Second opinions in oncology: the experiences of patients attending the Sydney Cancer Centre

Martin H N Tattersall, Rachel F Dear, Jesse Jansen, Heather L Shepherd, Rhonda J Devine, Lisa G Horvath and Michael J Boyer

ABSTRACT

Objective: To investigate the frequency, goals and outcomes of second-opinion consultations at the Sydney Cancer Centre.

Design, setting and participants: A questionnaire-based study of patients who registered to see a medical oncologist at the Sydney Cancer Centre between January 2006 and January 2008 and who were seeking a second opinion.

Main outcome measures: Proportion and demographic characteristics of patients who had previously seen a medical oncologist and who stated they were seeking a second opinion.

Results: 123 of 1892 new patients (6.5%) stated that they were seeking a second opinion, of whom 22 declined study participation, were excluded from study participation or had been referred specifically for enrolment in a particular clinical trial. Of the remaining 101 patients, 77 completed a questionnaire; 59 were women and 26 had a university degree. Reasons for seeking second opinions included: to obtain information related to treatment (54 patients), for reassurance about diagnosis or treatment (47), and dissatisfaction with the information given by the first medical oncologist (24). Sixty-four patients reported that they received new information at the second-opinion consultation, with 45 identifying discussion of treatment options and 34 identifying discussion of future or prognosis. Fifty-one patients reported how the second-opinion consultation differed from the first, identifying it as longer (24), and indicating that the oncologist answered concerns (26). Most patients were aware of multidisciplinary teams and treatment guidelines, but fewer had read guidelines.

Conclusions: Patients seeking a second opinion from a medical oncologist are typically more educated, younger and female, probably due to preferences for more detailed information. The most common reasons for seeking a second opinion were to obtain additional information or reassurance about recommended management.

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Seeking a second opinion occurs in most fields of medicine. A telephone survey of 2274 people in the United States in 1999 revealed that one in every five people who had visited a health professional in the past year had sought a second opinion.[1] In another study, 56.1% of 1020 people who self-reported having survived a cancer reported having sought at least one second opinion.[2] The reports from these studies do not document what patients believed to constitute a second opinion. We propose that a second opinion comprises the seeking (patient- or physician-initiated) of an opinion from a second health professional of the same specialty as one who has already given an opinion.

There are few reports on second-opinion seeking, and most relate to doctor-initiated review of anatomical pathology specimens or results of imaging studies.[3,4] A recent report on the results of a round-table discussion on second opinions discusses the reasons why patients seek second opinions from medical specialists and includes comments on discrepancies (mostly regarding pathology) between first and second opinions.[5]

Some patients in Australia are aware of their right to seek a second opinion, and many patients consult with more than one family doctor. The National Breast and Ovarian Cancer Centre recommends that patients consider seeking a second opinion,[6] and the New South Wales Department of Health Patient Rights Charter states that the public health services will "assist you to obtain a second opinion".[7] The Consumers' Health Forum of Australia website does not mention patients' rights to a second opinion.[8]

The growth of the Internet has provided a new means for patients to seek health information, and identify questions for doctors. It has been reported that patients with cancer in the United Kingdom use the Internet to find second opinions.[9] In the US, patients may self-refer for a second opinion, and an industry of providing remote second opinions has developed.[10]

To better understand the frequency, goals and outcomes of second-opinion consultations, we studied patients who presented to the Sydney Cancer Centre for a first consultation with a nominated medical oncologist and who indicated that they were seeking a second opinion.

METHODS

Patients

All new outpatients who consult with a medical oncologist at the Sydney Cancer Centre, Royal Prince Alfred Hospital (RPAH), complete a registration document that includes the question, "Have you previously seen a medical oncologist?" Between January 2006 and January 2008, those responding "yes" were approached after their consultation, either immediately or within a few days, and asked about the context in which they had previously seen a medical oncologist. Patients who indicated that they were seeking a second opinion were invited to participate in the study by completing a questionnaire; they saw one of seven medical oncologists appointed to the Sydney Cancer Centre.

Questionnaires

We developed a patient questionnaire that sought demographic and other patient characteristics, and explored the context of cancer treatment and reasons for seeking a second opinion. Patients were asked to select one or more answers from a range of specific options. They were asked whether they were seeking a second opinion because: they required more information about their cancer; they required more information about treatment options or decisions; they were dissatisfied with the information or communication received so far; or because they were seeking reassurance that the diagnosis or treatment already suggested was appropriate. These options were based on a previous analysis of second-opinion consul-

1 Characteristics of 77 patients with cancer who sought a second opinion from a medical oncologist

	No.*
Median age in years (range)	55 (23–84)
Women	59
Only English spoken at home	53
Married or de facto	66
Born in Australia	44
No medical or allied health training	69
Has university degree	26
Accompanied in the second-opinion consultation	63
Brought referral letter to second-opinion consultation	67
Brought pathology report to second-opinion consultation	41
Brought imaging films to second-opinion consultation	64
Started treatment recommended by their first-opinion oncologist	53

* Unless otherwise indicated. ◆

tations.[11] Patients were also asked about: whether they were accompanied in, and what items (eg, referral letter) they brought to, the second-opinion consultation; how the second-opinion oncologist was selected; the content of the second-opinion consultation; new information they received in the second-opinion consultation; how the second-opinion consultation differed from the first-opinion consultation; their knowledge and attitudes about multidisciplinary team care; discussion of treatment guidelines at the first-opinion consultation; and patient intentions regarding future care after the second-opinion consultation.

We also developed a questionnaire for completion by the second-opinion oncologists; this included questions about the content of the second-opinion consultation, follow-up that was planned, and to whom a letter was sent after the consultation.

The study protocol and questionnaires were approved by the Sydney South West Area Health Service Ethics Review Committee (RPAH Zone).

Statistical analysis

Demographic and other characteristics of the patients who sought a second opinion and completed the questionnaire were analysed using descriptive statistics. Exploratory univariate analysis (χ^2 testing) was performed to investigate associations between differences reported in the second-opinion consultations and age, sex, education level, occupation and reasons for seeking a second opinion. All analyses were performed using SPSS for Windows, version 14 (SPSS Inc, Chicago, Ill, USA).

RESULTS

Between January 2006 and January 2008, 1892 new outpatients were seen by medical oncologists at the Sydney Cancer Centre. After reviewing registration forms and speaking to patients about the context in which they had seen a medical oncologist previously, 123 (6.5%) were categorised as seeking a second opinion. Fifteen patients declined to participate in the study because they were not interested (5), too unwell (6) or had poor English comprehension (4). One patient was excluded due to having seen a surgeon previously (not a medical oncologist), and another was seeking a third opinion but could not be contacted by telephone. Five had been referred specifically for enrolment in a particular clinical trial. The remaining 101 patients consented to participate in the study, 77 of whom completed the questionnaire (76%); their median age was 55 years, and 59 (77%) were women (of whom 42 had breast cancer). These data contrast with those for the 1892 new patients seen in the study period, for whom the median age was 60 years, and 57% were women. Of the 77 participants, 53 reported that only English was spoken at home, 26 had a university degree (Box 1), and 53 had started treatment recommended by their first oncologist.

Patients could select more than one reason for seeking a second opinion. The most common reasons were: requiring more information about treatment options or decisions (54 patients); seeking reassurance that diagnosis or treatment already suggested was appropriate (47); requiring more information about their cancer (25); and dissatisfaction with the level of information or communication received so far (24).

Most patients (70/77) had sought a second opinion from a specific oncologist. Patients reported several reasons (and often more than one) for selecting the specific oncologist: recommended by a specialist (20 patients), by a friend (19), by a general practitioner (15), by a relative (13), and by a nurse or someone else from the hospital (6). Five patients identified the specialist using the Internet. The patients and the second-opinion oncologists had different recollections of the content of the consultation (Box 2). However, there was agreement relating to discussion of treatment options.

2 Reports of second-opinion seeking patients with cancer and their second-opinion oncologists on the content of the second-opinion consultation

Item discussed	Patient report ($n = 77$)	Oncologist report ($n = 77$)
Diagnosis	61	19
Pathology	46	7
Extent of cancer spread	38	9
Treatment options	61	71
Symptom control	15	11
Discussion of the future	33	58
Discussion of complementary therapies	3	3

Sixty-four patients reported that they received new information during the second-opinion consultation. For 45 of these patients, the new information related to treatment options, and for 34 patients, the new information related to prognosis or the future (Box 3).

Fifty-one patients responded to the question that explored differences between their first- and second-opinion consultations. Twenty-four patients reported that the second-opinion consultation was longer than the first, 27 reported that the second-opinion oncologist gave them greater confidence, 26 reported that the second-opinion

3 Reports of second-opinion seeking patients with cancer on new information received during their second-opinion consultation ($n = 64$)*

	No.
Cancer diagnosis	10
Clarification of extent of cancer spread	24
Discussion of treatment options	45
Information regarding future or prognosis	34
Discussion of treatment goals	17

* Data represent patients who reported that new information was received at the second-opinion consultation. ◆

oncologist answered concerns, and 24 reported that the second-opinion oncologist made them feel more confident (Box 4). For this group of 51 patients, significant associations with reported differences in the second-opinion consultations were detected for education level and sex. A larger proportion of patients who completed secondary education reported that the second-opinion oncologist made them feel more confident than those who reported completing tertiary education (67% v 36%; $\chi^2_1 = 4.29$; $P = 0.046$). A larger proportion of female patients than male patients reported that the second-opinion oncologist made them feel more confident (61% v 30%; $\chi^2_1 = 4.65$; $P = 0.048$).

A significantly larger proportion of patients who reported dissatisfaction with the level of information or communication received so far reported that the second-opinion oncologist answered their concerns, compared with those patients who did not report this dissatisfaction (92% v 37%; $\chi^2_1 = 11.92$; $P = 0.001$). Also, a larger proportion of patients who reported dissatisfaction with the level of information or communication received so far reported that the second-opinion oncologist listened more, compared with those who did not report dissatisfaction, but this trend was not statistically significant (62% v 32%; $\chi^2_1 = 3.65$; $P = 0.098$).

Two of 77 patients did not complete all the questions about multidisciplinary team care. Of those who did, 46 were aware of multidisciplinary teams and 55 were aware of treatment guidelines; however, only 15 patients had read treatment guidelines. Forty-seven patients reported that they believed that the first-opinion oncologist discussed their case with a multidisciplinary team and/or that the second-opinion oncologist would do so, and 62 reported that they believed discussion of cases like theirs with a multidisciplinary team was a good idea.

Most of the study participants (62/77) believed that they were making a choice between doctors, and 50 believed that they were making a choice between treatments. The second-opinion consultation resulted in a change either in treatment or in the supervising oncologist for 39 of the 77 patients. Twenty-two patients intended to continue to see the second oncologist and receive different treatment to that proposed by the first oncologist, while 10 patients planned to stay with the first oncologist but with a different treatment. Seven patients planned to switch to the second oncologist but continue to receive the originally recommended treatment. Thirty-three patients reported that their second-opinion oncologist offered to send them a copy of their letter after the consultation.

DISCUSSION

In our study, a small proportion of patients who registered to see a medical oncologist at the Sydney Cancer Centre (6.5%) stated that they were seeking a second opinion. Participants in our study commonly reported that their second consultation provided new information. They were also more likely to be women, and they were more likely to have a university degree than the overall Australian population (18%).[12]

Second-opinion seeking by patients with cancer raises the broader issue of what contributes to a good medical consultation. In line with previous findings,[11] it appears that younger, more educated and female patients with cancer prefer more detailed information, and when these expectations are not met, they are inclined to seek a second opinion. The doctor's communication style, personal characteristics and clinic schedule are also likely to have a strong influence on patients' perceptions of their status in the consultation. Our results cannot be used to determine whether particular oncologists' consultation styles contribute to patients' decisions to seek a second opinion. Studying the subset of oncologists whose patients seek a second opinion more commonly than average is a topic for future research. Health system factors may also contribute. Allocating adequate time for consultations with new patients, and ensuring availability of relevant patient information are likely to be important. Almost half of the participants in our study perceived that their second-opinion consultation was longer than their first.

There are few reports on patients who seek second opinions from medical specialists. In a retrospective audit of outpatient referrals to the internal medicine outpatient clinic at the University Hospital Groningen, Groningen, the Netherlands,[13] 117 female and 84 male patients who had visited the outpatient clinic for a second medical opinion were identified. Most (86%) were referred for a diagnostic problem. A new diagnosis was established in about 10% of cases.

In a questionnaire-based study of sociodemographic and clinical characteristics of 212 consecutive patients with cancer who sought a second surgical opinion (defined as patients who took the initiative for the second consultation themselves after being seen by a cancer surgeon in a general or university hospital), satisfaction with the first specialist, motivation for the second opinion, need for information, preference for participation in decisions, and hope for and expectation of a different second opinion were assessed.[14] Most patients were women (82%), of whom 76% were diagnosed with breast cancer, and most were seeking reassurance and more certainty about their treatment (62%). However, 38% had negative experiences or unfulfilled needs arising from their first-opinion consultation.

In our study, the most common reasons identified by patients for seeking a second opinion related to satisfying unmet information expectations after the first consultation, and seeking validation, or reassurance, that the original advice they had been given was correct. It is difficult to determine whether

4 Reports of second-opinion seeking patients with cancer on how their second-opinion consultation differed from their first-opinion consultation ($n = 51$)

	No.
Longer consultation	24
Shorter consultation	2
Oncologist listened more	20
Oncologist listened less	0
Oncologist seemed more knowledgeable	18
Oncologist seemed less knowledgeable	1
Oncologist answered concerns	26
Oncologist did not answer concerns	0
Oncologist *gave me* more confidence	27
Oncologist *gave me* less confidence	4
Oncologist *made me* feel more confident	24
Oncologist *made me* feel less confident	2
Oncologist was more friendly	21
Oncologist was less friendly	0
I received more information	25
I received less information	1
I received new information	26

the unmet information needs imply inadequate oncologist communication skills (and consultation methods), incomplete recall on the part of the patient or insufficient time allocated for the consultation.

The second-opinion consultation appeared to provide several benefits to patients. Most second-opinion seeking patients reported that they received new information at the second consultation; this was mainly related to treatment options (70%) and the future or prognosis (53%). The second-opinion oncologist also appeared to make some patients — those who were less educated and those dissatisfied with the level of communication in their first consultation — feel more confident.

The cost of funding second opinions must be acknowledged, as patients who stated that they were seeking a second opinion accounted for 6.5% of new medical oncology consultations in our study. Medicare has recently introduced an extra rebate for consultations lasting more than 45 minutes. With this increased rebate for longer consultations, time pressures may become less of an issue, but only if the clinic schedules include extra time for new patients. However, the rebate for longer consultations applies to the management of complex cases, with multisystem problems, and is not automatically applicable to long consultations for patients with high information needs.

In our study, the second-opinion consultation resulted in changes in treatment for 42% of patients. This finding is in line with a study of surgical oncology patients that showed that the second surgical opinion was identical to the first opinion for 68% of patients, there was a minor discrepancy between opinions for 16% of patients, and there was a major discrepancy between opinions for 16% of patients.[15] It is not possible to discern whether the changed treatment and/or recommendations in either study were based on presentation of new information or influenced by a more collaborative approach to decision making during the second-opinion consultation. The significance of differences in treatment recommendations in our study has not been explored.

Most second-opinion seeking patients in our study were aware of multidisciplinary teams and of treatment guidelines, but few had read treatment guidelines. These findings are disturbing. How accessible are treatment guidelines to patients with cancer? What will be the impact of the rapid expansion of multidisciplinary team meetings on second-opinion seeking that is initiated by cancer patients? Other authors have examined whether patient knowledge of adherence to guidelines by clinicians affects the desire of a patient to seek a second opinion and concluded that implementation of guidelines will not eliminate the need for second-opinion consultations.[16]

The generalisability of our findings is unclear. We believe that our results have implications beyond the field of oncology and recommend that additional studies of second-opinion seeking in specialist medical practice be undertaken. We speculate that more patients will seek second opinions specifically to access "new" drugs or particular clinical trial protocols, and these issues should be addressed.

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COMPETING INTERESTS

None identified.

AUTHOR DETAILS

Martin H N Tattersall, MD, MSc, FRACP, Professor of Cancer Medicine[1,2]
Rachel F Dear, MB BS, FRACP, Clinical Research Fellow[3]
Jesse Jansen, MA, PhD, Academic Research Psychologist, Screening and Test Evaluation Program,[3] and Research Fellow[4]
Heather L Shepherd, PhD, Post Doctoral Fellow[3]
Rhonda J Devine, RN, Research Nurse[3]
Lisa G Horvath, MB, FRACP, PhD, Head of Medical Oncology[2]
Michael J Boyer, MB, FRACP, PhD, Head of Sydney Cancer Centre[2]

1 Department of Cancer Medicine, University of Sydney, Sydney, NSW.
2 Department of Medical Oncology, Sydney Cancer Centre, Royal Prince Alfred Hospital, Sydney, NSW.
3 Department of Medicine and Centre for Medical Psychology and Evidence-based Decision-making, Central Clinical School, University of Sydney, Sydney, NSW.
4 NIVEL (Netherlands Institute for Health Services Research), Utrecht, Netherlands.

Correspondence: m.tattersall@usyd.edu.au

REFERENCES

1 Wagner TH, Wagner LS. Who gets second opinions? *Health Aff (Millwood)* 1999; 18: 137-145.
2 Hewitt M, Breen N, Devesa S. Cancer prevalence and survivorship issues: an analysis of the 1992 National Health Interview Survey. *J Natl Cancer Inst* 1999; 91: 1480-1486.
3 Cook IS, McCormick D, Poller DN. Referrals for second opinion in surgical pathology: implications for management of cancer patients in the UK. *Eur J Surg Oncol* 2001; 27: 589-594.
4 DiPiro PJ, van Sonnenberg E, Tumeh SS, Ros PR. Volume and impact of second-opinion consultations by radiologists at a tertiary care cancer center. *Acad Radiol* 2002; 9: 1430-1433.
5 Axon A, Hassan M, Niv Y, et al. Ethical and legal implications in seeking and providing a second medical opinion. *Dig Dis* 2008; 26: 11-17.
6 National Breast and Ovarian Cancer Centre. Who's involved in your treatment. Sydney: NBOCC, 2008. http://www.nbocc.org.au/breasthealth/treatment/whosinvolved.html (accessed Jul 2009).
7 NSW Department of Health. Your health services. Sydney: NSW Department of Health. http://www.health.nsw.gov.au/hospitals/healthcare/yourhealthservice.asp (accessed Jul 2009).
8 Consumers' Health Forum of Australia [website]. http://www.chf.org.au/ (accessed Jul 2009).
9 Ziebland S, Chapple A, Dumelow C, et al. How the internet affects patients' experience of cancer: a qualitative study. *BMJ* 2004; 328: 564.
10 Johns Hopkins Gastroenterology and Hepatology. Remote second opinion. Baltimore: Johns Hopkins University, 2006. http://www.hopkins-gi.org/CMS_Page.aspx?SS=&CurrentUDV=31&CMS_Page_ID=C61A7814-BCDA-4714-8DD5-799544105D7E (accessed Jul 2009).
11 Tattersall MHN, Devine R, Saul K, et al. Second opinions in oncology: an analysis of 40 2nd opinion consultations from a bank of 165 audio-taped initial consultations with 4 medical or radiation oncologists [abstract]. *Asia Pac J Clin Oncol* 2005; 1 Suppl: A22.
12 Maslen G. Australian students owe £3bn in loans. *Times Higher Education* (London) 2003; 28 Mar. http://www.timeshighereducation.co.uk/story.asp?sectioncode=26&storycode=175672 (accessed Jul 2009).
13 Mustafa MK, Bijl M, Gans ROB. What is the value of patient-sought second opinions? *Eur J Intern Med* 2002; 13: 445-447.
14 Mellink WA, Dulmen A, Wiggers T, et al. Cancer patients seeking a second surgical opinion: results of a study on motives, needs and expectations. *J Clin Oncol* 2003; 21: 1492-1497.
15 Mellink WA, Henzen-Logmans SC, Bongaerts AH, et al. Discrepancy between second and first opinion in surgical oncology patients. *Eur J Surg Oncol* 2006; 32: 108-112.
16 Moumjid N, Gafni A, Bremond A, Carrere MO. Seeking a second opinion: do patients need a second opinion when practice guidelines exist? *Health Policy* 2007; 80: 43-50.

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