Patients with colorectal cancer

A qualitative study of referral pathways and continuing care

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Background
This article explores the views of general practitioners on their referral of colorectal cancer patients following diagnosis to specialist surgeons.

Methods
Sampling was purposive. Nineteen GPs representing urban and rural areas participated in four focus groups.

Results
General practitioners viewed their relationship with surgeons to be of prime importance in the decision about whom to refer. This relationship allowed faster referrals and improved feedback from the specialist to the GP. General practitioners preferred referral to the private health services because they perceived delays in the public system and that referral and communication was easier with private specialists. Neither the volume of colorectal cancer work nor the availability of a multidisciplinary team influenced their decision making.

Discussion
The relationship and communication between GP and surgeon are important in facilitating the referral pathway and the continuing role that many GPs would like to have in the care of their patients.

Keywords
colorectal cancer; referral and consultation; general practitioners; qualitative research

Australia has one of the highest incidence rates of colorectal cancer (CRC) in the world with the second highest mortality rate.[1] This has provided justification for the National Bowel Cancer Screening Program.[2]

The steps in the care pathway following screening include diagnostic investigation, assessment and staging, surgery, and for some, chemotherapy and/or radiotherapy and an extended period of surveillance. General practitioners are also important in the early detection of patients presenting with signs and symptoms of CRC.[3] Despite the availability of a range of clinical guidelines for the management of CRC and recommendations to implement these guidelines,[4] many patients with CRC do not receive optimal treatment.[5]

The traditional choice of referral specialist by GPs is guided by previous referral experience, the quality of communication from the specialist and professional relationships developed through education or training.[6,7] The quality of communication between GPs and specialists has been variable, related to a number of issues including the means of communication and understanding of each other's needs and professional boundaries.[8]

The choice of surgeon made by referring GPs for their CRC patients has the potential to influence patient outcomes. Low case-volume general surgeons have been reported to have inferior survival and complication rates.[9] Multidisciplinary centres are able to provide a more comprehensive and considered approach to surgery and the use of adjuvant radiotherapy or chemotherapy.[10,11]

This study aimed to explore GPs' views on the pattern and factors influencing the referral of CRC patients following initial diagnosis with CRC and some of the issues involved in their continuing care after referral.

Methods

Sample

A purposive sampling strategy was used which aimed to recruit a range of GPs from three Australian states: southwestern New South Wales, southwestern Sydney (NSW), western Adelaide (South Australia) and rural Queensland. Participants were from rural and urban areas and included GPs whose practices included culturally and linguistically diverse populations. Four focus groups occurred over 4 months between May and October 2009.

Data collection

An open-ended focus group guide was developed. Discussions were recorded using a digital recorder and field notes were made during and after the focus groups. The sessions lasted 60–90 minutes. Recordings of the focus group discussions were transcribed and the notes of the facilitators included in the transcripts for analysis.

Data analysis

The analysis of themes was deductive based on an agreed framework.[12] The framework was generated from discussions in a multidisciplinary group, which included surgeons, cancer service providers and GPs, together with the researchers. MH and SP coded the transcripts and this was discussed with the other authors. Constant

comparative techniques were used to assist in uncovering the properties and dimensions of each category.[13] Data were coded using NVivo.[14] There was evidence of saturation of themes by the fourth focus group. Extracted themes were checked and verified, and any inconsistencies resolved through discussion.[15] Quotations were chosen on the basis of clearly representing a code and illustrating a broader theme.

The project was approved by the University of New South Wales Human Research Ethics Committee. All participants provided fully informed consent. The protection of anonymity and confidentiality were discussed with participants in each group.

Results

Nineteen GPs were recruited to four focus groups (*Table 1*). These were of mixed ethnicity and clinical experience.

Table 1. Gender and number of GP participants in the focus groups

State	Number of men	Number of women	Total
NSW – rural	3	1	4
NSW – urban	3	2	5
QLD	2	3	5
SA	4	1	5

GP role in the referral

The referral process

General practitioners described a range of methods that they used to contact surgeons to arrange consultations for patients diagnosed with CRC. Direct telephone contact was preferred because it was more likely to result in a rapid response. However, telephone referrals were difficult due to the number of referrals and limited time in an already crowded general practice work day. Some GPs delegated this task to others in the practice:

> 'I get the nurses … it's a waste of my time farting around on the end of the phone.' [QLD rural GP, female]

The waiting time between referral and securing a booked appointment with the surgeon was critically important to the GPs because of patient anxiety about their diagnosis, especially where there had already been delay in the diagnostic process. This was variable and the source of considerable frustration and uncertainty to GPs:

> 'Then we can't determine how long you're going to be waiting ... before this is done.' [SA urban GP, male]

When GPs took responsibility themselves for initiating communication (rather than delegating this to a staff member), they felt that a 'quality' referral was more likely to occur.

The nature of the relationship was important:

> 'You've got to pick up the phone and ring the surgeon "mate, what's happening there"?' [NSW urban GP, male]

The stronger the relationship between GP and surgeon, the more likely was it that the patient would be seen quickly and would have a good outcome:

> 'Strike up a referral relationship with one of them so we ... feel that we can get a good deal from them so occasionally when you do ring them up and say "look this guy really does need to be seen quickly like within a week or two" ... they say "fine send them down".' [QLD rural GP, male]

Organisational access and insurance status

The focus group participants felt there were important differences between public and private health systems. Most participants saw the private system as being problem-free in contrast with the public system, which was seen as providing good care but being difficult to access because of organisational barriers. The latter could be a frustrating and impersonal process. The policy for accessing public hospital services was often opaque to GPs with direct telephone verbal contact with the registrar/specialist being the most common strategy:

> 'But it's getting to the stage now both in the public system and in the private system where even for that style of appointment you have to speak to the specialist.' [QLD rural GP, male]

Of course, the private health system was largely unavailable to those without private insurance. Few had a solution to the problems in the public system. Some GPs felt that the use of a case manager may improve access and continuity especially for public patients.

The mode and urgency of the referral was influenced by the level of patient concerns. Often GPs considered using the private health system as a way of achieving more speedy access to services for patients who were particularly anxious:

> 'If people are really anxious I'm sure they would prefer to pay that much money and get it done quickly rather than going onto a waiting list.' [SA urban GP, male]

Choice of surgeon

Having a trusting professional relationship was a critical factor influencing the GPs' choice of surgeon. They described needing a personal and direct contact point with a specialist centre to initiate a referral. This contact needed to be a colleague who was well-known to the GP and trusted:

> 'Somebody you know, somebody who's good at it.' [NSW urban GP, male]

The GP-surgeon relationship also strongly influenced the quality and ease of communication between the two professionals and this in turn facilitated the referral process:

> 'We have to establish communication. We are the ones who have to do the research and make sure we've got a friend that's going to pick up the phone and is going to take us seriously that this patient needs help.' [NSW urban GP, female]

General practitioners reported choosing referral surgeons based on this relationship, their perceived technical capabilities and their previous style of communication with patients. They relied strongly on patient feedback about this communication style and as a source of information on the quality of care provided to their patients:

> 'Patients return and say "he's a lovely bloke and I understood, he spent some time, he was in the room, he was in the hospital after the operation and I spoke to him there, he spoke to my wife". So we get feedback so you know.' [NSW urban GP, male]

Trust based on personal experience and the relationship over time was a key factor influencing GPs choice of surgeon. This too was strongly influenced by feedback from patients:

> 'Especially in choosing the surgeon. If the surgeon can communicate with the patient … communication with the patient and also communication with yourself because it makes a difference … he's in good hands.' [NSW urban GP, female]

None of the GPs commented on the volume of CRC surgery or involvement of a multidisciplinary team as an indicator of quality or factor influencing their decision making. However, respondents did consider the general competence of the surgeon. There was no mention of patient request of surgeon being a significant factor in the GP's decision making.

GP involvement in continuing care

General practitioners felt they had an important continuing role in patient care following surgical referral. This included helping the patient to make choices for treatment being offered by the surgeon:

> 'So we need realistic expectations on both sides ... like the specialist knowing that the patient may not want to proceed with every option ... and a patient's understanding that these are the choices that they have ... I think that the GPs sometimes the mediator between the two.' [QLD rural GP, female]

General practitioners remained engaged and were kept informed through communication from surgeons, usually in the form of letters. However, some GPs felt excluded from the ongoing treatment process by the specialist or specialist service:

> 'It's just under specialist control and it's not really part of their relationship with you.' [SA urban GP, male]

The GP role included following up on progress and obtaining additional information beyond that already provided on behalf of the patient. General practitioners highlighted their role in interpreting complex medical terminology, explaining risk and providing guidance:

> 'You know some treatment decisions are made out here after they've been referred with no involvement by the GP and the patient is given options for treatment and often the patient would like – I'm sure the patient would like to discuss those options with … their GP.' [SA urban GP, male]

General practitioners felt that they had a role in coordinating the multidisciplinary team while acknowledging the roles of other secondary care staff in this. The GP's role included providing long term support and follow up after all the treatment had been concluded. They reported that some surgeons did not provide them with sufficient information to support them with their ongoing primary care. This impacted negatively on the GP's own quality of care.

Discussion

There are a number of limitations to this study. The GPs participating in this study were selected primarily on the basis of their state and urban/rural mix. Although there was general consistency and evidence of saturation of themes, the findings may not be generalisable to all GPs.

Most important among factors that affected referral of patients diagnosed with CRC, was the existing relationships between the GP and the specialist which, in the view of GP respondents, not only helped expedite referral but also improved the quality of care and feedback. This trust relationship was cultivated by GPs over time and was seen as a measure of their commitment to obtaining the best care for their patients. This was especially important for GPs in rural and remote areas where GPs advocated for patient needs including travel for diagnosis and treatment as well as follow up care.[16]

This trust has been demonstrated to be important in the inter-professional relationship between GPs and other health professionals.[17] Uncertainty is countered by trust in others' competence.[18] General practitioners are most comfortable with personal relationships rather than organisational arrangements.[16] Trust is often established via written or telephone communication and, perhaps most importantly, the report by patients of their experience of the other's care.

General practitioners perceived a significant gap between care in the private health system and the public health system in terms of speedy access to specialist care. General practitioners felt that influencing the referral process required overcoming barriers within the public health system. The challenge for medical specialists in large multidisciplinary cancer services is to see their role as including the development of better professional relationships with GPs on behalf of their teams through shared care and continuing education activities.[19]

General practitioners saw their role as one of coordinator, following up on the patient and providing more personal and comprehensible explanations of treatment. The GP's role in follow up was very dependent on information provided back to the GP by specialists about survival time and planned management, including radiotherapy and/or chemotherapy.[20,21] This is particularly the case for patients living in rural and remote areas who do not have easy or rapid access to specialist follow up. Patients receiving specialist secondary care treatment for cancer often simultaneously access their GP for psychological and emotional support, advocacy and primary care management of comorbidities.[22]

There is some urgency to improve the referral pathway with the reintroduction of the National Bowel Cancer Screening Program and the key role of GPs in this program. A range of initiatives has been established to improve referral pathways.[13,23] Despite these initiatives and National Health and Medical Research Council guidelines, there is very little information to guide clinicians on the optimal pathways and variations in care persist.

General practitioners did not mention the importance of having a large enough case load or the availability of multidisciplinary services, both of which may be important, especially for those with CRC who may benefit most from more technical experience. Although there is considerable variation in implementation of effective multidisciplinary care within secondary care,[24] multidisciplinary teams have been shown to increase the use of adjuvant chemotherapy and improve survival rates.[25]

Conclusion

This study illuminates factors influencing the referral pathway for patients following diagnosis with CRC. The professional relationship between GP and surgeon is most important and together with private health insurance may facilitate timely access to care. While this is broadly appropriate,

it does not necessarily achieve access to optimal care, especially for complex cases such as those with CRC.

Implications for general practice

- Strong inter-professional relationships between GPs and referral specialists are key factors in the referral pathway. These relationships are most influenced by the ease of access to appropriate and timely consultation, the quality of feedback from specialists and the reported experience of patients.
- While this is effective in dealing with some of the uncertainties in the referral relationship, it does not necessarily ensure that the most competent and comprehensive care is provided to patients.
- We need both public and private systems of care that offer GPs a personal, predictable and timely pathway to optimal quality care for their patients once they have been diagnosed with CRC.

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