How health system factors influence referral decisions in patients that may have cancer: European symposium report

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Abstract

Objective: To identify the system and other non-clinical factors that may influence a General Practitioners’ decision on whether to refer a patient who may have cancer. Study design: Expert group discussion and consensus formation. Methods: A group of eight General Practitioner (GP) researchers from Croatia, England, Slovenia, Spain, Sweden and Switzerland used brainstorming to identify the non-clinical factors that could affect GPs’ decision-making when faced with patients that might have cancer. The group refined and came to a consensus on these factors. Results: Many non-clinical factors are likely to have a significant impact on referral decisions. These include levels of gatekeeping responsibility, funding systems, access to special investigations, fear of litigation, and relationships with specialist colleagues. Conclusions: Many patients with cancer present without red-flag symptoms, but nevertheless still cause a feeling of concern in their GPs. How a health system is organised is likely to influence on how GPs act on those concerns.

Keywords: health care systems; primary health care; cancer; decision making; early detection of cancer

Introduction

There is wide variation in the cancer survival rates across Europe [1], and this leads to substantial excess mortality. For example, in Great Britain over 6,000 deaths a year that occurred within 5 years of diagnosis would have been avoided if survival in Britain had matched the mean for Europe [2, 3]; this represents 6-7% of its cancer-related mortality. The variation in 1-year survival rates is even higher. An analysis of EUROCARE-4 [4] results by 1-year survival [1] shows a group of countries (including Switzerland and Sweden) with consistently high survival estimates and another group of countries (including England, Slovenia and Croatia) with lower estimates. Spain lies near the middle of the table. Poor 1-year survival rates are generally taken to be an indicator of more advanced disease at diagnosis [3]. For those patients that survive at least a year after their initial cancer diagnosis, there is less national variation. While recent overall cancer survival trends show improvement [5], there is little narrowing in the differences between countries [6].

International variations in cancer outcomes are related to differences in stage at diagnosis, and this may be due to differences in diagnostic delay and awareness of symptoms [7, 8]. However, the challenge of where and how to achieve more timely diagnosis is a considerable one [9]. A General Practitioner (GP) will see only a handful of new cancers in any one year. GPs may go many years, or indeed a lifetime, without seeing certain rare cancers. In addition, most patients present with evolving and undifferentiated symptoms that are more likely to be interpreted as something other than cancer.

Various factors can trigger GPs to come to think of cancer in a clinical encounter [10]. Awareness of a risk of cancer can arise from: practising basic knowledge, for instance familiarity with “red-flag” symptoms; interpersonal

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The group was given the task of identifying the system and other non-clinical factors that could affect a GP's decision-making when faced with a patient that might have cancer. For this phase of creative problem-solving, a brainstorming technique was used. This method followed Osborn's guidelines [14]: criticism of ideas generated was not allowed; “freewheeling” was welcomed; quantity of ideas was encouraged; combination and improvement were sought. MH had a brief schedule of topics, not issued to the participants, which he used to ensure that the ideas generated touched on all major areas. In the second session, the group discussed, refined, grouped and came to a consensus on the previous day's list of factors. Participants captured the ideas on flip-chart pads; during the symposium MH also kept notes. These written records were used to produce a list of the factors that had been identified.

After the meeting, the list of factors was circulated to participants for validation and comment. Participants also gave copies to their local GP colleagues for comment. On the third iteration of this process, no significant changes were requested.

### Results

#### The gatekeeping roles of GPs

The six countries vary in the extent to which their GPs are gatekeepers. GPs in Sweden have no gatekeeping role, while in Switzerland a third of patients choose a health insurance model that uses GPs as gatekeepers. Croatia and Slovenia require their GPs to be gatekeepers within their public health systems, but private patients in those countries can see specialists without a GP referral. In Spain and the United Kingdom (UK), GPs have a gatekeeping role for all patients (Table 2). Whereas in the UK all GPs routinely see children and patients with gynaecological symptoms, in the other five countries those patients usually present to paediatricians (except in Sweden) and gynaecologists instead.

### Varying systems for funding medical care

How referrals are financed has a considerable effect on referral decisions. Medical systems where referral costs are usually met by insurance companies, so do not come out of hospital or primary care budgets (Croatia, Slovenia, Sweden, Switzerland), are likely to have no inhibitory effect on referrals. To some extent that is also the case where GPs and specialists share a budget (for instance in Swiss managed care systems), so who organises any necessary investigations is not important. In two of the participants' health systems, GPs who are considered to have “over-referred” may find their own income affected (Croatia, Spain). Having a budget or quota for specialist referrals or diagnostic tests tends to reduce referrals (Croatia and, for some tests, Slovenia and Spain). Other health systems explicitly put pressure on GPs to reduce referral rates (Croatia, Slovenia, Spain, UK).

### Referral systems and waiting times

Whereas some health systems encourage GPs to refer any patients with possible cancer early, even if there is a low risk of cancer (Denmark, Sweden), in others the
focus is perceived to be on how to save costs by reducing
the number of referrals (Croatia, Slovenia, UK). Complex
referral processes may also be a factor in deterring
referrals (Slovenia, Spain, UK).

Waiting lists for investigations or specialist appointments
also affect GP decision-making. Access to a fast-track
specialist appointment system for patients with suspected
cancer can be used to encourage referrals (Croatia, Slovenia,
Spain, UK), while in some of these jurisdictions GPs as a
whole have been criticised for purportedly overusing that
system, and asked to use it less (Croatia, Slovenia, UK).
Long waiting times may result in early referrals, where
the GP wishes to get patients into the “queue” quickly.
Conversely, long waits may discourage referral until the
patient has clear red-flag symptoms or signs, or positive
investigation results.

Ease of access to investigations
In some jurisdictions (Spain, Switzerland, Germany)
many GPs can perform in-house specialist investigations
themselves (for instance diagnostic ultrasound), and in
some cases they are paid for providing those facilities
(Switzerland, Germany). This may lower their threshold for
arranging such investigations. Other medical systems only
have those investigations available to GPs outside their
practices. There is variation in how much direct access GPs
have to such investigations, with some only being available
via specialist referral.

Relationship with specialist colleagues
The relationship with specialist colleagues is another key
factor. Whereas in some health systems specialists are
seen to welcome referrals (Switzerland, and to some extent
in Sweden), in others they are perceived as discouraging
them (Croatia, Slovenia, Spain, UK). The ease of being able
to telephone or email a specialist for informal discussion
and advice facilitates the care of patients who could have
cancer (Sweden, Switzerland, and to some extent in Spain),
as is the ability to refer to a specialist that the GP knows
personally (Sweden, Switzerland). Having a system that
prevents the GP from referring to a named specialist may
have an inhibiting effect on referrals (Croatia, Slovenia,
Spain, UK).

Fear of litigation or complaint
Fear of litigation, or complaint over a failure to refer, is
a significant factor in many countries (Croatia, Slovenia,
Spain, Switzerland, UK). In addition, some GPs may be
influenced in their decision-making by previous experience
of criticism from patients or colleagues when a serious
diagnosis was delayed due to a late referral. The opposite
experience is also possible, with criticism from patients or
colleagues who think that the GP should have managed a
presenting problem without referral (UK).

Effect of intensity of workload
A high workload may make GPs more likely to refer, in
an attempt to reduce follow-up appointments (Croatia,
Spain, Switzerland, UK). However, if there is an expectation
that the GP will write a detailed, comprehensive referral
letter, the time taken to do that may discourage the GP
from making a referral at that appointment (UK). In
Sweden, where a typical GP appointment is 30 minutes,
there is more time for patients to mention symptoms
that concern them, and more time for the GP to consider
whether investigation or referral is needed.

Clinical guidelines can affect referral decisions
Clinical guidelines can facilitate a GP’s decision to refer,
by giving advice on which patients need referral because
of a risk of cancer. However, some delegates reported
referral guidelines that mainly gave advice on how to avoid
inappropriate referrals (Croatia, Slovenia, Spain, UK).

Discussion
The readiness of GPs to act consists of personal attributes
(e.g. knowledge and attitudes about cancer, as well as
perceptions of the role of GPs) and system factors [15]. This
symposium identified many system and other non-clinical
factors that are likely to have a significant impact on referral
decisions. These include levels of gatekeeping responsibility,
funding systems, access to special investigations, fear of
litigation, and relationships with specialist colleagues. A
recent narrative review was unable to establish a causal
correlation between healthcare system characteristics and
cancer outcomes [13]. However, the authors conceded that
some system factors could have an influence on patient
and professional behaviour, and consequently contribute

<table>
<thead>
<tr>
<th>Country</th>
<th>Are GPs gatekeepers for patients seen within the public health system?</th>
<th>Are GPs gatekeepers for patients who pay for specialist care or are seen outside the public health system?</th>
<th>Do GPs see children?</th>
<th>Do GPs see patients with gynaecological problems?</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Croatia</td>
<td>Yes</td>
<td>No</td>
<td>Not usually</td>
<td>Not usually</td>
<td>10% self-refer and pay for specialist consultations Patients can self-refer for ultrasound and some other tests if they pay</td>
</tr>
<tr>
<td>England</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>10% self-refer and pay for specialist consultations</td>
</tr>
<tr>
<td>Slovenia</td>
<td>Yes</td>
<td>No</td>
<td>Not usually</td>
<td>No</td>
<td>25-30% of patients have private health insurance</td>
</tr>
<tr>
<td>Spain</td>
<td>Yes</td>
<td>No</td>
<td>Not usually</td>
<td>Not usually</td>
<td>Patients can self-refer to breast clinics</td>
</tr>
<tr>
<td>Sweden</td>
<td>Party</td>
<td>No</td>
<td>Yes</td>
<td>Not usually</td>
<td></td>
</tr>
<tr>
<td>Switzerland</td>
<td>About 33% of patients opt for a health insurance model that uses GPs as gatekeepers</td>
<td></td>
<td>Not usually</td>
<td>Not usually</td>
<td>Some patients are more likely to self-refer to specialists</td>
</tr>
</tbody>
</table>

Table 2 Gatekeeping characteristics of delegates’ countries.
to differences in cancer outcomes. There is evidence that, even when high level features suggest similar healthcare systems, there can be considerable variation in the way that healthcare is delivered [16].

The symposium's findings are consistent with studies which show that waiting times for tests and lack of referral guidelines are among the most important issues related to system delay [17, 18]. There is a clear difference in decision-making between the systems that have some special investigations done by GPs, and those that only have them as part of secondary care. In the former, doing the investigation is facilitated because it is seen as a quick, easy, and possibly income-generating way of making (or ruling out) a sinister diagnosis.

While there is a link between European health systems where GPs act as gatekeepers and poorer 1-year cancer survival rates [11], this symposium found that the degree of GPs' gatekeeping roles varied considerably between the participants’ countries. In addition, it may be that gatekeeping encourages GPs to use other diagnostic strategies, such as the ‘test of time’ [19], which could contribute to longer diagnostic intervals [13].

The considerable differences in healthcare funding systems were also seen by participants to have a clear impact on the referral decisions, particularly where a referral can affect the GP's own income, budget or referral quota. Some health systems specifically encourage GPs to refer patients who may have cancer, even in the absence of red-flag symptoms. Conversely, some implicitly discourage referrals, for example through financial penalties or waiting times.

GP decision-making is affected by how much local specialists welcome, or discourage, referrals. The level of rapport between GPs and those specialists is considered to be an important factor, as well as ease of access to specialists for advice before a referral decision is made.

Strengths and weaknesses of the approach

This symposium allowed experienced medical practitioners from six European countries to generate hypotheses, by comparing and contrasting their experiences of how their own health systems affect cancer referral decision-making. The countries represented are geographically diverse and show a wide variation in their 1-year cancer survival rates.

The findings draw attention to several factors that could feasibly contribute to key differences in the speed of cancer diagnosis in those countries. The results could inform the design of large-scale comparative European studies of cancer delay, since they highlight many of the variables that such a study must consider if meaningful comparisons are to be made.

However, this was a small piece of qualitative work that drew on the experience of eight GP researchers. The small number of participants involved means that system variations in other countries, or within the delegates’ own countries, cannot be accounted for, and this may have limited the breadth of the findings.

Conclusions

Although many patients with cancer present without red-flag symptoms, the GP's experience or "gut feeling" may cause a feeling of concern. How the health system is organised is likely to have a strong influence on how the GP acts on that concern. The multitude of factors affecting decision-making makes it likely that, even in the presence of red-flag symptoms, system factors are highly likely to affect whether or not a GP refers immediately. Reducing the time from presentation to specialist referral or investigation is an important step in improving cancer survival. The findings of the symposium propose important hypotheses on the factors that influence that time, and these warrant further research.

Conflicts of interest

Authors declare no conflicts of interest.

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