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Why do European Primary Care Physicians sometimes not think of, or act on, a possible cancer diagnosis? A qualitative study.

Short title: Reasons for delay in GP cancer diagnosis

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Why do European Primary Care Physicians sometimes not think of, or act on, a possible cancer diagnosis? A qualitative study.

Abstract

Background

While Primary Care Physicians (PCPs) play a key role in cancer detection, they can find cancer diagnosis challenging, and some patients have considerable delays between presentation and onward referral.

Aim

This study explores European PCPs' experiences and views on cases where they considered that they had been slow to think of, or act on, a possible cancer diagnosis.

Design and Setting

A multicentre European qualitative study, based on an online survey with open-ended questions asking PCPs for their narratives about cases when they had missed a diagnosis of cancer.

Method

Using maximum variation sampling, PCPs in 23 European countries were asked to describe what happened in a case where they were slow to think of a cancer diagnosis, and for their views on why it happened. Thematic analysis was used to analyse the data.

Results

A total of 158 PCPs completed the questionnaire. The main themes were: where patients' descriptions did not suggest cancer; when distracting factors reduced PCPs' suspicions of cancer; when patients' hesitancy delayed the diagnosis; where system factors hampered the

diagnostic process; when PCPs felt that they had made a mistake; and inadequate communication.

Conclusion

The study identified six overarching themes which need to be addressed. Doing so should reduce morbidity and mortality in the small proportion of patients who have a significant, avoidable delay in their cancer diagnosis. The 'Swiss cheese' model of accident causation shows how the themes relate to each other.

Keywords

Primary Health Care; Primary Care Physicians; Cancer; Europe; Diagnostic Errors; Qualitative research.

How this fits in

Primary Care Physicians can find cancer diagnosis challenging, and some patients have considerable delays between presentation and onward referral. When asked to describe what happened in such cases, PCPs described a variety of issues, often with many such factors in a single case. The 'Swiss cheese' model can be used to understand how these failures relate to each other.

Introduction

Primary Care Physicians (PCPs) play a key role in cancer detection.[1,2] However, cancer diagnosis can be challenging in primary care, as PCPs often see patients with non-specific symptoms that, while they could be due to cancer, are more often caused by benign conditions.[3,4] Early diagnosis of cancer can be a difficult task, requiring knowledge and clinical experience[5,6] and challenging decisions on referral.[7] System factors influence how quickly PCPs refer patients, these vary between the European healthcare systems,[8,9] and can even vary within a healthcare system due to differences in patient demographics and deprivation levels.[10]

Many patients with cancer are referred promptly by their PCPs, though some have considerable delays: in a United Kingdom study, 8.3% of patients were still unreferred 90 days after presentation.[11] Patients who experience referral delays are likely to have longer diagnostic intervals[12] and poorer cancer survival rates.[13] Cancer is one of the conditions that dominates diagnostic error reports from primary care.[7,14]

It is known that there can be missed opportunities to diagnose cancer in several phases of the diagnostic process,[8] but few studies have focused on PCPs' views. While one study explored European PCPs' views on how cancer diagnoses could be diagnosed in a more timely way,[15] another found that rural PCPs throughout Europe perceive greater cost, travel and access barriers for their patients than their urban colleagues,[16] and a Swedish study emphasised the challenges that PCPs face in sifting various symptoms and matching these to specific standardised cancer patient pathways,[17] there is a gap in the research on PCPs' own experiences of missing cancer diagnoses.

This study explores European PCPs' experiences and views on particular cases where they considered that they had been slow to think of, or act on, a possible cancer diagnosis.

Method

Study design

A multicentre European qualitative study, based on an online survey with open-ended questions asking PCPs for their narratives about cases when they had been slow to think of a diagnosis of cancer.

Development of the questionnaire

The Örenäs Research Group (ÖRG) is a European group of primary care researchers that studies the primary care factors that relate to cancer survival. A core group of ÖRG members designed a pilot questionnaire which was completed by fourteen PCPs. The final text of the survey included an invitation for a narrative: "*Please write a short description of a time when you were slow to think of a cancer diagnosis, or where you thought of cancer but were slow to do something about it*.", followed by three free-text questions: "*What happened?", "Why do you think it happened?"*, and *"If you saw this patient presenting in the same way today, what would you do differently*?". This paper analyses PCPs' replies to the first two of these questions.

Participants and recruitment

Participants were general practitioners (GPs) and doctors who had other specialist training but worked in the community and could be accessed directly by patients without referral.

ÖRG members from 23 countries ('local leads') helped us to recruit PCPs from each country. To achieve maximum variation,[18] we purposefully included a balance of female and male PCPs, a range of years of experience, and different practice locations (rural and non-rural). Consent was implied by agreeing to take part in the survey.

Data collection

Participants were sent a link to the on-line survey. To avoid the possibility that the meaning of the questions could change if translated, the survey questions were in English for all participants. Participants could answer the questions either in their own languages or, if they felt confident to do so, in English.

PCPs' demographic data concerning country, gender, whether they were a trainee, years of working experience (≤4 years, 5-14 years, ≥15 years) and practice setting (town/city, rural, island/remote, or mixed) were collected. Answers in native languages were translated into English either by professional translators or by translators whose native language was English. Data were collected between December 2020 and April 2021.

Analysis of data

We used thematic analysis,[19,20] an approach in which codes and themes are suggested by the data rather than by a theoretical framework. The phases of analysis included coding, followed by the identification and clustering of themes and subthemes, and the production of a descriptive thematic summary. There was considerable overlap between PCPs' responses to the questions "What happened?" and "Why do you think it happened?", so the data from these were combined before analysis. To manage the high volume of data we divided the core study group into three subgroups. The researchers independently coded

their subgroup's 53 randomly assigned participants' responses then compared them. Differences in researchers' codes were discussed, refined and agreed in online meetings. We then organised the data into themes and subthemes in multiple online meetings at which they were discussed and agreed.

Results

In total, 158 PCPs from 23 European countries submitted case descriptions and reflections (Table 1). Over half had at least 15 years of work experience, and just under a quarter were PCP trainees. One third of the respondents worked in rural or mixed areas.

Table 1. *Characteristics of the participants in the survey, N (%).*

Total participants		158 (100)
Gender	Women	89 (56.3)
	Men	68 (43.0)
	Prefer not to say	1 (0.6)
Work experience	<4 years	15 (9.5)
	5-14 years	46 (29.1)
	≥15 years	97 (61.4)
Training status	Established PCP	121 (76.6)
	Trainee	37 (23.4)
Area of work	Town or city	99 (62.7)
	Rural	33 (20.9)
	Island or remote	5 (3.2)
	Mixed	20 (12.6)
	Prefer not to say	1 (0.6)
Country	Bulgaria	10 (6.3)

Croatia	8 (5.1)
England	7 (4.4)
Estonia	6 (3.8)
Finland	5 (3.2)
Germany	5 (3.2)
Greece	8 (5.1)
Ireland	10 (6.3)
Israel	4 (2.5)
Italy	10 (6.3)
Latvia	10 (6.3)
Lithuania	6 (3.8)
Netherlands	3 (1.9)
Norway	7 (4.4)
Poland	7 (4.4)
Romania	8 (5.1)
Scotland	5 (3.2)
Slovenia	6 (3.8)
Spain	14 (8.9)
Sweden	8 (5.1)
Switzerland	3 (1.9)
Turkey	6 (3.8)
Ukraine	2 (1.3)

The analysis resulted in six themes, each with several sub-themes (Table 2). Many cases contained data belonging to several different themes. The themes and sub-themes are described below, with each quotation identified by participant number and country code.

Table 2: Themes and sub-themes

Theme	Sub-theme
Patients' descriptions did not suggest cancer	No 'red flag' symptoms or signs
	Symptoms typical of common non-malignant conditions
	Patients' views or explanations were misleading
	Patients said very little
Distracting factors reduced PCPs' cancer suspicions	Cancer risk perceived as low
	Investigations appeared to confirm a benign diagnosis
	The cancers were rare ones
	Improvement from symptomatic treatment
	The patients had had similar symptoms in the past
	Patients were frequent attenders
	Other health issues dominated or confused
	Impact from other people accompanying the patients
Patients' hesitancy delayed the diagnosis	Primary care organisational factors made patients delay their presentations
	Patients postponed follow-up
	Patients' social issues distracted from diagnostic process
System factors not facilitating timely diagnosis	High workloads
	Long waits for tests or specialist opinions
	Weaknesses in follow-up systems
	Limited PCP access to diagnostic tools and specialist consultations
	Gaps of continuity in primary care
	Unclear responsibilities and poor interaction with secondary care
	Lack of PCP experience and trainee supervision
PCPs felt they had acted wrongly	Poor or inadequate history taking or physical examination
	Too focused on specific symptoms or single possible diagnosis ('tunnel thinking')
	Delay in investigating or referring

Theme	Sub-theme
	Not noticing or not acting on abnormal test results
	Follow-up not planned or forgotten
	Trusting reassuring specialist opinions
	Not taking patients seriously enough
	Adapting to/accepting patients' ideas about the diagnosis
Problems with communicating adequately	Not giving enough explanation to patients or being assertive enough with them
	Reluctance to worry the patients
	Unusual dynamics in patient-doctor relationships
	Poor communication with secondary care and other healthcare providers

Patients' descriptions did not suggest cancer

Some PCPs explained why they had not interpreted their patients' stories and presenting symptoms as being indicative of cancer. They wrote that their patients' descriptions did not raise any suspicion of cancer, or that they noticed no 'red flags' suggesting cancer. Some patients' symptoms were interpreted as being typical of common non-malignant conditions:

> *I received a call from a patient who was complaining of a sore throat and a pain in the neck. It was the time of COVID pandemic, so my first thought was that he had some kind of infectious disease with respiratory symptoms […] my findings were compatible with the diagnosis of the respiratory infection (112/C)*

Patients' explanations could be misleading if they were related to other conditions. Some patients did not talk much about their symptoms or did not persist in telling the doctor about them:

Well, my thought is that I, as GP, after some time just stopped investigating thoroughly because I thought it went away - the patient stopped complaining. I think she thought that she was annoying me with her complaints since all those tests were normal. (82/A)

Distracting factors reduced PCP's cancer suspicion

Many factors could distract PCPs from considering cancer. The risk of cancer was sometimes perceived as low. Laboratory tests and physical examinations that were normal, or that appeared to confirm another diagnosis, reduced cancer suspicions, as could having symptoms from a rare cancer. Symptomatic improvement could also be a factor:

My patient was a 36-year-old woman with anaemia. Her only complaint was weakness. I done CBC [blood count] - found HGB [haemoglobin] 98, prescribed her [iron] Fe 160 mg a day. After a month her HGB rose to 110, she started to feel better. We continued Fe for 6 months (26/A)

When patients had a history of similar symptoms in the past, or were frequent attenders, this influenced PCPs' perceptions, so that they did not pay so much attention to these symptoms even where there were cancer risk factors:

The patient was well known to me after many years with many consultations because of different problems and complaints: muscular problems, chronic irritable colon and anxiety. She was a cigarette smoker. She started coughing, and I was late to refer her to an x-ray of lungs. She had suffered for similar problems for many years, and was one of my patients with most consultations during the last years. I bagatellised [played down] her symptoms. (136/V)

Sometimes other pre-existing or evolving health issues dominated PCPs' thoughts, making it difficult to get a clear overview and act appropriately:

> *During extensive blood-tests for examination of fatigue in a 56-year-old woman I found an unspecific monoclonal gammopathia [...] because of stable values, I informed the patient and planned to control the values twice a year the next years. However, during the following year, the patient developed poor mental health, and the follow-up of the values was forgotten in all the other follow-up throughout the following years. (83/P)*

PCPs also described how they could be influenced and distracted by people accompanying patients:

> *Her husband influenced me. I let him to influence my decision because there was a tension between them during the visit and the patient was ignoring her husband in an impolite manner. (44/T)*

Patients' hesitancy delayed the diagnosis

Sometimes primary care factors contributed to delayed presentations from their patients:

> *She didn´t want to seek help because there were no GPs working there permanently, […] there was lack of them. She waited until there was GPs working permanently. (97/I)*

In other cases, follow-up visits or tests were postponed by the patient because of practical difficulties or an unwillingness to be tested:

> *An old woman had cough for several months and came to my surgery for consultation. I advised for an x-ray but she had no way to go to the city at the time and she decided to postpone the examination. (14/L)*

Social problems related to patients themselves or their family members could distract patients from their own health problems. This could interfere with the PCPs' investigation plans:

> *She lives alone with her daughter (who provides no type of support and causes social problems) […] she presents with a general deterioration and weight loss. Analytical tests (48h) are programmed and an appointment in 5 days to complete the anamnesis and physical examination. The patient doesn't show up for the appointment. […] Probably this is all due to the social problems and lack of support in her care. (53/D)*

System factors not facilitating timely diagnosis

Health care organisational factors could hamper the diagnostic process. Some PCPs described how they struggled with stress, work overload and lack of time, where they felt pressured to act quickly as there were many other patients waiting for assessment, as in this example where a PCP explained why they had not followed cancer guidelines:

> *The patient is requiring his repeat prescription. You are constrained from time, because 15 more appointments is waiting for you with similar request that is repeat prescription. (68/L)*

Long waiting times for tests or specialist opinions and weaknesses in follow-up systems could contribute to delayed diagnosis. Limited PCP access to tests could interfere with the cancer diagnostic process:

> *…referred to ENT, then waited 2 months for CT chest - diagnosed right sided advanced lung cancer with paratracheal invasion; Pathway issue, lack of access to diagnostics etc. (70/O)*

Respondents also described problems due to a lack of continuity in patient care. When secondary as well as primary care was involved, or when the PCP initiating the investigation was not available, there could be lack of clarity as to who should be responsible for the next step:

> *Skin biopsy was taken [...] The result were not checked until 6 months later. The doctor was on [...] summer holidays and also patient forgot to ask the PAD diagnosis. It was found by accident when [...] doctor checking the old lab results. (118/U)*

Lack of PCP trainee experience and supervision could result in doctors managing symptoms, without thinking about what they could indicate:

> *60 years old man came with low back pain. We made X-ray, blood tests. He had a fracture of L5. The pain was getting worse, and he died in a few months. I didn't have such experience. There were no programs for prevention of cancer and any trainings for GP about cancers. (57/E)*

PCPs felt they had acted wrongly

Some PCPs thought that they had directly contributed to delayed cancer diagnoses, for example because their history-taking or examination were inadequate. Some described 'tunnel thinking', when they were too focused on a single possible diagnosis early in the diagnostic process:

> *I diagnosed costal fractures without pneumothorax, clinically. I said it would take time to get well. She waited and waited, I told her to have patience. She did not get better. After months I took an x-ray – lung cancer with metastasis to bones, pathological fractures […] One diagnosis made me not see the other. (30/V)*

PCPs gave examples of where follow-ups were forgotten or not planned, or when they had overlooked or did not act on abnormal test results:

> *I overlooked atypical leukocytes in an around 70-75y male patient. [...] Our haematology lab sheet is very long with about 30 indicators, some of which are quite often out of normal range (e.g. RDW or monocytes). I just overlooked it. (148/Q)*

Trusting reassuring opinions from specialists could stop them searching for other possible explanations for their patients' symptoms:

> *A woman in her 30s had dyspepsia and reflux. [...] I consulted with a gastroenterologist who deemed the patient too young to have serious stomach cancer risk. [...] Her young age and the gastroenterologist's consultation put me at ease. (117/F)*

Some PCPs made the mistake of accepting patients' ideas about a benign diagnosis. This stopped them investigating and safety-netting:

> *'An employee around 60 years at my former clinic came to me with a fatigue. She had been feeling tired from half a year. She had been able to change her work content avoiding activities she felt increased the fatigue. […] Both I as a doctor and she as a patient zoomed in on "burn-out".´(98/I).*

Problems with communicating adequately

PCPs mentioned a variety of issues relating to problems with communication with the patient, their relatives or colleagues. They described the need on the one hand to be assertive and informative enough about the necessity for investigations and referrals, and on the other hand the wish to avoid worrying patients unnecessarily. Several PCPs saw this as their own failure in communication and engagement:

I advised for an x-ray but she had no way to go to the city at the time and she decided to postpone the examination. A month later she came again and suffer from haemoptysis […] Patient was reluctant and I was not as persuasive as I ought to be in order to force her seeking evaluation from a specialist sooner. (14/L)

[…] (on reflection) I realise that I had a reluctance to refer as I thought this would cause alarm. I think this is subconscious, and had I considered cancer as a possibility I would, of course, have referred, but I wonder if my brain was steering me towards reassurance to avoid causing worry? (62/H)

Unusual dynamics in the patient-doctor relationship could affect the diagnostic process.

His wife was a doctor and she often prescribed an antibiotic for infections herself […] Since he was also treated by his wife, he wasn't consistently managed by me. (38/K)

Respondents also described poor communication, either from secondary care or from other healthcare providers:

The patient came with MRI [magnetic resonance imaging] report to her GP practice but the description of the spine MRI was very detailed and long and importantly there were no final conclusions or advice for clinicians regarding further steps. Two GPs saw the report but missed information written in small letters there might be metastases in the thoracic spine. (138/G)

Colleagues with poor fluency in the local language could be a problem:

The radiologist was a foreigner and the report was difficult to understand because of language problems. (84/V)

Discussion

Summary

Our results present European PCPs' reflections on a complex, challenging task that they frequently face: making a timely diagnosis of cancer. We identified six themes representing different layers of patient-, PCP- and system-related factors that can interfere with the cancer diagnostic pathway. Communication challenges had an impact on all our themes, and they were repeatedly described by the PCPs and expressed in various ways. The 'Swiss cheese' model of accident causation is a way of visualising how patient harm happens, based on a systems approach.[21] In a complex healthcare system, errors are prevented by a series of defences, barriers and safeguards, represented by slices of cheese. The holes in the slices represent unintended weaknesses in different parts of the system: when the holes in the slices align, a risk passes through all the holes, and this leads to a harmful failure of the system. The model is relevant to our findings, with our six themes mapping across to slices that represent safeguards or facilitators to timely cancer diagnosis, and the holes in them representing weaknesses in that part of the primary care process. Figure 1 gives an example of a pathway to a delayed cancer diagnosis that a participant reported to us, with case-specific holes in all six theme-related safeguards/facilitators.

Strengths and limitations

This is the first multinational study focusing on the experiences and reflections of PCPs who self-identified as having been slow to think of, or act on, a possible cancer diagnosis. It offers a comprehensive insight into the lessons to be learned from participants' cases in 23 European countries covering different health care systems, PCP demographics, work

experiences and practice settings. A multinational team from the ÖRG carefully developed and piloted the questions, then performed the qualitative analysis, and so were able to consider the cultural and health care contexts of the participating countries. The large range of participating countries and the commonalities of PCPs' experiences across those countries means that the identified themes are likely to be relevant to PCPs in other countries and healthcare systems.

The survey invited participants to share a single case, which could have prompted participants to select their most memorable cases rather than more common or typical ones. However, participants could have submitted several cases if they wanted to. Recall bias was possible, as some events had taken place several years earlier. Social desirability bias was possible, as participants may have answered questions in a way that they thought would be viewed favourably by the researchers. Participants may also have given incomplete descriptions, or there may have been response bias, because of fear of litigation or complaint; however, we made it clear that participants' responses would be anonymised. While the questionnaire language was English, which was not the native language of most participants, local study leads were asked to recruit only participants who would be likely to understand the survey questions. Some answers were translated by national teams which may have resulted in missed nuances; however, many languages were represented in the analysis team. While we did not assess for data saturation, we had rich data from 158 PCPs, all their responses were analysed, and it is unlikely that new themes would have emerged with additional respondents.

The data came from GPs in 23 European countries, each with their own cultural viewpoints, healthcare systems and GP training processes.[22] While it may therefore be that some of the

themes that we identified are more commonly encountered in some countries than others, we found that GPs from all the countries described issues that were encompassed by a wide range of our themes.

Comparison with existing literature

Our findings map across to those of other studies. One confirms that missed diagnostic opportunities can occur on several occasions, and can relate both to health-care systems and to individuals.[7] Other researchers have also found that system factors include lack of continuity in primary care and time pressures, as well as poor access to testing with long waiting times,[233,244] and confirmed our findings of problems relating to gaps of continuity in primary care, fragmented care and trainee supervision.[7,233,244] In a 20-country European Delphi study, general practitioners came to a consensus that having quicker and easier communication with secondary care, shorter waiting times and getting prompt advice from secondary care were essential for early cancer diagnosis.[255]

Other researchers have also described our findings that presentation of non-specific symptoms, the presence of other comorbidities, and symptomatic improvement, can be barriers to diagnosis.[8,244,266,277] There is evidence that this can result in longer diagnostic intervals, for example for colorectal cancer diagnosis in patients with mental health and gastrointestinal co-morbidities.[288] Some of our participants reported delays in diagnosis due to poor history-taking or physical examination, and one author points out that these basic skills continue to be paramount.[299]

Some of our findings reflect those of another researcher, who reported that having an alternative working diagnosis, not reconsidering an initial diagnosis, and lacking follow-up were associated with long times to referral for patients with colorectal cancer.[266] Our

respondents' reports of inadequate plans for follow-up, as well as reassurance from normal test results, have also been reported by other researchers.[8,30,311]

Implications for research and practice

This study offers a model of how a variety of factors can cause unintended weaknesses in the primary care diagnostic pathway, resulting in a delayed cancer diagnosis. The model could be used to support the training of primary care clinicians, so that they are aware of the potential 'holes in the Swiss cheese' and how to avoid them.

Our findings suggest that there needs to be cancer-specific training for PCPs, focusing on a systemic approach when organising tests and referrals, reviewing test results, and the use of follow-up and safety-netting. There is also a need for 'safe spaces' for PCPs to discuss, share and learn from their own experiences of delayed cancer diagnosis. Healthcare systems need to be aware of the impacts on timeliness of cancer diagnosis from high PCP workload and poor continuity of PCP care, inadequate communication pathways between primary and secondary care, and poor access and waiting times for diagnostic tests and specialist opinions. Future studies should analyse how common the factors identified in this study are, quantify the effect that each of them has, and find out whether some are specific to particular healthcare systems.

European PCPs described cases where they considered that they had been slow to think of, or act on, a possible cancer diagnosis. The six overarching themes represent different layers of patient-, PCP- and system-related factors that can interfere with the cancer diagnostic pathway, with communication challenges being common to all of them. The 'Swiss cheese' model of accident causation shows how the themes relate to each other. Addressing these

issues should reduce morbidity and mortality in the small proportion of patients who have a significant, avoidable delay in their cancer diagnosis.

Declarations

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Author contributions

All authors participated in the study design, were involved in the data collection and analysis, contributed to the manuscript and approved the final version. DP, MH and TK jointly supervised the project.

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Data sharing

To avoid the risk of identification of individual participants or patients, the datasets generated and analysed during the current study are not publicly available. However, they

are available (with any identifying information redacted) from the corresponding author on reasonable request.

Competing interests

None declared.

Patient consent for publication

Not required.

Ethical approval

See supplementary file. The University of Bern, Switzerland, recruited participants from five of the countries in the study. In the other countries, invitations were sent by local study leads, and these leads either achieved local ethical approval or gave statements that formal ethical approval was not needed in their jurisdictions.

References

1. Johansen ML, Holtedahl KA, Rudebeck CE. A doctor close at hand: How GPs view their role in cancer care. Scand J Prim Health Care. 2010;28:249-55.
2. Mitchell GK, Burridge LH, Colquist SP, Love A. General Practitioners' perceptions of their role in cancer care and factors which influence this role. Health Soc Care Community. 2012;20:607-16.
3. Hamilton W. Cancer diagnosis in primary care. Br J Gen Pract. 2010;60:121-8.
4. Ingebrigtsen SG, Scheel BI, Hart B, Thorsen T, Holtedahl K. Frequency of 'warning signs of cancer' in Norwegian general practice, with prospective recording of subsequent cancer. Fam Pract. 2013;30:153-60.
5. Baerheim A. The diagnostic process in general practice: has it a two-phase structure? Fam Pract. 2001;18:243-5.
6. Johansen ML, Holtedahl KA, Rudebeck CE. How does the thought of cancer arise in a general practice consultation? Interviews with GPs. Scand J Prim Health Care. 2012;30(3):135-40.
7. Singh H, Schiff GD, Graber ML, Onakpoya I, Thompson MJ. The global burden of diagnostic errors in primary care. BMJ Qual Saf. 2017;26:484-494.
8. Lyratzopoulos G, Vedsted P, Singh H. Understanding missed opportunities for more timely diagnosis of cancer in symptomatic patients after presentation. Br J Cancer. 2015;112 (Suppl 1):S84-91.
9. Harris M, Vedsted P, Esteva M, et al. Identifying important health system factors that influence primary care practitioners' referrals for cancer suspicion: a European cross-sectional survey. BMJ Open. 2018;8:e02290.

10. Zhou Y, Mendonca SC, Abel GA, et al. Variation in 'fast-track' referrals for suspected cancer by patient characteristic and cancer diagnosis: evidence from 670 000 patients with cancers of 35 different sites. Br J Cancer. 2018;118:24-31.

11. Swann R, McPhail S, Witt J, et al; National Cancer Diagnosis Audit Steering Group. Diagnosing cancer in primary care: results from the National Cancer Diagnosis Audit. Br J Gen Pract. 2018;68:e63-72.

12. Swann R, Lyratzopoulos G, Rubin G, Pickworth E, McPhail S. The frequency, nature and impact of GP-assessed avoidable delays in a population-based cohort of cancer patients. Cancer Epidemiol. 2020;64:101617.

13. Hanna TP, King WD, Thibodeau S, et al. Mortality due to cancer treatment delay: systematic review and meta-analysis. BMJ. 2020;371:m4087.

14. Fernholm R, Pukk Härenstam K, Wachtler C, Nilsson GH, Holzmann MJ, Carlsson AC. Diagnostic errors reported in primary healthcare and emergency departments: A retrospective and descriptive cohort study of 4830 reported cases of preventable harm in Sweden. Eur J Gen Pract. 2019;25:128-35.

15. Harris M, Thulesius H, Neves AL, et al. How European primary care practitioners think the timeliness of cancer diagnosis can be improved: a thematic analysis. BMJ Open. 2019;9:e030169.

16. Murchie P, Khor WL, Adam R, et al. Influences of rurality on action to diagnose cancer by primary care practitioners - Results from a Europe-wide survey in 20 countries. Cancer Epidemiol. 2020;65:101698.

17. Hultstrand, C, Coe AB, Lilja M, Hajdarevic S. GPs' perspectives of the patient encounter - in the context of standardized cancer patient pathways. Scand J Prim Health Care. 2020;38:238-47.

18. Patton, MQ. Qualitative research and evaluation methods (3rd ed.). Thousand Oaks, CA: Sage Publications; 2002.

19. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology. 2006;3, 77–101.

20. Braun V, Clarke V, Gray D (Eds.). Collecting Qualitative Data: A Practical Guide to Textual, Media and Virtual Techniques. Cambridge: Cambridge University Press; 2017.

21. Reason J. Human error: models and management. BMJ. 2000;320:768-70.

22. Badinella Martini M, Garattini L, Nobili A, Mannucci PM. Why so many different specialty training programmes in general practice in Europe? Internal and Emergency Medicine. 2022;17(7):1851–1854.

23. Green T, Atkin K, Macleod U. Cancer detection in primary care: insights from general practitioners. Br J Cancer. 2015;112(Suppl 1):S41–S49.

24. Botey AP, GermAnn K, Robson PJ, O'Neill BM, Stewart DA. Physician perspectives on delays in cancer diagnosis in Alberta: a qualitative study. CMAJ Open. 2021;9:E1120-1127.

25. Tzanis G, Harris M, Brekke M, et al. What factors empower general practitioners for early cancer diagnosis? A 20-country European Delphi Study. Prim Health Care Res Dev. 2022;23:e76.

26. van Erp NF, Helsper CW, Olyhoek SM, et al. Potential for Reducing Time to Referral for Colorectal Cancer Patients in Primary Care. Ann Fam Med. 2019;17:419-27.

27. Mitchell ED, Rubin G, Merriman L, Macleod U. The role of primary care in cancer diagnosis via emergency presentation: qualitative synthesis of significant event reports. Br J Cancer. 2015;112 Suppl 1:S50-6.

28. Walter FM, Emery JD, Mendonca S, et al. Symptoms and patient factors associated with longer time to diagnosis for colorectal cancer: results from a prospective cohort study. Br J Cancer. 2016;115:533-41.

29. Hamilton W. The future of diagnosis in general practice. Br J Gen Pract. 2020;70:319-320.

30. Hardy V, Yue A, Archer S, et al. Role of primary care physician factors on diagnostic testing and referral decisions for symptoms of possible cancer: a systematic review. BMJ Open. 2022;12:e053732.

31. Poon EG, Kachalia A, Puopolo AL, Gandhi TK, Studdert DM. Cognitive errors and logistical breakdowns contributing to missed and delayed diagnoses of breast and colorectal cancers: a process analysis of closed malpractice claims. J Gen Intern Med. 2012;27:1416-23.

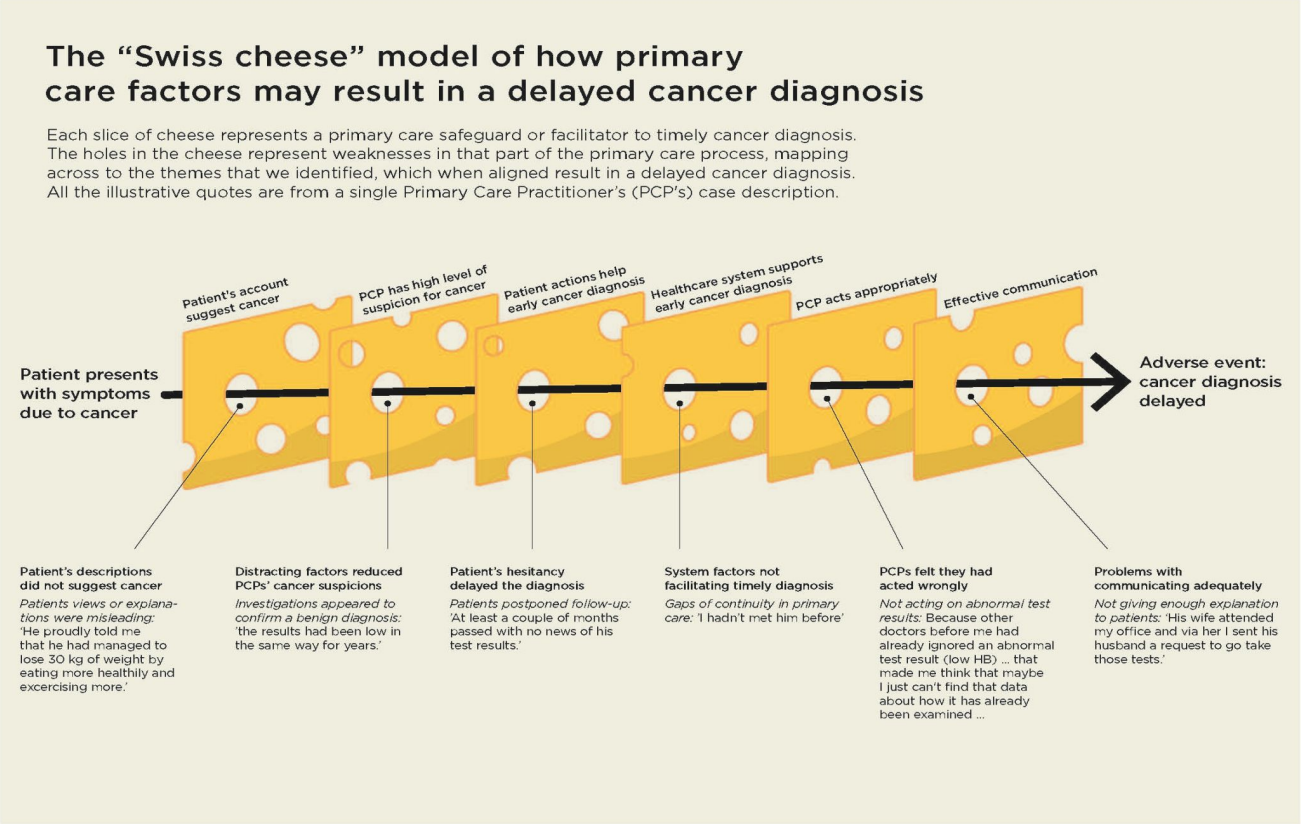

Figure1. The "Swiss cheese" model of how primary care factors may result in a delayed cancer diagnosis