Cancer patients' concerns regarding access to cancer care: perceived impact of waiting times along the diagnosis and treatment journey

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Waiting times can raise significant concern for cancer patients. This study examined cancer patients’ concern levels at each phase of waiting. Demographic, disease and psychosocial characteristics associated with concern at each phase were also assessed. 146 consenting outpatients (n = 146) were recruited from two hospitals in Sydney, Australia. Each completed a touch-screen computer survey, asking them to recall concern experienced regarding waiting times at each treatment phase. Approximately half (52%) reported experiencing concern during at least one treatment phase, while 8.9% reported experiencing concern at every phase. Higher proportions of patients reported concern about waiting times from: deciding to have radiotherapy to...
commencement of radiotherapy (31%); the first specialist appointment to receiving a cancer diagnosis (28%); and deciding to have chemotherapy to commencement of chemotherapy (28%). Patient groups more likely to report concern were those of lower socio-economic status, born outside Australia, or of younger age. Although a small proportion of patients reported very high levels of concern regarding waiting times, the experience of some concern was prevalent. Opportunities for reducing this concern are discussed. Vulnerable groups, such as younger and socio-economically disadvantaged patients, should be the focus of efforts to reduce waiting times and patient concern levels.

Keywords: cancer patients, health services accessibility, psychosocial aspects, diagnosis, treatment, vulnerable populations.

INTRODUCTION

The importance of access to high-quality cancer care

Cancer is an international health priority and a major cause of morbidity and mortality worldwide (World Health Organisation 2009). Accordingly, the identification of key indicators of high-quality cancer care has received much attention (Organisation for Economic Development and Co-operation 2009; Institute of Medicine 2011). Access to care is a key indicator of quality care, as indicated by its inclusion in key documents assessing care standards (The Royal College of Physicians & The Royal College of Radiologists 1993; New South Wales Health 2003; Health Canada 2004; Agency for Healthcare Research and Quality 2009) and population health monitoring (Andersen 2008). Access to care involves not just the availability of a service, but also the ability to utilise that care (Aday & Andersen 1974). The receipt of timely attention is central to high-quality care in that delays in receiving care may lead to more advanced disease (Mohammed et al., 2011) and subsequently reduced length of life (Richards et al. 1999; Fahmy et al. 2006; Teppo & Alho 2009).

Timely access to cancer care as a measure of quality

A number of authors have explored delays in the processes of cancer care from the first experience of a symptom to the receipt of treatments (Salomaa et al. 2005; Evans et al. 2007; Olesen et al. 2009). These explorations provide a useful framework for conceptualising the patient experience as a series of ‘waiting times’ between crucial treatment phases. Olesen et al. (2009) identified these crucial phases as the time between the:

1. First contact with a primary care provider and initiation of symptom investigation;
2. Initiation of symptom investigation and subsequent referral;
3. Hospital/specialist referral and first hospital/specialist visit; and
4. Referral for treatment and the commencement of treatment.

Internationally, guidelines or standards in relation to acceptable waiting times for these crucial phases of cancer care vary (The Royal College of Physicians & The Royal College of Radiologists 1993; Department of Health 2000; Manpower and Standards of Care in Radiation Oncology Committee 2000; New South Wales Health 2003). Such guidelines are generally focussed on maximising a patient’s length of life. However, there is a growing emphasis on the need to minimise psychosocial impacts which may be caused by delays in care (Department of Health 2000; Jones et al. 2001; New South Wales Health 2003; Cancer Care Ontario 2008).

The literature has typically focussed on waiting times (delays) which can have a direct impact on disease outcome. Regardless of whether there is medical risk associated with a delay in accessing care, such delays may have an important psychosocial impact on the patient and his or her family. The consumer experience is an important element for assessing the impact of structures and processes in the care pathway (Sanson-Fisher et al. 2009) given that these elements are often not observable to consumers. It has been argued that endpoint measures, such as patient satisfaction with care, represent an external validation of realised access to care (Aday & Andersen 1974). Previous studies have focussed on patient satisfaction (Cancer Institute New South Wales 2009) and actual waiting times (Gorey et al. 2009; Bilimoria et al. 2011) without gaining a clear sense of the level of patient concern which arises as a result of the perception of waiting.

A relatively new approach to assessing the impact of waiting times on patients is to assess the level of concern arising at critical phases of care. Patient concern regarding waiting times may represent a combination of: (1) the actual or perceived medical risk associated with a delay; (2) patient expectations of care and treatment; and (3) the quality of communication about the waiting times provided by health professionals. Despite reported variations
Factors potentially associated with patient experiences of timely access to care

Models which conceptualise access to care from the patient’s perspective have identified a range of factors which may be related to actual utilisation of health services, including patient attitudes, socio-demographic characteristics, and structural aspects of treatment centres (Andersen 1995). A number of factors have also been associated with delays in access to cancer care, including greater geographical distance from care (Sowden et al. 1997; Campbell et al. 1999; Jones et al. 2008; Onega et al. 2008; Drury & Inma 2010), income (van Doorslaer et al. 2006), ethnicity (Shi & Stevens 2005) and health insurance (Hoffman & Paradise 2008). Therefore, these factors might also be associated with greater levels of patient concern about such delays.

While the evidence regarding the effect of socio-demographic factors, such as increased distance to care, on disease outcomes is mixed (Sowden et al. 1997; Campbell et al. 1999), equity of patient access is considered an integral part of providing high-quality care (Institute of Medicine 2001). Therefore, an exploration of patient concerns regarding waiting times for treatment and care should also explore the role that socio-demographic factors may play in experiencing such concerns.

Aims

Among cancer patients attending outpatient radiation therapy appointments, this study aimed to identify:

1. The proportion of patients reporting any level of concern regarding the time elapsed between each of:
   - First symptom-related visit to the General Practitioner (GP), and referral to a cancer specialist,
   - Referral to a cancer specialist, and first appointment with the cancer specialist,
   - First appointment with the cancer specialist and receiving a cancer diagnosis,
   - Decision to have surgery and the date of surgery,
   - Decision to have chemotherapy and the commencement of chemotherapy;
   - Decision to have radiotherapy and commencement of radiotherapy;
2. The proportion of patients reporting ‘any’ level of concern for multiple phases of treatment.
3. Associations between demographic characteristics, disease characteristics, and self-reported psychological distress, and reporting any level of concern at each phase of treatment.

METHODS

Design and ethical approval

A cross-sectional, self-report survey regarding cancer care experiences was completed by participants via touchscreen computer. Ethical approval for the study was obtained from the New South Wales (NSW) Population and Health Services Research Ethics Committee and the University of Newcastle Human Research Ethics Committee. Relevant institutional ethics approvals were also obtained.

Sample

Participants were cancer outpatients recruited from radiation therapy treatment units at two hospitals in Sydney, Australia between March and September 2010. Eligible patients were: aged 18 years or older; diagnosed with any type of cancer; and sufficient in English to complete the survey. Patients who were attending the clinic for the first time were excluded, as at least one prior visit was considered necessary in order to answer a number of the items in the wider cancer survey. Patients who were judged by staff as physically or mentally incapable of completing the survey were also excluded.

Procedure

A nurse from each clinic identified eligible patients from daily clinic appointment lists. Patients were then approached by a research assistant (RA) while waiting for their appointment. Consenting participants were asked to complete a survey using a touch-screen computer. The RA explained the survey content and navigation and logged participants onto the survey using a unique ID code. Participants were given the option of resuming the survey after treatment if they were unable to complete it prior to their appointment.
Measures

Previous research (Salomaa et al. 2005; Olesen et al. 2009), best practice guidelines (New South Wales Health 2003) and consultations with oncologists were used to identify significant treatment phases throughout the cancer journey where waiting times may occur. Survey items were revised following pilot testing with 66 cancer outpatients attending radiation clinics over a 2-week period in February 2010. The patient survey was programmed into a Dell touch-screen computer using Digivey survey software. The following modules were embedded within the larger survey.

**Level of concern regarding waiting times at each treatment phase** Six items addressing the six treatment phases (outlined in the aims above) were presented, with respondents indicating their recalled level of concern regarding waiting times for each phase.

For example: ‘The length of time I waited between my doctor deciding I was ready for surgery and having surgery to remove the cancer was...’ – Not at all concerning; Slightly concerning; Moderately concerning; or Very concerning. Each item response scale also included a ‘not applicable’ option such as ‘Have not had surgery to remove the cancer’.

**Demographic and disease characteristics** Data on: age; gender; postcode; country of birth; health insurance status; living arrangements; cancer diagnosis; cancer recurrence; time since diagnosis; treatment aim; number of outpatient appointments; and number of oncology appointments, were also collected via patient self-report. Socio-economic status (SES) was categorised as low, medium or high based on the Socio-economic Index for Areas (SEIFA) (Australian Bureau of Statistics 2006). Geographical location was categorised as urban, regional and rural and was determined by postcode using the Accessibility/Remoteness Index of Australia (ARIA+) (Trewin 2006).

**Levels of clinical distress** The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith 1983) was used as a psychometrically rigorous measure of clinically significant distress at the time of the survey. Caseness for anxiety or depression was defined as a score of eight or above on the corresponding subscale of the HADS (Love et al. 2002). HADS subscale scores were included in statistical models as variables which could be potentially associated with levels of reported concern (Moorey et al. 1991; Lloyd-Williams 2001; Keller et al. 2004; Walker et al. 2007).

Statistical analysis

Frequencies, proportions and 95% confidence intervals (CI) were used to describe the demographic characteristics of participants and their levels of concern regarding waiting times, both overall and at each relevant phase of treatment. Chi-square and logistic regression analyses were used to determine associations between patients’ demographic characteristics, disease characteristics and levels of psychological distress, and experiencing concern for each phase of treatment. The following demographic, disease, and distress characteristics were included in the chi-square analysis: gender; SES (SEIFA); geographical location (ARIA+); health insurance; living arrangements; country of birth; treatment aim; time since diagnosis; cancer recurrence; anxiety; and depression. For each phase of treatment, variables with a value of $P < 0.25$ on the chi-square test were retained for inclusion in the logistic regression. Patient age in years was also added to all logistic regressions as a continuous variable. Variables with a value of $P < 0.10$ in the logistic regression were removed, and regressions were rerun with the remaining variables to identify significant associations.

RESULTS

Response rate and demographic characteristics

Of the 246 eligible patients, 218 consented to take part, giving a consent rate of 89%. Of the 218 patients who began answering the questionnaire, 146 completed it giving a completion rate of 67%. Non-completion was primarily due to appointment waiting times being shorter than expected.

The demographic and disease characteristics of participants are presented in Table 1. The age of participants ranged from 19 to 90 years, with a mean age of 60 [SD = 14.1 years]. Almost 70% of patients reported they were unsure whether or not they had had a recurrence of their cancer or a secondary cancer diagnosis. One-fifth of patients reported that they lived alone. There were no patients from rural areas, as defined by ARIA+ (Trewin 2006).

Proportion reporting concern at each time period

**Any level of concern** As shown in Table 2, the proportion of patients reporting any level of concern (slight,
Of the patients who expressed concern at each treatment phase, more than half reported they were moderately or very concerned at the following phases: from the decision to have chemotherapy, to the commencement of chemotherapy (55%); from the decision to have surgery, to the date of surgery (52%); and from the first symptom-related visit to the GP, to gaining a referral to a cancer specialist (50%). Slight levels of concern (72% of all patients concerned) were predominant for the waiting time from the first appointment with cancer specialist, to receiving a cancer diagnosis.

**Proportion reporting any level of concern at multiple phases of treatment**

Over 50% of participants reported experiencing concern about waiting times at one or more phases of cancer treatment relevant to them. Within those experiencing concern, 17% of individuals (8.9% of all respondents, 95% CI = 5.2–15) reported experiencing concern regarding waiting times at every phase of cancer treatment relevant to them. Forty-three per cent of all respondents (95% CI = 35–51) reported concern at some of the phases of treatment relevant to them, while 48% (95% CI = 40–56) reported concern at none of the phases of treatment they had experienced.

**Associations between some level of concern and demographic, disease, and distress characteristics for each phase of treatment**

**First symptom-related visit to the GP, to referral to a cancer specialist**  Four variables had a value of $P < 0.25$ on the chi-square test: time since diagnosis, $P = 0.17$; cancer recurrence, $P = 0.18$; country of birth, $P = 0.06$; and anxiety, $P = 0.16$. However, following logistic regression analysis, no significant association between these variables and concern at this phase of treatment was found.

**Referral to a cancer specialist, to the first appointment with the cancer specialist**  No variables had a value of $P < 0.25$ after performing the chi-square test indicating no

| Table 1. Participant demographic and disease characteristics ($n = 146$) |
|---------------------------------------------------------------|
| **Patient demographics** | $n$ (%) | 95% CI |
| **Gender** | | |
| Male | 70 (48) | 40–56 |
| Female | 76 (52) | 44–60 |
| **Cancer type** | | |
| Breast | 50 (34) | 27–42 |
| Prostate | 25 (17) | 12–24 |
| Head and neck | 13 (8.9) | 5.2–15 |
| Brain | 9 (6.2) | 3.2–12 |
| Colorectal/bowel | 9 (6.2) | 3.2–12 |
| Other | 40 (27) | 21–35 |
| **Time since diagnosis** | | |
| $\leq 2$ years | 122 (84) | 77–89 |
| >2 years | 24 (16) | 11–23 |
| **Second cancer diagnosis or recurrence** | | |
| Yes | 38 (26) | 19–34 |
| No/not sure | 108 (74) | 66–81 |
| **Stage of treatment** | | |
| Receiving treatment | 140 (96) | 91–98 |
| Finished treatment | 6 (4.1) | 1.8–8.9 |
| **Perceived treatment aim** | | |
| Cure | 70 (50) | 42–58 |
| Prevention | 58 (41) | 33–50 |
| Palliation | 12 (8.6) | 4.9–15 |
| **Health insurance** | | |
| Hospital and/or extras | 87 (61) | 53–69 |
| No | 56 (39) | 31–47 |
| **Country of birth** | | |
| Australia | 108 (74) | 66–81 |
| Other | 38 (26) | 19–34 |
| **Living arrangements** | | |
| With others | 117 (80) | 73–86 |
| Alone | 29 (20) | 14–27 |
| **Outpatient visits to clinic** | | |
| $\leq 10$ | 85 (58) | 50–66 |
| >10 | 61 (42) | 34–50 |
| **Appointments with cancer specialist** | | |
| $\leq 4$ | 110 (75) | 68–82 |
| >4 | 36 (25) | 18–32 |
| **Socio-economic status** | | |
| Low/medium | 30 (21) | 15–29 |
| High | 113 (79) | 71–85 |
| **Geographical location** | | |
| Metropolitan | 118 (83) | 75–88 |
| Regional | 25 (17) | 12–25 |

*Socio-economic status was categorised as low (SEIFA Deciles 1–3 or <930), medium (SEIFA Deciles 4–7 or 930 to1012) or high (SEIFA Deciles 8–10 or >1012) (Australian Bureau of Statistics 2006; Linacare 2007).†Geographical location was categorised as Metropolitan (ARIA+ Index <0.2), Regional (ARIA+ Index 0.2–5.92), or Remote (ARIA+ Index >5.92) (Trewin 2006).
association between concern at this phase of treatment and patients’ demographic, disease or distress characteristics.

**First appointment with the cancer specialist, to receiving a cancer diagnosis** Two variables (cancer recurrence, $P = 0.16$ and country of birth, $P = 0.02$) had values of $P < 0.25$ on the chi-square test. While neither of these variables showed a significant association with concern, the logistic regression analysis did reveal a significant association between patient age and concern. For younger patients, the odds of reporting concern about waiting times from the first appointment with the cancer specialist, to receiving a cancer diagnosis was increased ($OR = 1.03, SE = 0.02, P = 0.04, 95\% CI 1.00–1.06$).

**Decision to have surgery, to the date of surgery** Following chi-square analysis, five variables had values of $P < 0.25$ including: SES, $P \leq 0.01$; geographical location, $P = 0.07$; time since diagnosis, $P = 0.14$; cancer recurrence, $P = 0.13$; and country of birth, $P = 0.07$. Logistic regression analysis showed that, compared with patients from high socio-economic backgrounds, patients with low to medium SES had almost six times higher odds of reporting concern about waiting times from the decision to have surgery, to the date of surgery ($OR = 5.94, SE = 3.44, P < 0.01, 95\% CI 1.91–18.46$). The odds of reporting concern at this phase of treatment were also three times higher for patients who were not born in Australia, compared with those who were ($OR = 3.06, SE = 1.61, P = 0.03, 95\% CI 1.09–8.57$).

**Decision to have radiotherapy, to the commencement of radiotherapy** While gender ($P = 0.11$), health insurance ($P = 0.23$), and living arrangement ($P = 0.17$) variables were added to the logistic regression analysis, no associations for reporting concern at this treatment phase were found.

**Decision to have chemotherapy, to the commencement of chemotherapy** Similarly, country of birth ($P = 0.05$) was added to the logistic regression model for this phase of treatment, and although there was a strong association between country of birth and concern, it was not significant at the $P < 0.05$ level.

**DISCUSSION**

Concern about waiting times was reported across all phases of treatment

This study is unique in focusing on level of patient concern associated with perceived waiting times for diagnosis or treatment phases. One-fifth of radiation oncology outpatients who participated reported experiencing substantial levels of concern about the time which elapsed between the treatment phases examined. Levels of concern were considered to be moderate to high for about half of those who reported concern. Waiting time related to receiving a cancer diagnosis was the only phase where slight levels of concern were predominantly reported. This is surprising given that previous studies have reported high rates of anxiety while waiting for test results to confirm a cancer diagnosis (Poole 1997; Dragset et al. 2010). There has been considerable attention to communication skills training for oncology professionals to assist in the delivery of bad news (Ellis & Tattersall 1999; Back et al. 2005). Therefore, this finding may reflect that health professionals have greater skills and awareness of the need to provide appropriate reassurance to patients waiting for the results of diagnostic tests than for other phases in the care trajectory.
Patient concern may relate to expectations that any delay will reduce the chances of a positive treatment outcome, along with anxiety regarding expected risks and side effects of treatment. As cancer diagnosis and treatment pathways are often lengthy, multi-staged, physically difficult and uncertain in outcome (Fitch et al. 2003; Clark & Talcott 2006), some level of patient concern may be unavoidable. This might be considered a strong imperative for attempting to minimise any avoidable distress for this population.

Concern about waiting times was relatively widespread across participants

Close to half of the sample reported concern at some phase of the cancer diagnosis and treatment pathway, with 8.9% reporting concern at every phase. Therefore, it appears unlikely that concern about waiting times is confined to a subgroup of individuals who are consistently bothered by waiting times. Further, individuals who were categorised as possible or probable cases of anxiety or depression [according to the HADS], were no more likely to report concern about waiting times than those falling below the 'caseness' threshold. Consistent with previous findings, it appears likely that factors associated with the experience of waiting [uncertainty combined with the actual length of time] may be the primary drivers of concern, rather than factors intrinsic to the patient or the disease type [Fitch et al. 2003; Sanmartin et al. 2007].

Which groups appeared to be particularly vulnerable?

Contrary to our expectations, relatively few associations were identified between disease or socio-demographic factors and levels of concern. Younger patients had slightly higher odds of reporting concern about waiting times from their first appointment with the cancer specialist to receiving a cancer diagnosis. It may be that younger adults are particularly concerned by delays during the diagnostic pathway. Compared with high SES patients, patients of low to medium SES had almost six times higher odds of reporting concern about the time taken to access surgery. The odds of reporting concern about the time taken to access surgery were also three times higher for patients who were born outside Australia, compared with Australian-born patients. Cancer patients have reported a fear of the cancer spreading during the time between diagnosis and surgery [Fitch et al. 2003] and high levels of psychological distress and uncertainty preoperatively [Drageset et al. 2010]. Living in a disadvantaged area or being born in another country may present particular difficulties for arranging timely admission for surgery [Thomas et al. 2009]. Some variations by SES in median waiting times for elective surgery in Australia have been reported [Australian Institute of Health and Welfare 2010], and migrant groups diagnosed with cancer have been reported to have poorer outcomes than non-migrants [Gotay et al. 2002]. These findings suggest the need to explore the source of concerns about waiting times in these groups. Regardless of whether these groups actually wait longer for surgery, there is a need for additional communication, assistance or support to help manage their particular needs during the waiting time leading up to surgery [Coates 1999; Fitch et al. 2003].

Inclusion of non-English speaking patients was beyond the scope of the present study. However, given the elevated levels of concern among English speaking patients born outside of Australia, it seems that exploration of the concerns and experiences of non-English speaking patients may be an important area for future investigation. Studies of the concerns of more culturally and linguistically diverse samples which permit a comparison of English and non-English speaking patients levels of concern may be helpful to explore this further [Gotay et al. 2002].

How might concerns be addressed or minimised?

One of the primary paths to reducing the concern over waiting times is improvements in referral patterns and treatment booking systems to minimise actual waiting times. For example, NSW Health [New South Wales Department of Health 2011] has waiting time information which is accessible online and by telephone similar to that used in the UK and Canada [Cancer Care Ontario 2008; National Health Service 2011], to assist referring doctors and their patients in choosing the most suitable treatment centre for surgery. Improving information and support options throughout the treatment trajectory is also likely to be important, not least in terms of informing patients at each step how long the wait could or should be, whether the wait is or is not likely to have an impact on their treatment outcome, and avenues for accessing information for any concerns or queries they may have while waiting.

Limitations

The study methodology has a number of limitations including a relatively small sample of patients who were receiving radiotherapy at one of two public hospitals in metropolitan NSW Australia. This approach provided limited power to identify associations and to generalise to broader patient groups. It should also be noted that SES was assessed as an ecological [area-based] measure rather
than a more direct assessment of individual-based markers such as household income [Taylor et al. 2001]. The survey also required patients to report on their level of concern retrospectively. Therefore, it is possible that recall bias or the outcomes of treatment may have affected patient evaluation of their level of concern at the earliest phases of diagnosis. It should also be noted that reported level of concern about waiting time may not be directly related to actual time elapsed, which was not recorded for this study.

CONCLUSION

While it is not yet known whether longer waiting times at different phases of the illness trajectory are associated with poorer clinical or psychosocial outcomes, cancer outpatients express concerns associated with waiting times across almost every care phase from pre-diagnosis to treatment. Patient self-reported concern about waiting times provides an endpoint assessment of an important aspect of quality of care. Further investigations of the factors which underlie these concerns are warranted to understand and intervene in a manner which minimises distress to this very vulnerable patient group.

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REFERENCES

Absalom, K., Greenfield, D., Ross, R., Horne, B., Davies, H., Glaser, A., Simpson, A., Waite, H. & Eiser, C. (2006) Predictors of clinic satisfaction among adult survivors of childhood cancer. Europe-an Journal of Cancer 42, 1421–1427.

Aday L.A. & Andersen R. (1974) A framework for the study of access to medical care. Health Services Research 9, 208–220.

Agency for Healthcare Research and Quality (2009) National Healthcare Quality Report. AHRQ, Rockville, MD, USA.

Andersen R.M. (1995) Revisiting the behavioral model and access to medical care: does it matter? Journal of Health and Social Behaviour 36, 1–10.

Andersen R.M. (2008) National health surveys and the behavioral model of health services use. Medical Care 46, 647–653.

Australian Bureau of Statistics (2006) Information Paper: An Introduction to Socio-Economic Indexes for Areas (SEIFA). Available at: http://www.abs.gov.au/ausstats/abs@.nsf/mf/2039.0/

Australian Institute of Health and Welfare (2010) Australian Hospital Statistics 2008–09. AIHW, Canberra, Australia.

Back A., Arnold R.M., Baile W.F., Tulsky J.A. & Fryer-Edwards K. (2005) Approaching difficult communication tasks in oncology. CA: A Cancer Journal for Clinicians 55, 164–177.

Bilimoria K., Ko C.Y., Tomlinson J.S., Stewart A.K., Talamonti M.S., Hynes D., Winchester D.P. & Bentrem D.J. (2011) Wait times for cancer surgery in the United States: trends and predictors of delays. Annals of Surgery 253, 779–785.

Campbell N.C., Ritchie L.D., Cassidy J. & Little J. (1999) Systematic review of cancer treatment programmes in remote and rural areas. British Journal of Cancer 80, 1275–1280.

Cancer Care Ontario (2008) Ontario Cancer Plan 2008–2011. Cancer Care Ontario, Toronto, ON, Canada. Available at: http://www.cancercare.on.ca/common/pages/UserFile.aspx?fileld=13808

Cancer Institute New South Wales (2009) NSW Cancer Patient Satisfaction Survey 2008. Cancer Institute NSW, Sydney, NSW, Australia.

Clark J. & Talcott J.A. (2006) Confidence and uncertainty long after initial treatment for early prostate cancer: survivors’ views of cancer control and the treatment decisions they made. Journal of Clinical Oncology 24, 4457–4463.

Coates A.S. (1999) Breast cancer: delays, dilemmas, and delusions. The Lancet 353, 1112–1113.

Department of Health (2000) The NHS Cancer Plan: A Plan for Investment, A Plan for Reform. Department of Health, London, UK.

Dragest L.S., Lindstrom T.C. & Underlkl K. (2010) Coping with breast cancer: between diagnosis and surgery. Journal of Advanced Nursing 66, 149–158.

Drury V.B. & Inna C. (2010) Exploring patients experiences of cancer services in regional Australia. Cancer Nursing 33, E25–E31.

Ellis P.M. & Tattersall M.H. (1999) How should doctors communicate the diagnosis of cancer to patients? Annals of Medicine 31, 336–341.

Evans J., Ziebland S. & Mcpensor A. (2007) Minimizing delays in ovarian cancer diagnosis: an expansion of Andersen’s model of ‘total patient delay’. Family Practice 24, 48–55.

Fahmy N.M., Mahmud S. & Aprikian A.G. (2006) Delay in the surgical treatment of bladder cancer and survival: systematic review of the literature. European Urology 50, 1176–1182.

Fitch M.I., Gray R.E., McGowan T., Brunskill I., Stegges S., Sellick S., Beziak J. & Mcleese D. (2003) Travelling for radiation cancer treatment: patient perspectives. Psycho-Oncology 12, 664–674.

Gesell S.B. & Gregory N. (2004) Identifying priority actions for improving patient satisfaction with outpatient cancer care. Journal of Nursing Care Quality 19, 226–233.

Gorey K., Luginaah I., Holowaty E., Fung K. & Hamb C. (2009) Wait times for surgical and adjuvant radiation treatment of breast cancer in Canada and the United States: greater socioeconomic inequity in America. Clinical and Investigative Medicine 32, E239–E249.

Gotay C., Holup J.L. & Pagano I. (2002) Ethnic differences in quality of life among early breast and prostate cancer survivors. Psycho-Oncology 11, 103–113.

Groff S.L., Carlson L.E., Tsang K. & Potter B.J. (2008) Cancer patients’ satisfaction with care in traditional and innovative ambulatory oncology clinics. Journal of Nursing Care Quality 23, 251–257.

Health Canada (2004) A 10-year plan to strengthen health care. [News Release]. Available at: http://www.hc-sc.gc.ca/hcssl/delivery-prestation/ftpcoallab/2004-fmm-rpm/index-eng.php
Hoffman C. & Paradise J. (2008) Health insurance and access to health care in the United States. Annals of the New York Academy of Sciences 1136, 149–160.

Institute of Medicine (2001) Crossing the Quality Chasm: A New Health System for the 21st Century. National Academy Press, Washington, DC, USA.

Institute of Medicine (2011) Patient-centred Cancer Treatment & Planning: Improving Quality of Oncology Care: Workshop Summary. National Cancer Policy Forum, Board on Health Care Services, Washington, DC, USA.

Jones A.P., Haynes R., Sauerzapf V., Crawford S.M., Zhao H. & Forman D. (2008) Travel time to hospital and treatment for breast, colon, rectum, lung, ovary and prostate cancer. European Journal of Cancer 44, 992–999.

Jones R., Rubin G. & Hungin P. (2001) Is the ‘waiting game’: a critical examination of access to cancer care in the United States. Annals of the New York Academy of Sciences 944, 311–315.

Keller M., Sommerfeldt S., Fischer C., Lehnert T. (2004) Recognition of distress and psychiatric morbidity in cancer patients: a multi-method approach. Annals of Oncology 15, 1243–1249.

Linacare S. (2007) Australian Social Trends 2007: low income low wealth households. cat. no. 4102.0. Australian Bureau of Statistics: Canberra.

Lloyd-Williams M. (2001) Screening for depression in palliative care patients: a review. European Journal of Cancer Care 10, 31–35.

Love A., Kissane D.W., Bloch S. & Clarke D.M. (2002) Diagnostic efficiency of the Hospital Anxiety and Depression Scale in women with early stage breast cancer. Australian and New Zealand Journal of Psychiatry 36, 246–250.

Manpower and Standards of Care in Radiation Oncology Committee (2000) Definition of RT Waiting. Canadian Association of Radiation Oncologists [CARO]. Available at: http://www.caracro.ca/About_Us/Publications.htm

Mohammed N., Kestin L.L., Grills I.S., Battu M., Fitch D.L., Wong C.Y.O., Margolis J.H., Chmielewski G.W. & Welsh R.J. (2011) Rapid disease progression with delay in treatment of non-small-cell lung cancer. International Journal of Radiation Oncology Biology Physics 79, 466–472.

Moorey S., Greer S., Watson M., Gorman C., Rowden L., Tunmore R., Robertson B. & Bliss J. (1991) The factor structure and factor stability of the hospital anxiety and depression scale in patients with cancer. The British Journal of Psychiatry 158, 255–259.

National Health Service (2011) Guide to waiting times. Available at: http://www.nhs.uk/choiceintheNHS/

New South Wales Department of Health (2011) Monthly Hospital Performance Reports. NSW Health, Sydney, NSW, Australia.

New South Wales Health (2003) A Clinical Service Framework for Optimising Cancer Care in NSW. NSW Department of Health, North Sydney, NSW, Australia.

Olesen F., Hansen R.P. & Vedsted P. (2009) Delay in diagnosis: the experience in Denmark. British Journal of Cancer 101 (Suppl. 2), S5–S8.

Onega T., Duell E.J., Shi X., Wang D., Demidenko E. & Goodman D. (2008) Geographic access to cancer care in the U.S. Cancer 112, 909–918.

Organisation for Economic Development and Co-operation (2009) Health Care Quality Indicators data: cancer care. Available at: http://www.oecd.org/health/hcqi

Poole K. (1997) The emergence of the ‘waiting game’: a critical examination of the psychosocial issues in diagnosing breast cancer. Journal of Advanced Nursing 25, 273–281.

Richards M.A., Westcombe A.M., Love S.B., Littlejohns P. & Ramirez A.J. (1999) Influence of delay on survival in patients with breast cancer: a systematic view. Lancet 353, 1119–1126.

Salomaa E.R., Sallinen S., Hiekkanen H. & Liippo K. (2005) Delays in the diagnosis and treatment of lung cancer. Chest 128, 2282–2288.

Sammartin C., Berthelot J.-M. & Mcintosh C.N. (2007) Determinants of unacceptable waiting times for specialized services in Canada. Health Policy 2, E140–E154.

Sanson-Fisher R., Carey M. & Paul C.L. (2009) Measuring the unmet needs of those with cancer: a critical overview. Cancer Forum 33, 200–203.

Shi L. & Stevens G.D. (2005) Disparities in access to care and satisfaction among U.S. children: the roles of race/ethnicity and poverty status. Public Health Report 120, 431–441.

Sowden A., Aletras V., Place M., Rice N., Eastwood A., Grilli R., Ferguson B., Posnett J. & Sheldon T. (1997) Volume of clinical activity in hospitals and healthcare outcomes, costs, and patient access. Quality in Health Care 6, 109–114.

Taylor R., Mamoon H.A., Morrell S. & Wain G.V. (2001) Cervical screening by socio-economic status in Australia. Australian and New Zealand Journal of Public Health 25, 256–260.

Teppo H. & Alho O.P. (2009) Comorbidity and diagnostic delay in cancer of the larynx, tongue and pharynx. Oral Oncology 45, 692–695.

The Royal College of Physicians & The Royal College of Radiologists (1993) Reducing delays in cancer treatment: some targets. The Royal College of Physicians on behalf of the Joint Council for Clinical Oncology, London, UK.

Thomas B., Groff S., Tsang K. & Carlson L.E. (2009) Patient ethnicity: a key predictor of cancer care satisfaction. Ethnicity and Health 14, 351–358.

Trewin D. (2006) Australian Social Trends 2006. Australian Bureau of Statistics, Canberra, Australia.

Van Doorslaer E., Masseria C., Koolman X. & For the OECD Health Equity Research Group (2006) Inequalities in access to medical care by income in developed countries. Canadian Medical Association Journal 174, 177–183.

Walker J., Postma K., McHugh G.S., Rush R., Coyle B., Strong V. & Sharpe M. (2007) Performance of the Hospital Anxiety and Depression Scale as a screening tool for major depressive disorder in cancer patients. Journal of Psychosomatic Research 63, 83–91.

World Health Organisation (2009) Fact Sheet No.297: Cancer. Available at: http://www.who.int/mediacentre/factsheets/fs297/en/index.html

Zigmond A. & Snaith R.P. (1983) The hospital anxiety and depression scale. Acta Psychiatrica Scandinavica 67, 361–370.