliative care in family practices, here defined as patients aged 45 years with a GPs’ no-answer to the SQ.

Design and setting

Secondary analysis. Cross-sectional descriptive study in family practices in 5 Belgian areas.

Methods

GPs were recruited by targeted sampling. As a first part of an implementation research project, participating GPs provided demographic information about themselves and also provided a response to the SQ for all patients who came to the practice in ten consecutive office days. A summary table describing the gender, age, location of contact (surgery, patient’s home, or nursing home) of the
patients was provided by each GP.

**Results**

56 GPs provided complete data for the practice summary tables. In total 9,150 patients were described (all ages, all settings), of which 506 patients (6%) had a SQ-no-as-answer. The distribution of SQ-no-as-answer patients per setting was 152/7659 (2%) patients seen in family practice surgeries, 139/998 (14%) patients seen in their homes, and 215/493 (44%) patients seen in nursing homes.

**Conclusions**

There was quite a large number of SQ-no-as-answer patients, with possible palliative care needs. To enhance implementation of early palliative care, future research should compare results of SQ and other screening tools with palliative care symptoms assessments.

**Key words:** Epidemiology, Terminal illness and palliative care, Quality Assurance

**How this fits in**

Primary care practitioners should screen for possible palliative care needs. The surprise question is a method for palliative care needs screening. In 10 consecutive working days 56 general practitioners registered 6% no-answers to the SQ in a population of 9150 patients, which is considered a large proportion of this group.
Introduction

Offering palliative care to patients should be based on palliative care needs rather than on a terminal prognosis. This is considered a task for all physicians, and particularly for GPs because they are in close contact with the largest part of the population.\(^1\)

In many countries, the surprise question (SQ)\(^2\), alone or in combination with other prognostic tools, is suggested as a screening method for palliative care needs.\(^1,3\) A patient for whom a “No”-answer to the SQ is given (“No, I would not be surprised if this patient would die within 12 months”), is expected to have palliative care needs.\(^4,5\)

Pro-Spinoza was a Belgian project, sponsored by the National Institute for Health and Disability Insurance, which evaluated the implementation of the Care Pathway for Primary Palliative Care.\(^6,7,8\) In this project, there were two eligibility criteria for early palliative care: being 45 years or older and the GP stating that the patient has a SQ-no-as-answer.\(^8\)

In Belgium, family practice is known to be transitioning from mostly single-handed practices towards more group practices.\(^9\) Patients are free to choose their GP anytime they want to see a GP. That is why there are no patient lists available for individual family practices. The lack of clearly defined practice populations complicates calculations of practice prevalences.\(^10,11\)

This secondary study within the larger pro-Spinoza study had two aims, both contributing to the understanding of implementing the complex intervention of screening of (early) palliative care patients\(^12\). The first aim was to report SQ screening results in Belgian family practices, according to setting (location of contact), which could be: GP surgery, patients’ homes and nursing homes. The
second aim was to compare characteristics of participating GPs who completed data collection on the SQ with participating GPs who did not complete data collection.

Methods

Study design

This was a cross-sectional study of GPs’ practices in Belgium and is reported following the STROBE-checklist (Supplementary Table 1).

For this study the researchers decided to use a pragmatic method, i.e. by asking GPs to register a list of the patients seen in 10 consecutive working days. This means that this study is not a population-based survey. It is a cross-sectional study of patients coming to the participating GPs’ practices, i.e. always for a clinical reason.

Setting

This project ran in five Belgian areas (the areas around Antwerp, Brussels, Hasselt, Mons and Namur). These areas encompass five palliative care networks. Recruitment of participating GPs occurred from January 2014 until March 2016.

Participants

Recruitment methods included: educational sessions, GP practice visits, letters, emails and phone calls. Approximately every six months, another area started recruitment and data collection. This means that some areas had more recruitment and data collection time than others.
The recruitment of local GPs was facilitated as much as possible by already existing relationships of local GPs with the research team, with the palliative care networks or with the GPs’ circles. GPs’ circles are local associations of mostly 50 to 100 GPs, with a main purpose of organizing out-of-hours duties and postgraduate education for their members. The only exclusion of GPs was the refusal to participate. The research team recruited a diverse group of GPs (single-handed vs group, fee-for-service vs capitation based, male vs female, diverse age groups). More details about recruitment methods and success are described elsewhere.14

Sample Size

We worked with a targeted sample of GPs. The sample size calculated for the main study was 180 GPs.8 A formal sample size calculation has not been done for this secondary analysis, which serves as an exploration of this issue.

Variables

As part of the pro-Spinoza study8, participating GPs were asked to record prospectively this information about all patients seen in ten consecutive working days: gender, age, location of contact (in the surgery, at patient’s home during a home visit, or in a nursing home) and their “yes” or “no” answer to the SQ (“would you be surprised if the patient lived one year after today: yes or no”). Through a secure, online platform, GPs provided demographic information about themselves in addition to the two standardised summary tables which provided the responses about the patients (see Supplementary Box 1 for the questionnaire).
The summary table about SQ prevalence focused on patients of 45 years or older. This choice was made based on two reasons: (1) dying people below 45 years are (at least in Belgium) expected to be followed up more closely by specialists than by GPs; starting from 45 years dying people are expected to be followed up at least partly by family doctors, and (2) the authors did not want to restrict the research population to the elderly, retired population, because that limits the diversity of palliative care pathologies.

**Statistical Methods**

The data from the GPs were checked by the researchers. Any summary tables that were incomplete, contained the same number values throughout, or included guesses (e.g. gender distribution was exactly 75%/25%) were removed from the analysis. The analysis on itself was a description in percentages of proportions found: general demographics of the full sample, and proportions of SQ-no-as-answer patients per setting and per age/gender category.

Because one of the main goals of the larger project was to obtain insights in implementation mechanisms, a simple comparison was made between participating GPs having filled in the summary tales correctly and those who filled in the tables incorrectly for the relevant GPs’ background characteristics (SPSS v25: Cross-tabs, Chi squares).

**Ethics**

The informed consent procedure and confidentiality issues for the parent study from which this data is derived were approved by the Ethical Commission of the University of Antwerp (number 13/35/333, date: 7/10/2013) and by the Belgian Commission for the Protection of Privacy (statement SCSZG/13/251, date: 19/11/2013).
Results

Participant characteristics

Of 112 participating GPs, 65 filled a baseline questionnaire. Of these, 9 summary tables were excluded due to incomplete data. Therefore 56 GP practices were included in the final analysis. Table 1 provides the comparison between those included and those excluded. Supplementary Table 2 provides the original dataset, and shows why 9 data rows were excluded.

Although not significant, there were some remarkable differences between the two groups in Table 1. Particularly men, GPs in their early or in their late career phase, GPs with more than 5 palliative care patients in the last year, and single-handed GPs provided incomplete data for the practice population registration tables.

Proportion of patients eligible for early palliative care

The GPs registered 9150 patients in the 10 working days window (i.e. an average of 16 patients on a working day), of which 5479 patients (60%) were older than 45 years, 5463 patients (60%) were female and 7659 patients (84%) were seen in GPs’ surgeries. Five hundred and six patients (6%) were older than 45 years and also had a SQ-no-as-answer. This means that 1 in 20 patients of all ages (506/9150), or 1 in 11 patients aged 45 years or more (506/5479), who were seen by a GP were possibly eligible for (early) palliative care.

Table 2 shows the general demographics of this total patient population. Of 9150 patients, 5479 patients (60%) were 45 years or older and 5462 patients (60%) were women.
Table 3 shows the total number per setting (GPs’ surgery, home visits, institution/nursing home visits) and the number of patients who were eligible for early palliative care, i.e. being 45 years or older and having a SQ-no-as-answer. The prevalence of eligible patients was 2% in the GPs’ surgery, 14% in patients’ homes, 44% in nursing homes and 6% overall.

All data of the summary tables are to be found in Supplementary Table 3.

Discussion

Summary

The primary aim of this secondary analysis was to report SQ screening results in Belgian family practices. GPs registered 9150 patients over 10 working days and answered the SQ for all patients older than 45 years. This study found that 1 in 11 patients of at least 45 years (506/5479), and 1 in 20 patients of all ages (506/9150) were considered eligible for early palliative care and should be screened more thoroughly for palliative care needs, for instance by a palliative care symptoms assessment like the (Integrated) Palliative Outcome Scale\textsuperscript{15,16}.

In the setting of home visits, the proportion of early palliative care eligibility rose to approximately 1 in 10 patients. In the setting of visits to nursing homes, where all residents are older than 45 years, this prevalence rose to almost 1 in 2 patients.

Characteristics related the most (although not significantly) with GPs not having completed data collection were: male sex, late career phase, single-handed practice. Lack of significance could be related to the small sample size.
**Strengths and limitations**

This is one of the first Belgian studies reporting screening results of early palliative care patients in primary care, here operationalised as SQ-no-as-answer patients aged 45 years or over. However other studies comprise the general population and/or focus on people of 65, or 75 years or older, in this study the age of 45 was chosen as the limit. Taking the same age group as in other studies could have improved the comparability with these other studies.

The assessment of patients with the SQ has shown, in this study, to be a feasible intervention. It could be a possible important first step in identifying patients who might benefit from anticipatory care planning and palliative care.

In the parent study, there is a risk for selection bias on the level of the GP practices. These participating GPs are perhaps not representative for GPs in Belgium. A Belgian GP workforce capacity study showed that in 2016, 59% of active GPs were men (while 46% of our 56 GP respondents were men, see Table 1) and that 52% of active GPs were older than 55 years (while only 23% of our 56 GP respondents practiced medicine more than 30 years, see Table 1).

Furthermore, there might be a selection bias of patients: only patients visiting their GPs with clinical problems were included, thus raising the risk of palliative care needs compared to the whole patient population. Nevertheless, selecting only patients a GP had contact with reflects daily GP practice, and narrows the research-practice gap.

Recruitment and data collection support strategies are described elsewhere in more detail. Many GPs stated that the online data collection was difficult to handle. This methodological challenge reduced the available amount of data.
Comparison with existing literature

A Belgian study investigated the use of the PICT, a modified Supportive and Palliative Care Indicator Tool (SPICT\textsuperscript{20}) including the SQ, followed by general and disease-specific indicators quite similar to the SPICT indicators.\textsuperscript{17} In the report, there were no separate data available on the prevalence of SQ-no-as-answer patients, but 4% of patients seen by participating general practitioners were considered PICT positive and 14% of nursing home patients were considered PICT positive.\textsuperscript{17} This is a lower number than in nursing home patients in our study (44%), potentially because of the extra criteria of the PICT on top of the SQ.

In a Catalonian study, the SQ-no-as-answer prevalence was 1% in the primary care setting (of one primary care center) and 62% in the nursing home.\textsuperscript{5} The NECPAL positive prevalence (SQ-no-as-answer and positive in one of the NECPAL domains) was quite similar in this study: 1,0% in the primary care setting and 53,9% in the nursing homes.\textsuperscript{5} Here, the general SQ-no-as-answer prevalence is lower than in our study, because this study investigated the whole practice population and our study only investigated patients seen during 10 days. The nursing homes in Catalonia have a higher percentage of SQ-no-as-answer patients (62%) than in our study (44%). This difference could be based on differing nursing home demographics. In Belgium, there are around 70 beds in residential long-term care facilities per 1.000 people aged more than 65 years, while in Spain (for Catalonia alone, no data were found) there are around 45 similar beds per 1.000 people of this age group.\textsuperscript{21}

An Australian RCT compared the predictive value of screening tools (SQ or SQ followed by SPICT) vs unguided intuition.\textsuperscript{22} GPs identified more patients at risk of dying using SQ (11.8%) than when they used intuition (5.4%; p=0.01). Screening
tools had higher sensitivity and lower specificity than intuition, but there was no
difference in positive or negative predictive value.

In a Dutch case vignette study, the original SQ (SQ1: “Would I be surprised if
this patient were to die in the next 12 months“?) is considered to have a low
specificity, leading to overidentification of patients eligible for early palliative
care. To make early palliative care more feasible, a second SQ was added
(SQ2: “Would I be surprised if this patient is still alive after 12 months“?). These
two SQs together encouraged GPs to deliver anticipatory palliative care,
compared with the original SQ alone and compared with having no SQ to help. In
a Dutch explorative study, two GPs answered both SQs for their patients of 75
years and older. Of 292 patients, SQ1 was answered with 'no' for 161 patients. Of
these, SQ2 was answered with 'yes' in 22 patients. This group (SQ1-no-answers,
SQ2-yes-answers) discussed more frequently and more palliative care aspects
with the GP. So, the ‘double surprise question’ seems a useful enhancement of
the original SQ.

**Implications for research and/or practice**

The most important implication from this research is that palliative care needs
are prevalent in primary care. 1 in 20 patients of all ages, seen in 10 office days,
possibly have palliative care needs. To recognize these needs will remain the first
step of any care pathway or protocol. However, to study whether the SQ or any
other screening tool is a valid proxy for palliative care needs, a prospective study
is recommended in which results of screening tools are compared with palliative
care needs/symptoms assessments like the Integrated Palliative Outcome Scale.
The methodology adopted in the parent study of this secondary analysis shows that it is feasible to obtain responses online. However, this led to data being excluded due to it being incomplete.

GPs who were male, single-handed and/or in their late career phase, seemed less involved in primary palliative care research activities than other GP profiles, possibly because they lacked support with data collection\textsuperscript{14}. These preliminary findings could refine recruitment and participant monitoring strategies in primary palliative care research.

Because of the higher context-specific proportions there, this research suggests that GPs visiting patients at home or in a nursing home should be mindful of palliative care needs.

**Conclusion**

The SQ appears a feasible screening tool for GPs. When asking data collection from GPs, a research team should offer support, presumably the most for male, single-handed GPs in their last career phase.

The proportion of SQ-no-as-answer patients is quite high in primary care settings, particularly in nursing homes. A no-answer to the SQ is not enough to warrant a high intensity palliative care to a specific patient, but should be a trigger to think of ways to integrate anticipatory care planning and palliative care needs assessments in the daily care of the SQ-no-as-answer patient.

**Funding**

The Belgian National Institute for Health and Disability Insurance sponsored the pro-Spinoza project evaluating the implementation of the Care Pathway for Primary Palliative Care in five Belgian regions.
Ethical approval

The informed consent procedure and confidentiality issues for the parent study from which this data is derived were approved by the Ethical Commission of the University of Antwerp (number 13/35/333, date: 7/10/2013) and by the Belgian Commission for the Protection of Privacy (statement SCSZG/13/251, date: 19/11/2013).

Competing interests

The authors do not have competing interests.

Acknowledgements

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Bibliography


Table 1. Participant characteristics compared between GPs with complete summary tables and GPs with incomplete summary tables (pro-Spinoza, 2013-2016)

<table>
<thead>
<tr>
<th></th>
<th>Complete tables</th>
<th>Incomplete tables</th>
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</thead>
<tbody>
<tr>
<td><strong>N</strong></td>
<td>56 (100%)</td>
<td>9 (100%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>26 (46%)</td>
<td>7 (78%)</td>
</tr>
<tr>
<td>Women</td>
<td>30 (54%)</td>
<td>2 (22%)</td>
</tr>
<tr>
<td><strong>Years of experience as GP</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 10</td>
<td>23 (41%)</td>
<td>3 (33%)</td>
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<tr>
<td>10 – 30</td>
<td>20 (36%)</td>
<td>1 (11%)</td>
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<td>&gt; 30</td>
<td>13 (23%)</td>
<td>5 (56%)</td>
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<tr>
<td><strong>Self-declared time schedule</strong></td>
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<tr>
<td>Full-time GP</td>
<td>40 (71%)</td>
<td>8 (89%)</td>
</tr>
<tr>
<td>Part-time GP</td>
<td>16 (29%)</td>
<td>1 (11%)</td>
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<tr>
<td><strong>Number of extra activities</strong></td>
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<td></td>
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<tr>
<td>None</td>
<td>21 (38%)</td>
<td>3 (33%)</td>
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<tr>
<td>1</td>
<td>23 (41%)</td>
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<tr>
<td>2 or more</td>
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<td>2 (22%)</td>
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<td><strong>Number of palliative care patients in the last year</strong></td>
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<td></td>
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<td>None</td>
<td>6 (11%)</td>
<td>1 (11%)</td>
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<tr>
<td>1-5</td>
<td>36 (64%)</td>
<td>4 (44%)</td>
</tr>
<tr>
<td>5-10</td>
<td>11 (20%)</td>
<td>3 (33%)</td>
</tr>
<tr>
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<td>1 (11%)</td>
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<tr>
<td><strong>Type of practice</strong></td>
<td></td>
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<tr>
<td>Single-handed</td>
<td>11 (20%)</td>
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<tr>
<td>Duo</td>
<td>9 (16%)</td>
<td>1 (11%)</td>
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<td>Group</td>
<td>31 (55%)</td>
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<td>Community health center</td>
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<td><strong>Administrative support</strong></td>
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<td>23 (41%)</td>
<td>4 (44%)</td>
</tr>
<tr>
<td><strong>Paramedical support</strong></td>
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<td></td>
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<tr>
<td>Paramedical support</td>
<td>26 (46%)</td>
<td>5 (56%)</td>
</tr>
<tr>
<td>No paramedical support</td>
<td>30 (54%)</td>
<td>4 (44%)</td>
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</table>
Table 2. General demographic characteristics of described patients (pro-Spinoza, 2013-2016)

<table>
<thead>
<tr>
<th></th>
<th>Men (%) of general total</th>
<th>Women (%) of general total</th>
<th>Total (%) of general total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Younger than 45 years</td>
<td>1516 (17 %)</td>
<td>2155 (24 %)</td>
<td>3671 (40 %)</td>
</tr>
<tr>
<td>45 years or older</td>
<td>2172 (24 %)</td>
<td>3307 (36 %)</td>
<td>5479 (60 %)</td>
</tr>
<tr>
<td>Total</td>
<td>3688 (40 %)</td>
<td>5462 (60 %)</td>
<td>9150 (100 %)</td>
</tr>
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</table>
Table 3. Distribution of patients eligible for early palliative care, per setting (pro-Spinoza, 2013-2016)

<table>
<thead>
<tr>
<th>Setting</th>
<th>Total</th>
<th>45 years or older AND SQ-no-as-answer</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>GPs' surgery</td>
<td>7659</td>
<td>152</td>
<td>2%</td>
</tr>
<tr>
<td>Patient’s home</td>
<td>998</td>
<td>139</td>
<td>14%</td>
</tr>
<tr>
<td>Nursing home</td>
<td>493</td>
<td>215</td>
<td>44%</td>
</tr>
<tr>
<td>Total</td>
<td>9150</td>
<td>506</td>
<td>6%</td>
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