

Original Article

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Abstract

Introduction: Delays in the diagnosis of cancer were found to be a worldwide matter, and the early cancer detection has been targeted as a way to improve survival. Quantitative studies from Saudi Arabia reported a high number of cancer cases presenting at cancer centres for the first time with more advanced stages of the disease progression compared to Western countries without exploring the reasons for this phenomenon. Worldwide research identified several factors that contribute to delay in the diagnosis and treatment of cancer which were attributed to both patient and healthcare system. However, it was argued that variation in the operation of health systems and the socio-cultural context across countries makes it difficult to generalise findings beyond individuals' countries. This necessitates country specific research to investigate why patients in Saudi Arabia present to cancer centres with late/advanced stages of their diseases.

Research aim and objectives: The aim of this study is to identify and explore the factors that contribute to late-stage presentation of common cancers in Saudi Arabia. The main objective of this study is to understand the help seeking journey taken by patients with cancer from the time they discovered or felt their symptoms until the time they have their treatment initiated.

Methods: Qualitative interviewing was used to collect data from 20 patients and 15 health professionals. The interviews were transcribed and then were subjected to the thematic analysis using a framework approach developed by Ritchie and Spencer (1994).

Results: While some findings support what previous studies found as contributing factors responsible for delayed presentation of common cancers, this study identified several factors, which are believed to be country-specific. The 'role of General Practitioner (GP)', 'challenges facing GPs' and 'ambiguity of the referral system' were found to be factors that contribute to delay in the diagnosis and treatment of cancer in Saudi Arabia.

Conclusion: This research identified several factors that need to be investigated in the future using quantitative methods. There is a need to investigate the extent of using alternative medicine and its possible association with late presentation of cancer.

Introduction

Over the course of the last 20 years, a high number of patients presenting at cancer centres in Saudi Arabia were diagnosed with advanced disease. This has been the case for common cancers, such as breast cancer (40%),¹ nasopharynx (79.2%)² and colorectal cancer (64%).³ The extent of and reasons for late-stage presentation in Saudi Arabia are still to be investigated; however, worldwide systematic reviews^{4–7} and other studies that included common cancers^{8–11} have shown that this is a global issue, that there are many factors involved that relate to health providers and patients and that there are also disease/clinical factors, such as the type of cancer, size, site and growth rate.^{4,9} However, variations in cancer survival rates and outcomes among countries have been reported,¹² which has prompted researchers to focus on the role of early diagnosis.

Several studies have reported that factors associated with health providers were under-researched and needed further investigation.^{13–16} In fact, research has shown that patients' pathways to Health Care Practitioners (HCPs) and the initial management of their condition in primary care settings were found to be key determinants of cancer outcomes.⁴ Despite the efforts and the wide range of studies that aimed at improving the early diagnosis of cancer, it has been argued that research in this area is complex and that the pathways to cancer diagnosis and treatment are often not straightforward.¹⁷ A number of researchers in this field have argued that it is becoming increasingly difficult to generalise findings from studies on different types of cancers with different symptoms when health system operations and cultural issues differ from one country to another.^{10,18} The problems with generalisability necessitate more research efforts from different countries to increase our knowledge in this field.

Studies about cancer delay in Saudi Arabia are limited to reporting a high number of late-stage cases presented at cancer centres in Saudi Arabia compared with Western countries.^{1–3} Despite free healthcare services, it is not yet known why patients in Saudi Arabia present

with their diseases at cancer centres in the advanced/late stages. So far, none of the published studies has investigated the reasons for the 'late-stage presentation' of these common cancers at cancer centres in Saudi Arabia.

This study was conducted in the Saudi health setting between 2010 and 2012. The cancer context in Saudi Arabia suffers from a lack of knowledge regarding the extent of delays compared to the substantial work done in Western Europe. To date, far too little attention has been paid to the contributing factors that can occur along the pathway from patients first noticing the symptoms until the initiation of treatment that may lead to late presentation of common cancers in Saudi Arabia.

Besides the acknowledgement that health system factors were under-researched, the Saudi healthcare context is, however, different from those studies reporting factors relating to their own health systems. This necessitates country-specific research in the area to bring new insights into the existing knowledge. While substantial work has been undertaken to understand patients' experiences with different types of cancers, far too little attention has been paid to include health professionals' perspectives in studies reporting factors associated with health systems. As health providers, their experiences and opinions should add more insights and thoughts from different perspectives to our knowledge base.

Methods

This study adopted a qualitative method using in-depth interviews with 20 patients who presented with late stages of different common cancers at two cancer centres in Saudi Arabia. The study also involved the views of 15 health professionals who provide cancer care in the Saudi health system from the primary care setting along the pathway to cancer treatment provided in oncology centres.

Inclusion and exclusion criteria for patient recruitment as follows:

Inclusion	Exclusion
1. Patients who presented with advanced stages of symptomatic common diseases, such as breast, lung, thyroid, colorectal, leukaemia, head and neck cancers and lymphomas.	1. Patients who are not fit for long conversations.
2. Patients over 20 years old to avoid children and young age groups where cancer is uncommon.	2. Patients with rare, unknown primary or asymptomatic diseases, or with delay due to slow-growing tumours.
	3. Children.
	4. Patients unable to consent (e.g., mentally ill, language difficulties and dementia).

In the interviews, patients were asked in a similar way to tell their stories from the time of feeling the symptoms until the time they saw their oncologist. This is the opening and the main question, which aimed to give participants the freedom to determine the time when they first felt the symptoms until their treatment was initiated. As a storytelling approach was used to collect interview data, an interview guide was not used. Each participant had a different story; however, the research question was always taken into account when asking probing questions. The events of

the story initiated instant probing questions that asked participants to clarify important issues and explain why decisions or actions were taken. The length of patients' interviews was between 40 and 60 minutes. Although patients were given the time to talk about their help-seeking journey, questions such as how patients felt regarding their illnesses were not asked, which shortened the interview time.

The 15 interviews with the doctors who participated in this study were related to their capacity to provide further information on the data collected from the 20 patients. The views of doctors from all three levels of healthcare (primary, secondary and oncology centres) provided additional and important knowledge about certain aspects of the health services that could not be explained by patients, and these interviews highlighted issues pertaining to patients' help-seeking behaviour.

Oncologists' interviews took place at their workplace in both the oncology centres during the time the researcher spent at both centres when the patients were being interviewed. While specialists and GPs were selected from different provinces, three specialists were selected from the same provinces where the GPs were recruited.

Before the recruitment process took place, a Research Ethics Committee approval letter was obtained for this study from the University of Sheffield. Data were collected using a audiotape recorder, and each participant was assured that all information saved on personal computers will be password protected and that audiotapes will be destroyed within 6 months after transcribing. Participants were asked to sign a consent form, and the choice to withdraw at any time was given and clearly explained.

Data Analysis

This research aimed to explore the contributing factors that may cause patients with common cancers to present to cancer centres at late/advanced stages of their diseases in Saudi Arabia. Data were collected using in-depth interviews from two sources: patients and health professionals. A major feature of qualitative data is its richness and holistic nature, which will result in a detailed description of issues to be covered.¹⁹ This can be seen as the strength of qualitative data; however, holistic and rich information needs to be reduced and displayed in a systematic way to be able to draw conclusions and verifications from it.²⁰ This is part of the data-analysis process. Thematic analysis using the systematic framework developed by Ritchie and Spencer²⁰ was chosen as an appropriate approach for the current research for several reasons. First, it provides systematic and visible stages for the analytical processes, meaning that funders and others can clearly see what results have been obtained from the data in what stages.²¹ Second, framework analysis differs in that it is better adapted to research that has specific questions, a limited time frame and a pre-designed sample. Third, the prime concern of framework analysis is to describe and interpret what is happening in a particular setting.²⁰

Faced with a large body of material generated by in-depth interviews, NVivo 8 provided the ability to store, code and retrieve the data. Although the data were analysed using the framework analysis described earlier, NVivo 8 was used to organise and save the work for easy retrieval. Fonts and colours were used to visually identify different concepts within the text. The electronic linkage provided relative ease and rapidity of data retrieval. NVivo 8 has the ability to link similar themes that emerged from different interviews by using the 'see also' links. The field notes taken during interviews were added to each

source as memos. Although most themes were identified prior to using the software, additional themes were identified due to the easy access to the data and the way in which it was searched through and visualised.

Result

The role of GPs at the Primary Health Care Centre (PHCC)

Analysis showed that some patients did not think about consulting the GPs at primary care centres when they experienced their symptoms. They provided various reasons, related to their past experiences and interactions with GPs in the primary care setting. Some patients felt that there was a denial from GPs in primary care when they tell them about symptoms that could be important to disclose. The names given to all the participants in this study are not their real names.

'he never looked at my nose every time I told him about the nasal bleeding' (Saleh).

Saleh is a diabetic patient and his GP knows about the diabetes. There could be a communication problem in Saleh's case, because the doctor assumed that the bleeding could be related to the diabetes, as Saleh assumed when he appraised the bodily changes. The point is that Saleh considered this to be a denial, therefore had a negative impression about the GP and never came back to primary care until the frequency and amount of bleeding pushed him to access the Emergency Room (ER) at one general hospital in his town.

One patient claimed that he presented with a sore throat and a swelling in his neck and that his GP did not even look at his neck when he consulted him at the first time:

'The swelling was obvious to anyone, but the doctor quickly looked at my throat with that flat wood stick and prescribed the antibiotics straightaway' (Mohammed).

Mohammed had leukaemia. He had a continuous sore throat and neck pain and had had a swelling in the neck for long time which he had treated with antibiotics. Leukaemia is sometimes difficult to diagnose. However, Mohammed did not return to his GP.

'They just look at you quickly in the PHCC and they give you painkillers or antibiotics which I can buy from the chemist' (Saeed).

There seemed to be a negative impression and low expectations of primary care. Jaber had a nasopharyngeal cancer and had the same view towards GPs, but with more explanation:

'GPs in PHCC normally give you these medications and will ask you to come back if it did not work; and then give you different medications' (Jaber).

Patients were likely to undermine the role of GPs as active practitioners in healthcare provision. Some patients stated that they only visited GPs in primary care for purposes such as immunisations, to obtain referrals or to obtain free medication:

'I would go for immunisation, for Hajj time, you know, or to have referral to the hospital if I need to' (Maha).

Based on patients' stories, female patients were likely to avoid male doctors when they decided to consult GPs in primary care:

'... too many women patients in the waiting area... so I went to another female doctor in the private primary clinic and I showed her the swelling and she said this is nothing to worry about' (Zahra).

The data gathered from other sources (specialists and oncologists) had shed some light on what emerged from patients' data

regarding the general negative impression about the role of GPs in primary care and their abilities to be an active practitioner in the health system. Specialists pointed out some challenges around referrals that may explain further the perceived role of GPs in primary care:

'So when it comes to referrals it is a headache, patients normally ask for referrals anyway and sometimes we receive unnecessary referrals because patients insist' (Dr Nader).

One oncologist thought that the patients in advanced stages presenting at the cancer centres were misdiagnosed earlier in the pathway to the primary care setting:

'GPs are not experienced to recognise the warning signs and give painkillers and other medications for long time until the disease progressed' (Dr Salman).

Just as some patients who seemed to underestimate the role and knowledge of GPs, some oncologists thought that the knowledge of GPs may not be sufficient to suspect or diagnose cancer cases:

'... I don't think the GPs in primary care will suspect cancer as one possible diagnosis, so they will keep prescribing medications for whatever symptoms patients bring to them' (Dr Maha).

This was also raised by a specialist who argued that the limited knowledge and the experiences of GPs regarding cancer signs might be a reason for the delayed presentation of cancer cases:

'GPs normally refer patients with severe symptoms, but you know, their knowledge in cancer is limited anyway' (Dr Khan).

There was recognition from one GP about the lack of cancer knowledge among doctors in primary care:

'Sometimes it is the experience of the doctors; they do not have the knowledge to suspect the cancer' (Dr Sarah).

Similar to what emerged from patients' data, it is likely that a general belief among health professionals is that doctors in primary care do not have the level of knowledge to help recognise symptoms that could be signs of cancer. Criticisms from specialists might be based on past experiences from cases referred to them from primary care. While GPs have no direct contact with oncologists, it can be assumed that the criticism or opinions of oncologists might have originated because of patients' histories.

Challenges facing GPs in primary care

In order to understand the overwhelming role of GPs in Primary Health Care Centres (PHCCs) in Saudi Arabia, it is important to understand the GPs' points of view. Some patients felt that the GP clinics are overloaded, and the GP did not have the time to listen to their complaints or the time to fully examine the patient. This has been a topic raised by GPs who participated in this study.

'Sometimes we have too many patients and there should be three or four doctors in the PHCC but there is only one or two doctors for different reasons such as holidays, coverage in other PHCC. One doctor has no time to examine the patient properly' (Dr Ali).

Three GPs argued that they sometimes see between 70 and 100 patients a day because of the walk in system which means that they had to compromise the consultation time to see all patients arriving to the waiting area during working hours (8:00 am–4:00 pm). This means that with an average of 80 patients a day, and if the GP and the nurse work continuously for 8 hours, the GP can only spend 6 minutes with each patient.

'We are so busy, at this time, each one of us see more than 80 patients a day, here in this PHCC, other centres in other areas maybe worse' (Dr Ali).

One female doctor claimed that cover for female GPs is always an issue. Female doctors need to cover for other female doctors in other PHCCs during periods of annual leave and that the situation is even more complicated due to transportation restrictions in the country regarding females in general. Dr Ayshah stated that there is only one way to cover for each other during holidays:

'The regional directorate of PHCCs cannot always provide accommodation or transportations for female GP, instead they inform the other PHCC to send their female patients to me here—if they have no female GP for any reason' (Dr Ayshah).

One female GP claimed that there is a limited number of female GPs and she had to cover two PHCCs in the region because one female doctor was on holiday and she can only see female patients and children.

'I think the big problem is too many patients and less time available to doctors. No time to fully examine the patient' (Dr Ahmed).

Turning to the main theme and highlighting the possible shortages in the number of GPs and the clinics in primary care which are likely to be overloaded, one GP argued that some doctors in primary care were overwhelmed by the number of patients waiting to be seen:

'It is very difficult to take him to the bed and examine him like what is written in books, we do not have time while there are other five patients knocking on the door to see you at the same time' (Dr Ahmed).

Due to the lack of time doctors spent with their patients, patients were only given insufficient information and guidance regarding their condition or what to do next.

'They did not tell me anything, but I think they knew that I had cancer' (Saleh).

Ambiguity of the referral processes

This theme has emerged from data obtained from patients and was further highlighted by data obtained from health professionals. Analysis suggests that the referral processes from GPs at primary care to general hospitals are problematic. There seem to be no specific guidelines; not only for suspected cancer symptoms but also for referral processes from one healthcare level to another.

Eventually, some GPs claimed that their referrals are not being taken seriously by specialists at general hospitals:

'Doctors in general hospitals do not take care of our referrals, sometimes they do not read it, so why we are sending referrals' (Dr Sarah).

The GPs claimed that the specialists in general hospitals did not send any feedback when they sent referral letters:

'No feedback, the percentage of the feedback is about 5%, it should be 100%. We discussed this many times with the management and they always say different excuses' (Dr Ahmed).

However, a specialist at one general hospital described the heavy demand on the services provided at general hospitals. He criticised the number of unnecessary referrals sent by GPs:

'Some referrals are unnecessary. The GP should manage those cases' (Dr Shaker).

There could be some underestimation of GP roles. However, patients' power or political issues appeared to be evident here. Apart from those specialists who claimed that they receive unnecessary referrals from GPs, the specialists attributed this to the fact

that patients put pressures on GPs to refer them to the hospital for different reasons and the GPs used the 'elective' option sometimes without clear medical justification.

Discussion

Primary care in Saudi Arabia is a gate-keeping system like other systems in Europe such as those in the UK and Denmark.²² However, the difference is that primary care in Saudi Arabia is not a list system (where a pre-booked appointment is needed to be able to see a GP). Rather, it is a walk-in system that has its own advantages and disadvantages. The advantage is its flexibility, as patients can see a GP any time when they need to. The disadvantage is that the GP has no control over the number of patients that he can see each day. Patients can turn up any time during working hours, and the GP may have to compromise on the length of consultations to be able to see all of the patients. Patients with mild conditions may find it easier to turn up at any time and may therefore take the place of those patients who are in real need of seeing the GP. This issue has an impact on patients' help-seeking behaviours. Apart from their illnesses and distress, patients who are in need of a consultation know that they have to wait long hours before being seen by a GP. When they are seen, the length of the consultation might not be long enough to explain and discuss their symptoms with the GP. This was evident from patient interviews, where they argued that GPs did not even listen to them. Doctors in primary care agreed that this was the situation in primary care settings where fewer doctors had to see a large number of patients per day. The negative impression about GPs in primary care may result from poor communication, which is a common source of dissatisfaction with medical care.²³

The negative impression about GPs and their roles as gate-keepers has been reported in UK studies as a barrier to seeking.^{24,25} This indicates that the GPs in the UK have the control over what cases need referrals and patients cannot obtain a referral without a clinical decision. This does not seem to be the case in the Saudi primary care setting. The GPs stated that the 'elective' option on the referral form meant that patients could request a referral to secondary care and that the GP had to justify the reason for referral to the specialist who would have to deal with the case. This had created a conflict between GPs, patients and specialists at general hospitals, causing unnecessary referrals and long waiting lists in most clinics and for other services at general hospitals. It is not clear if there is a real shortage of doctors in primary and secondary care or whether this is due to how the system works. This issue is highly relevant to care seeking and the late presentation of cancer cases, which necessitates future research. Overall, this study suggests that there are concerns among specialists and oncologists about the role of primary care in the early detection and diagnosis of cancer rooted in the lack of communication between the three levels of healthcare and the negative impression of them perceived through interaction with the patients.

This study has limitations. The final sample was selected purposively by the researcher from a group of patients who finally agreed to participate to include patients with different types of cancers and different demographic characteristics. However, the samples used in qualitative research tend to be small, which means that potential cases that could have offered further detailed exploration of the topic might have been missed. In addition, the small sample did not offer verification of the magnitude of the effect and

the frequency of each factor identified, which makes it difficult to generalise the findings to the wider population in the cancer context of Saudi Arabia. Therefore, the findings cannot be used to inform interventions without further research.

Conclusion

Factors, such as 'attitude towards health services', 'accessibility of healthcare' and 'referral system', were factors that were found to be similar to those that have been previously reported in the published literature.^{8,9,26,27} Engaging the health professionals in this research added more clarity and insights into the research findings. They were able to shed some light on certain areas of the health system that they believed were outside of the patients' knowledge, such as the referral process. Not much research has included both patients' experiences and health professionals' views within the same study. Although a limited number of health professionals participated in this research, it is believed that the information they provided was crucial to the understanding as to why certain factors were of significance.

While this research identified several factors that may contribute to the late presentation of cancer cases in Saudi Arabia and did succeed in generating theories, further research will add to the robustness of the research findings. This should include patients' and health professionals' perspectives. More importantly, quantification and evaluation of the extent of delay in each variety of cancer is required to be able to form solid data to enable both local and foreign researchers to compare and contrast their findings with worldwide studies.

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