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**‘Patient satisfaction in the
ambulatory oncology setting:
Are patients’ needs being met?’
A Descriptive Study**

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Signed Statement

This work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text.

I give consent to this copy of my thesis, when deposited in the School Library, being available for loan and photocopying.

Deborah Hoberg
10/07/2011

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Abstract

Background: Cancer is a leading cause of death in Australia. Its increasing incidence and prevalence predicts that by age 85 one in two Australians will face a cancer diagnosis. Improved diagnostics and treatment advances now mean that many more Australians are living with cancer and recent drug and technological advances have allowed the move from a predominantly inpatient setting to that of outpatient clinics and day centres.

Purpose: The study aimed to examine patient satisfaction in a single institution outpatient oncology centre with the primary aim of recording baseline data. Data collected from the study will be used to identify any areas of unmet needs and to identify areas requiring further improvement or development as well as to evaluate future initiatives with the primary aim of building a service that is better aligned to patient needs and therefore increases patient satisfaction.

Methods: A modified version of the EORTC-IMPACT32 with 8 additional questions was administered to 168 adult oncology patients who attended a single institution cancer centre for either intravenous chemotherapy or routine follow up during active treatment. All participants were provided with a participant information sheet outlining the aim and purpose of the study and consent was implied by completion of the questionnaire.

Results: One hundred and sixty eight participants took part in the study reporting mean satisfaction scores for all 14 aspects of care above 85. Scores were compared with previously determined acceptable levels adopted from surveys undertaken with inpatients in Western Australia and South Australia and showed wait time, exchange of information between caregivers and nurses availability and information provision to be areas requiring improvement. Age, gender, primary diagnosis, length of time as patient and treatment route were not found to predict satisfaction. The most common issues commented upon in the free text section related favourably to staff and unfavourably to the suggested introduction of paid parking.

Conclusions: Overall satisfaction rates were quite high. Low scoring areas were identified as areas requiring improvement however it appears that the tool may not be sensitive enough for quality improvement purposes due to its limitations. Areas requiring further research have been identified.

1. Introduction

Introduction

This thesis is the result of a study undertaken to examine patient satisfaction with care in the outpatient oncology setting and seeks to satisfy the thesis requirement for the Master of Nurse Practitioner degree. It was conducted in a private community practice setting. Whilst the practice was established in 1995 it has operated out of a series of makeshift buildings until its recent move to new premises in July 2009 located within a purpose built medical centre. This study sought to examine the patient's perception of care and services to establish baseline data for quality improvement purposes. This chapter will introduce the study and outline the specific research questions. An overview of each chapter has also been included along with a discussion of the study's significance.

Context of the study

Cancer accounts for 19% of the total disease burden in Australia. It affects one in three Australian people, is the second most common cause of death in this country, exceeded only by cardiovascular disease, and costs the Australian Government approximately 3.8 billion dollars annually. (1) The Australian Institute of Health and Welfare figures show that in 2005 there were over 100,000 new cases of cancer diagnosed and they further predicted that this would increase by over 3000 extra new cases annually from 2006 to 2010. (2) A 2002 report prepared by the Clinical Oncological Society of Australia, The Cancer Council of Australia and the National Cancer Control Initiative begins its introduction by summarising what health professionals working in the area of cancer care already know, that the impact of cancer, unlike most other major causes of morbidity and mortality in Australia, is not decreasing. Both the absolute number of new cases each year and the prevalence

are increasing as people live longer, and all three agree that current models of care will require some restructuring to adequately manage the increasing number of patients and the associated healthcare issues that this will bring. (3)

The treatment and care of cancer patients has experienced a major shift in recent times from high cost inpatient services to the outpatient setting. (4) Improved diagnostic procedures which allow for earlier detection of some cancers, better treatment options, the advent of oral chemotherapeutic agents and newer drugs to manage side effects have greatly impacted on the way care is provided and have improved patient outcomes and quality of life for cancer patients who can now be treated on an outpatient basis with much less disruption to their normal lives. Healthcare funds offer greater reimbursements to the hospitals to treat patients in the outpatient setting, minimising the overall cost of treatment by reducing or avoiding the enormous cost of inpatient care as well as allowing for a larger number of patients to be treated without the need to wait on available hospital beds. (4) But as the ambulatory oncology setting grows to accommodate this new trend it must employ the same quality improvement processes that have been used in the inpatient setting to evaluate its services or risk creating inadequately designed and resourced services together with negative patient experiences.

Purpose of the study

Technological and drug advances have seen a significant shift from hospital based cancer care to that of outpatient clinics and day infusion centres with safety and efficacy. Patients routinely express a preference for outpatient and home based care without sacrificing quality knowing that they will spend less time in a sterile treatment facility and more time healing at home. (3) Extensive literature supports the use of measuring patient satisfaction as a quality improvement process in healthcare facilities in an effort to determine whether services provided meet the needs of patients and to monitor and evaluate service performance. (5-9) The purpose of this

study was to assess patient satisfaction in an innovative ambulatory oncology setting. The primary objective was to record baseline data to determine patient's perceptions of the current service and to identify any areas of unmet needs in an effort to gauge current performance and drive future service developments.

Research question

The research questions were:

1. Are patients satisfied with the care and services currently provided by the cancer centre?
2. Do they feel their needs are being met?
3. Were there any factors able to predict satisfaction? In particular was oral therapy associated with altered perception?
4. Can data collected identify areas of need as determined by patients?
5. By evaluating the baseline data can recommendations be made to direct future service developments in an effort to improve overall performance and contribute to better patient outcomes?

Significance of the study

The results of this study will provide the cancer centre with baseline satisfaction data. This data will be used to gauge current performance and to identify areas of need as well as highlight any areas that require development or improvement. This study will allow the service the opportunity to utilise the baseline information for comparative data when considering future service improvements. Information gathered will assist clinicians and policymakers to identify opportunities to improve care by addressing any unmet needs and allow future service development to be better aligned to the individual needs and expectations of patients, thereby increasing their satisfaction with care, and improving the overall quality of care delivered. Additionally, it is hoped that this dissertation will add to the existing literature examining patient satisfaction with care in outpatient oncology care. Whilst numerous studies have been

undertaken internationally a lack of Australian data exists and none were located that have been done in a private practice setting.

Quality improvement

The Australian and New Zealand College of Anaesthetists (ANZCA) defines quality improvement as 'an organised process that assesses and evaluates health services to improve practice or quality of care'. (10) The aim of quality improvement is to ensure high standards of clinical practice through a process that is continuous, consumer focused and preventative in nature. Quality programs within organisations are designed to continuously evaluate clinical care and processes to ensure standards are regularly improved. Participating in accreditation is now an accepted part of any healthcare institutions continuous quality improvement processes. Accreditation is a process by which status is obtained by that organisation after an independent external review to assess whether the organisation meets required state and national industry appropriate standards. Whilst not required by law or legislation accreditation impacts upon funding from health insurance companies who will only pay basic rates to healthcare facilities who haven't participated in an accreditation process. Health insurance companies have also begun to recommend hospitals as their preferred providers based on accreditation status. (10-12)

While cancer care has traditionally been measured with objective measures such as survival, clinicians are now increasingly incorporating quality of life outcomes to care. (6, 13) Hospitals have widely accepted patient satisfaction as one of the key indicators in the continuous quality improvement process, using information gained to evaluate the services provided, benchmark standards, gain accreditation and determine areas in need of improvement. (6, 9) However, it is only in recent years that cancer care has adopted patient satisfaction as one of their indicators. Sitzia & Wood write in their 1998 review of literature that this may be due to the attitudes of some health professionals who have countered that in an area such as cancer care

'patient satisfaction is irrelevant in the face of curative or indeed palliative benefits of chemotherapy'(p. 1). (14) Thankfully, today's policy makers disagree.

The changing landscape and its challenges

The 1980's saw the beginning of the shift in cancer care to the outpatient setting. This shift was made possible by technological and drug advances and driven by the increasing number of cancer patients requiring treatment in an era of resource constraints. Similarly health funds offer larger reimbursements to persuade clinicians to utilise outpatient services in preference to the much greater cost of inpatient care.(4) Issues that once either weren't there or were dealt with as needed by the availability of medical and nursing staff 24 hours a day in the inpatient setting have impacted on the way patients are cared for and have become important aspects of the service provided by clinicians in the outpatient setting. Better diagnostics and treatment options, and the introduction of widespread screening programs, which now allow for earlier detection of cancers, Australia's aging population and the increasing survival rate of many of the common cancers have meant that more people are now being diagnosed and living longer with cancer. This has led to an increase in the amount of patients being treated and requiring long term follow-up in the outpatient setting, which in turn has resulted in increased waiting times and overcrowding. (2, 4, 15)

Whilst treatment and drug advances have greatly improved the management of side effects existing literature shows this to be one of the most important issues that patients are faced with in the outpatient setting. (16-18) How to manage these symptoms at home, away from the watchful eyes of healthcare providers is anxiety provoking in most patients and previous research has proven that being able to contact someone by phone who can answer health related issues has so far been problematic. (6, 19, 20) A compounding factor in this issue is the findings from current literature that suggests problems with the provision of information in almost all areas

of cancer care including recognising what is expected and what is not, how to manage the side effects of disease and treatment and when and from whom to seek help.(16)

The advent of oral agents

One of the most rapidly developing areas in cancer care today is the advent of oral chemotherapeutic agents and so-called targeted therapies: drugs that are not classical cytotoxic chemotherapeutics, but agents which inhibit critical cellular or molecular processes such as receptor tyrosine kinases. Whilst several have been available for many years, the last few years have seen this number increase dramatically, with reports that an estimated 20 – 25% of all drugs currently in development being new oral chemotherapeutic agents. (21) Oral agents can be used alone or in conjunction with intravenous therapy. Data shows that they are as effective as intravenous agents however their main advantage is that of convenience.(22) The choice of oral versus intravenous chemotherapy is usually determined by histology and is rarely a reflection of a patient's disease status, their symptoms or their performance status, as many of the oral agents have now shown to provide improved quality of life, disease free progression and/or long term stable disease benefits in clinical trials. (22, 23) Patients using oral agents no longer require lengthy visits to cancer centres for intravenous infusions or require longer term intravenous access with its accompanying care and maintenance issues when a simple oral formulation can provide an equivalent level of treatment. Quality of life is often greatly improved as patients spend less time within the confines of a hospital or outpatient clinic and more with their family and friends and maintain a greater sense of control during their cancer treatment. (21, 24)

The introduction of these oral agents has changed the landscape of cancer care and greatly improved treatment options for patients with certain tumour types however several issues have been identified with their use. Issues such as patient and

caregiver education, adherence and compliance, drug interactions and the frequency of routine monitoring and assessment and management of any toxicities have arisen. (21, 24, 25) Patient education has for the most part been the responsibility of the oncology nursing staff but for patients receiving oral agents this education is either provided by the oncologist when they prescribe the medication or the pharmacist who dispenses it. Nursing staff working in intravenous infusion centres spend time educating patients, providing them with verbal and written information regarding the medications being administered, the possible side effects and when and from whom to seek assistance. They are readily available for questions and advice and are ideally placed to monitor a patients' performance status and toxicity profile and intervene accordingly, often building strong patient relationships; a relationship that patients receiving oral therapy only generally do not have access to. Regular review of patients taking oral medication only occurs solely in the outpatient setting, inpatient care and therefore access to nursing staff occurs only if major issues occur. (25)

Adherence to oral antineoplastic agents is of great concern and the few published studies to date have highlighted the extent of the problem. A study undertaken on breast cancer patients given an oral cyclophosphamide regimen reported only 57% adherence rates. (26) Another study using a convenience sample of 597 women with early-stage breast cancer found that 17% of those prescribed tamoxifen discontinued it within the first two years and 68% of these women took it for less than 12 months. (27) Patients may be prone to self modulating their dose of drug without informing their health professional. They may increase their recommended dose because they perceive their current dose to be ineffective or because of toxicities which lead them to reduce their dose. Adherence can be complicated by the behavioural changes required; some oral agents require that patients watch when and what they eat in relation to doses to prevent nausea or drug interactions. Because patients taking oral agents spend less time with their health professionals than those receiving intravenous therapy more extensive follow-up is required to adequately monitor

compliance and adherence, toxicity issues and disease response which in turn impacts upon the service provided in an already overcrowded outpatient setting. (28)

Oral agents whilst more convenient, are still dangerous cytotoxic drugs and require correct storage, handling and administration. Several authors agree that specialist oncology nurses involved at the beginning of a patients' treatment plan being developed would ensure patients are adequately educated and closely followed thereby potentially increasing adherence and safety. (21, 24, 25) Routine monitoring and follow-up of these patients is one area that oncology services have begun to develop as part of a cancer workforce restructure, utilising advanced practice nurses or nurse practitioners in nurse led clinics in an effort to provide efficient, cost effective services whilst attempting to reduce the overload on outpatient clinics. (29)

Outline of the study

This chapter has introduced the study and provided an overview and a background, highlighting some of the issues to emerge in the provision of outpatient cancer care. It outlines the purpose of the study, states the research questions and the significance of the study.

The second chapter will provide a literature review on patient satisfaction in oncology care, looking at the tools that have been used to collect data and outlining the findings and any limitations of previous research.

Chapter three will describe the research method used in this study. The setting, population and sample will be clearly defined as will the recruitment process. This chapter will also include a description of the instrument used as well as information regarding the validity and reliability of the tool. A description of the data analysis will be provided along with discussion regarding the ethical considerations of the study.

Chapter four will detail the findings of the study in relation to patient satisfaction with care and services in a single institution ambulatory oncology centre. Mean satisfaction scores will be reported and compared between different treatment groups

to determine whether access to nursing staff is a factor in patient satisfaction. Exploratory data analysis using correlation coefficients was performed in an attempt to identify any variables that influenced patient satisfaction scores.

Chapter five will provide a discussion regarding the findings of this study and in relation to the existing body of knowledge on patient satisfaction in oncology care. The discussion will outline new information learned from the study as well as any areas that differ from previous research in this area and their significance to practice. Limitations of the study will be discussed along with any recommendations for further research where information was found to be lacking.

Summary

The past ten years have seen a dramatic change in the way cancer patients are treated. Instead of lengthy hospital admissions and sterile ward environments patients can now receive their cancer treatment with much less impact on their daily lives. Better diagnostic tools, new treatment modalities and drug advances have allowed many more patients to be treated in the outpatient setting; a move encouraged by government bodies, insurance companies and private entities attempting to reduce and minimise costs and better utilise available resources. Ensuring these services are patient centred and responsive to the people who use them requires continuous quality improvement. This study aims to evaluate patient satisfaction with care in a single facility to determine whether it meets the needs of its patients and to evaluate data collected in an effort to identify areas that require further development.

2. Literature Review

Introduction

This chapter will provide a literature review evaluating the existing research on patient satisfaction in cancer care. Largely international, few Australian studies have been done and whilst a large percentage of them have been carried out in the outpatient setting several studies conducted in the inpatient setting have been included because of their similar findings.

Literature search, time span and databases

A comprehensive search of electronic databases and bibliographies of relevant journals was undertaken. Databases accessed electronically included Cumulative Index of Nursing and Allied Health Literature (CINAHL), Scopus, PubMed and Google Scholar. Only articles written in English were included. No particular time span constraints were applied due to the relative recentness of the issue, the earliest study located was undertaken in 1996.

Search terms

Key search terms were used singly and in combination and included: patient satisfaction, outpatient cancer care, oncology, and quality improvement. The search aimed to identify existing literature related to patient satisfaction in the outpatient oncology setting and its use as a quality measure. Literature was selected based on its relevance to the current study.

Satisfaction as an outcome measure

Consumer satisfaction is a key measure of quality in many areas today. Marketing strategies have shown that organisations who strive to offer services or products aligned with the needs of their consumers not only survive but thrive in the current

economic climate. (30) Healthcare has only recently adopted this quality improvement approach to its products and services, although many contributing factors have encouraged its widespread acceptance. Healthcare consumers now have a greater involvement in the entire healthcare process and demand excellence in the care and services they receive.(31) Draper, Cohen and Buchan (32) agree writing that current healthcare consumers 'are more likely to be conceptualized as active decision makers, rather than passive recipients of decisions made by others' (p. 463). Healthcare facilities are required to participate in quality improvement processes such as accreditation, which monitors, evaluates and improves the quality of services within an organisation. (33)

Modern healthcare managers have adopted a new language where terms such as clinical indicators, evidence based and benchmarking are commonplace. Benchmarking, the process of establishing a standard of excellence and comparing what is done with that standard in the hope of improving product and service quality whilst maximising expenditure has become a common process in institutions that seek to provide and maintain best practice in care. (34) Evidence based practice (EBP), though founded in the discipline of medicine, is now evident in all areas of nursing. Curran defines evidence based practice as 'the integration of individual clinical expertise, built from practice, with the best available clinical evidence from systematic research applied to practice' (p. 193). (35) EBP is a core educational component of undergraduate and postgraduate nursing degrees, and many clinical areas of hospitals and medical practices now have direct web access via computer to sites where current best practice can be located instantly from centres around the world that collect and collate evidence based clinical information, such as the Joanna Briggs Institute. (36) These are some of the recent issues impacting upon healthcare; and their widespread adoption into clinical practice has helped drive the quality movement.

Extensive literature supports the use of patient satisfaction as a key measure of quality in healthcare. (6, 7, 20, 32, 35, 37) Research in this area has shown that a patient's satisfaction level directly impacts upon their attendance and treatment compliance. It can reflect the quality of interactions between the medical and nursing staff and the patient, impacting upon clinical outcomes. (6, 37, 38)

Ware, Snyder, Wright and Davies cited in Goldzweig, Meirowitz, Hubert, Brenner, Walach, Perry, Hasson-Ohayon and Baider (p. 1560) (38) write that patient satisfaction is reliant on three variables; 'the patient's personal preferences, their expectations and the realities of the care they received'. Though most agree that the role a patient's wishes and expectations play in the decision making process remains unclear. (38, 39) Healthcare researchers acknowledge that measuring satisfaction with care in the oncology setting is of particular importance, as a cancer diagnosis and many cancer treatments have the ability to profoundly impact upon a patient's quality of life. Their often lengthy and multi modal treatment requires continual supportive care and educational. (9, 16) Whilst measurement of patient satisfaction is thought to be flawed due to the fact that no unified definition of satisfaction exists, self administered surveys seeking patient's perceptions of the care they receive still remain the most accessible way to gauge performance, evaluate services and identify areas for improvement from the people that are using those services. (20, 32, 38)

A literature search revealed several studies that assessed patient satisfaction with care in oncology settings. (6, 7, 16-20, 37, 40-43) Self reported questionnaires were used in all of them, the majority of questions in each required likert-type scale responses, which have proven to be a good measure of patient satisfaction in healthcare settings. (44, 45) Most also contained some open ended questions aimed at eliciting information on areas that patients either thought hadn't been covered by the set questions or felt strongly enough about to comment on. Common factors that influence patient satisfaction in cancer care were identified in several studies as

being individual demographic characteristics of patients, the interpersonal aspects of care, patient-centred care, wait times, continuity of care and the physical environment of the clinic. (7, 14, 46)

One of the very first studies located that uses patient satisfaction as an outcome measure to identify areas of improvement in outpatient oncology care was conducted in Norway in 1996. (41) The primary aims of the study were to determine the physical status and assess health related quality of life, evaluate patient satisfaction and in turn to identify areas that require improvement at a single institution in the Norwegian capital. The study found that there were two main elements affecting patient satisfaction; whether patients felt their doctor was concerned about their problem and whether they felt that they had received adequate answers to the questions that they posed. Whilst the authors contend that some of this is a reflection of the individual doctors 'personal skill and training' (p. 28) and therefore less likely to be a variable that can be altered; they conclude that the factors that can be improved such as sufficient time spent with each patient, provision of quality information and overall length of visit time should be key areas for service improvement. (41)

A 1997 study by Thomas conducted in an outpatient department of a public hospital in the United Kingdom, examined patients satisfaction with their clinic attendance. (43) Staff at the clinic had identified an issue with discharging long term follow up patients, which they felt was impacting upon their ability to accept new patients and to adequately care for their acutely ill patients. The aim of the study was to determine what patients actually got out of their clinic visit; whether attending was anxiety-provoking or the visits provided reassurance, as well as to gather information about the current strengths and weaknesses of the service. Two hundred and fifty two patients, who had attended the clinic for more than three months completed a 30 item questionnaire, designed and piloted specifically for this study. Questions covered areas such as frequency of attendance, access to the clinic, waiting time, anxiety

caused or reassurance gained from the visit, continuity of care, satisfaction with information provided and the patient's perception of discharge. Twenty six of the questions used a graded response and four open ended questions were used to gather information relating to the best and worst aspects of the clinic. Thomas found that patients reported the best aspect of the clinic to be the staff. Eighty five percent of responses to the open ended question enquiring about the best aspect were favourable comments about the staff. Where patients did not always see the same doctor they felt reassured by the presence of a Macmillan nurse, who provided information and promoted continuity of care, thereby reducing the anxiety related with seeing a different physician on occasion. Twenty percent of the total sample had attended the clinic for ten years or more and felt 'worried at the thought of being discharged to their general practitioners (GP's) (p. 53). (43)

The worst aspect reported was wait time. Forty nine percent of all comments related to waiting. The length of time, lack of refreshments and dismal surroundings were all commented on unfavourably. Despite the lengthy wait time, which was described by 27% of patients as 'excessively long', Thomas reports the most surprising aspect of the study to be the high level of reassurance that patients report because of their clinic attendance. Fifty one percent of participants 'always' felt reassured and another 41% were 'usually' reassured after attending a follow-up consultation (p. 52). (43) The study showed an overall high level of satisfaction with the clinic which Thomas concludes was due to the staff's ability to provide care and comfort in a friendly and reassuring manner. The study demonstrated several areas requiring improvement such as a need to develop a more formal follow up for cancer patients with the idea of a nurse led clinic being discussed to facilitate this. (43)

A much larger study by Gesell and Gregory, which collected and analysed data from 5907 patients who utilised the outpatient oncology services of 23 hospitals across America, was used to prioritise areas that required service improvements with the

aim of increasing patient satisfaction. (37) Areas identified included the provision of information to patients, family members and caregivers, reducing waiting times, meeting the emotional and psychosocial care needs of patients and more streamlined and better managed care coordination. Another study by Groff, Carlson, Tsang and Potter looked at the impact of environment on patient's satisfaction. Using two subsets of the population; one who remained at an older facility while the other group moved to a new facility located in a quieter area and designed with attention paid to decor and ambience as well as to issues of privacy and better planning of appointment schedules. The study showed that satisfaction scores were higher in areas such as physical environment and wait times for the patients who had moved to the new facility but remained the same for both groups in all other areas. (7)

A 2003 Canadian study by Gourджи and colleagues to identify areas of importance to patients and measure patient satisfaction levels as a way of improving the service in a patient centred way, found that wait time was a significant contributor to patients dissatisfaction. Undertaken in a comprehensive cancer centre located within a large teaching hospital in Montreal, they hypothesised that the ever increasing numbers of cancer survivors requiring long term follow up has impacted negatively on wait times in the outpatient setting. This is the only study located that had been carried out in the outpatient oncology setting to state predefined markers of satisfaction as determined by the local regional health board. They explain that rates of 90 to 100 percent are considered excellent; 80 to 90 acceptable; 65 to 80 as fair and less than 50 percent as unacceptable. (6)

Richard and colleagues examined data from 276 single institution respondents in Montreal with the aim of identifying areas that patients considered priorities for change. (20) Using a 21 item likert-type scale questionnaire developed from their previous experience with surveys and after panel discussions with providers and patients, they found that overall patients were very satisfied with the care they

received at the clinic. The two lowest areas of satisfaction but with the highest rank of importance to patients were clinic wait times and the ability of patients to contact someone by telephone that could answer their health related queries. Interestingly, the clinic had previously attempted to reduce and better utilise wait times by moving to a larger, more aesthetically pleasing facility, providing more informational material and support services and adopting an online appointment program designed to better coordinate services. In addition they had recently employed nurse navigators to assist patients with their information and coordination needs as well as to increase patient's access to their healthcare providers. One hundred and three patients who were followed by a nurse navigator ranked higher in wait time satisfaction and had higher overall satisfaction scores than those patients without a nurse navigator. The authors thought that this may be because of the patient-centred role of the nurse navigator which focuses on providing support and education as well as acting as patient advocate. (20)

A 2004 study examined patient satisfaction in a single surgical unit in the United Kingdom. Patients with oesophageal and gastric cancers were recruited prospectively over a two year period and asked to complete, at home, a questionnaire developed by The European Organisation for Research and Treatment of Cancer (EORTC). Ninety one patients fitting the inclusion criteria completed the questionnaire with mean satisfaction scores ranging from 72 for doctors to 42 for comfort and cleanliness. Multivariable analysis showed that overall satisfaction was predominantly influenced by the patients satisfaction with the doctors, nurses and the comfort and cleanliness of the facility, however it also showed that not all aspects of the patients experience contributed equally to their satisfaction levels.(42)

Kleeberg and colleagues used patient satisfaction and quality in care to examine how patients assess the care they receive and to what extent patient's needs are met. (17) Four thousand six hundred and fifteen respondents were recruited from 50

private oncology practices and day hospitals in Germany and asked to complete the Patient Satisfaction and Quality in Oncological Care (PASQOC) survey. Sixteen of these institutions had previously participated in a survey using the same questionnaire in 2002. The PASQOC addresses 15 different dimensions of satisfaction with care, covering general as well as disease specific questions. The study found that whilst satisfaction was generally high areas such as shared decision making, doctor patient communication and the provision of information regarding the treatment of side effects required improvement. (17) Questions regarding information and management of side effects recorded the highest scores, indicating a moderate level of dissatisfaction with this area; 47% of patients felt that they had not received enough information regarding how to self manage their pain whilst 49% reported not having had a discussion regarding the probability of side effects prior to the commencement of treatment. The 16 institutions who participated in both the 2002 and the 2004 study revealed no real quality improvement growth; five of the centres showed some improvement in five or more care dimensions, six showed worsening scores in at least five care dimensions. The authors state that whilst the study was carried out with the primary aim of providing feedback from patients directly to their healthcare professionals rather than seeking quality improvement in practices they acknowledge that the results should be used to assist decisions in this area however further add that the individual practices will determine how the information is used. (17)

Predictors of patient satisfaction

A number of studies have been carried out that investigated the factors that influence patient satisfaction in oncology. (16, 17, 41, 47) Sandoval and colleagues conducted a multifacility study in Canada with 2790 patients. Patients were divided into three subgroups; patients having single modal treatment chemotherapy ($n = 1044$), patients having single modal treatment radiotherapy ($n = 994$) and patients having multi-modal treatment chemotherapy and radiotherapy ($n = 752$). Results were

calculated based on a 'problem score' percentage, the higher the percentage the more patients perceived an aspect of care to be a problem that they thought could be improved upon. Patients in the chemotherapy group reported waiting longer than expected for chemotherapy as the most problematic area as well as not knowing the next step and providers not knowing their medical history. Patients in the radiotherapy group reported not having enough information in relation to physical energy changes and not knowing who to go to with questions as their most problematic areas, and patients in the chemo radiotherapy group recorded high scores for longer than expected wait times for chemotherapy and the lack of sufficient information regarding relationship changes. The authors found no significant differences between age, gender and predictors of patient satisfaction but did report that all three groups had a positive correlation with 'self-assessed health' (p. 270), which affirms the thinking that the better the patients current health status, the greater the likelihood of a better overall care rating. (47)

Australian Studies

Whilst several international studies using patient satisfaction as a measure for service improvement were located, few Australian studies have been published. A 1990 study by Wiggers and colleagues examined patient perceptions of 232 ambulatory oncology patients across four outpatient services in New South Wales (NSW) about the importance of and satisfaction with nine aspects of patient care. The nine aspects of care covered were technical competence, communication skills, interpersonal skills, accessibility of care, continuity of care, hospital and clinic care, non medical care, finances and family care. These were chosen after an extensive literature search and discussion with cancer care providers and a panel of patients. A 60 item questionnaire was developed and piloted specifically for the study and data collected showed that most patients thought all items on the questionnaire were important aspects of cancer care. Findings from the study demonstrate that patients place greater importance on the technical aspects of their care than they do on the

emotional and psychosocial aspects although they report feeling dissatisfied with the provision of information in all areas.(18)

In 2007 the Cancer Institute of NSW in conjunction with NSW Health undertook a patient satisfaction survey across its eight area health services, looking at cancer patients perceptions of inpatient and outpatient care. The survey was repeated in 2008 and 2009 and some of the data gathered was benchmarked against Canadian figures. Canada was chosen because of the similarities between the health care systems and their cancer control initiatives, although due to differences in the scales of the instrument used only limited data was available for comparison and only applied to the outpatient population. (48) The NSW study found that patients were reasonably satisfied with the level of care that they received, six areas rated higher than that of Canada; however, several unmet needs were identified. These were management of pain/discomfort, helpfulness of staff, information relating to rights and responsibilities and symptom control of treatment related toxicities. Limitations from the study were acknowledged as all participants came from the public system, where they have less choice in their treatment centres and are known to be more critical. (19)

Another NSW study used a modified version of the same questionnaire used for this study, the EORTC IN-PATSAT32 to assess in-patient care of a specific tumour group. Sixteen additional questions were added to the original questionnaire covering issues such as quality of food, dietary information, efficiency of staff, admissions and nursing, family care and discharge/follow-up information. Fifty two women admitted for more than an overnight stay and cared for by the gynaecological oncology team were invited to participate and completed the survey. There was a 100% response rate, though a small sample size. Overall satisfaction scores were fairly high, with mean scores for all aspects of care greater than 60%. The high response rate and high overall scores may reflect the fact that patients were inpatients awaiting surgical

treatment when they were asked to participate in the study. Previous studies have found that patients score favourably on some satisfaction surveys for fear that expressing dissatisfaction may result in them receiving unfavourable treatment or care.(18) The highest scores reported related to doctors, their availability, interpersonal skills, exchange of information and their technical competence, whilst the lowest scores related to access to and in the hospital, the quality of food and wait times for treatment. The authors also write that the study identified areas of nursing care thought to lacking and that 'steps have been taken' (p. 182) to address these however they don't elaborate any further on what the issues were or how they are being addressed. (40)

Similar or different?

Whilst the literature revealed several studies of patient satisfaction with care in the oncology setting the data collected from each study has been gathered in different ways and used for different purposes and the settings and specifics of each study vary greatly (see Table 1 for a description of these studies). Different questionnaires have been adopted in each study and in cases where already validated tools were used even these have been altered in some way to gather the specific data required for each study. Lis, Rodeigher and Gupta (p. 302)(9) write that 'generalising from the existing findings is somewhat problematic' because studies 'differ on so many dimensions'. Overall satisfaction rates in all studies ranged from quite high in areas representing doctors and nurses, and their technical skills, moderately high for the interpersonal aspects of care and lower in areas of information provision and wait times. Several authors agree that this may reflect an inability on the patient's part to reliably judge the correctness of a diagnosis or treatment regimen but their ability to appraise the way healthcare professionals interact with them and the amount and type of information provided to them. (9, 14) Whilst previous satisfaction surveys conducted in the oncology setting report high levels of satisfaction, they appear to lack a predefined baseline level of satisfaction which could then be used to determine

areas requiring improvement. (6, 7, 14, 20, 37, 42)

Summary

This literature review has attempted to provide an overview of existing literature on patient satisfaction in oncology and report some of the findings from each study that appear to impact upon patients' satisfaction with the care they receive. Issues regarding wait times, information provision and management of side effects feature heavily and work needs to be done not only in determining where issues exist but also in how best to improve these to increase patient satisfaction. It appears that the choice of tool to be used should be guided by how the institution intends to use the data and that without a unified baseline level of satisfaction with which to benchmark against areas of dissatisfaction rather than low scoring areas of satisfaction should be the impetus behind service improvement.

Table 1 Patient satisfaction with cancer care services studies

Author/Year Place of study	Type of study, sample size, response rate	Setting	Study tool, number of items	Areas of satisfaction	Areas of dissatisfaction
Gourdji 2003 Canada ⁽⁶⁾	Cross-sectional, convenience sample 124, 77%	Outpatient, single facility	Satisfaction questionnaire (SEQUS), 26	Time spent with staff, information regarding medication side effects	Waiting times, inability to contact staff by phone when seeking advice, wait times, Limited pharmacy enquiry into current medications
Gesell 2004 USA ⁽³⁷⁾	Random sample 5907, 30%	outpatient, 23 facilities	Anonymous survey, 28	Care coordination, staff were sensitive to individual difficulties, inconveniences and emotional needs	Ease of finding ones way, wait times and staff courtesy, not what was next
Groff 2008 USA ⁽⁷⁾	Prospective, non-randomised Pre – post 759, 92%	outpatient, single institute multi-site	Patient satisfaction questionnaire (PSQ-III), 50	Lung: wait time, continuity of care, environment & trust in staff. Head & Neck & Gynae: wait time	Gynae: physical environment
Richard 2010 Canada ⁽²⁰⁾	Cross-sectional, convenience sample 276, 48%	outpatient, single facility	Anonymous questionnaire (Androfact), 21	Information provision regarding treatment times and places, feeling safe during treatment	Wait times, inability to contact staff by phone for health advice
Bredart 2001 Netherlands ⁽¹⁶⁾	Consecutive case series, 133, 73%	Inpatient single facility	Comprehensive Assessment of satisfaction (CASC), 61	Longer hospital stay than expected	Provision of information on medical issues, illness, tests and where to seek help
Fossa 1996 Norway ⁽⁴¹⁾	Consecutive case series, 1993 – 559, 84% 1991 – 211, 91.9%	Outpatient single facility	Self made Questionnaire	Doctors skill and training, attention paid to patients issues, questions answered	Wait time, not having sufficient time with the specialist

Thomas 1997 England ⁽⁴³⁾	Convenience sample, 256, 98.5%	Outpatient single facility	Self made questionnaire	Amount of information provided to patients, interpersonal skills of doctors and nurses, knowledge	Wait time, dismal environment lack of refreshments
Kavadas 2004 UK ⁽⁴²⁾	Consecutive case series, 126, 79.8%	Inpatients Single facility	EORTC QLQ-PATSAT32, 32	Doctors, nurses, wait time, information exchange	Access to the hospital, comfort and cleanliness
Kleeberg 2008 Germany ⁽¹⁷⁾	Consecutive case series, 5600, 82%	Outpatient Multiple facilities	Patient satisfaction and quality in Oncological care (PASQOC), 63	The doctor-patient relationship, nursing and other staff, further support in everyday life	Management of side effects, pain management, shared care decision making
Wiggers 1998 Australia ⁽¹⁸⁾	Consecutive case series, 276, 84%	Outpatient Multi – facility	Self made questionnaire	Doctors technical skills, certain interpersonal skills, i.e. willingness to discuss issues with patients, correct treatment	Limited choice of doctors in public sector, health care reimbursements, symptom management at home, added support outside the clinic
Arora 2010 Australia ⁽⁴⁰⁾	Cross-sectional convenience sample 52, 100%	Inpatient single facility	Modified EORTC IN-PATSAT 32, 48	Frequency of doctors visits, standard of care, friendly and efficient admissions staff, availability and cleanliness Rooms	Access (parking, transport), quality of food, ability to find way around hospital, speed of answering call bells
NSW Cancer Institute 2010 Australia ⁽¹⁹⁾	Consecutive case series, in 2008 4358, 53.2%	Inpatient and outpatient services, Multi – facility	Satisfaction questionnaire (NRC-Picker), 96	Inpatients – staff camaraderie, how they treated patients, nurses availability and courtesy Outpatients – patient respect, trust in staff	Inpatients – response to call bells, ease of finding someone to talk to Outpatients – not enough information on patient rights

3. Methods

Introduction

This chapter outlines the methodology used in the study. It details the design used, the setting and the sample and provides a comprehensive description of the tool used to collect the data, the procedure for recruiting and completing the questionnaire, ethical considerations and analysis of the data.

Design

A descriptive design using a cross-sectional convenience sample and utilising an existing validated questionnaire was employed in this study to assess patients' satisfaction of the care and services provided in a single institution. Descriptive studies determine 'what is' and commonly use survey methods such as questionnaires to collect descriptive data. Questionnaires are a popular and cost effective method of data collection in descriptive studies, costs can be kept to a minimum depending on the method chosen for dissemination and return. (49) Self reported questionnaires are inexpensive to administer, much less labour intensive and usually anonymous which encourages honest replies. Their use ensures the absence of interviewer bias whilst in person distribution of questionnaires increases the rate of response.(49, 50)

Setting

The study took place in a private outpatient cancer centre, located approximately five kilometres from the city of Adelaide, and situated on the first floor of a purpose built comprehensive cancer centre. The newly designed building, which opened in 2009, also accommodates a day surgery suite, radiotherapy, radiology and pathology services as well as private gastroenterology, urology, eye and endocrinology

practices. The cancer centre incorporates the private consulting rooms of a large oncology and haematology practice with ten consulting doctors, a large clinical trials area and a co-located infusion centre staffed by specialist oncology Registered Nurses with 27 treatment chairs, two beds and a procedure room. The cancer centre is open Monday to Friday between 8.00 am and 6.00pm. A Google search revealed several international stand alone cancer centres with similar co-located treatment and care setups, such as the London Oncology Clinic in Harley Street and the Medicor Cancer Centres in Canada however failed to locate any in Australia. Whilst many stand alone cancer centres exist worldwide, they are predominantly attached to larger hospitals and the choice to have them off site appears to have been one made solely on the availability of space.

Study population

Participants were recruited from an adult outpatient oncology population of a private day hospital. Patients are from a predominantly high socioeconomic background with a current or previous diagnosis of cancer or malignant haematological disorder. The cancer centre reception staff greets between 150 - 250 patients per week depending on the availability of the consulting doctors and the cyclic nature of chemotherapy. From this, a convenience sample of potential participants who fit the inclusion criteria were invited to take part in the study.

Procedure

Patients were invited to participate in the study by the reception staff in both the reception area of the private practice and the reception area of the infusion centre. The administrative staff member assigned to work in the nurses' station of the infusion centre each day also took the opportunity to enquire of patients as to whether they had been asked to participate and took the opportunity to invite them if they replied in the negative. Participants who agreed were provided with written

information introducing the researcher and outlining the aim and purpose of the study, an estimated length of time that it would take to complete the questionnaire and information regarding whom to contact and how this could be done if participants had questions, issues or complaints (Appendix 1). Patients were asked to complete the questionnaire during their visit, however, a stamped, self addressed envelope was provided to 11 patients who felt unable to complete it during their visit. Reasons given in all cases related to either lack of time in the clinic on this occasion or feeling unwell on the day. Participants were not paid for their participation nor received any inducements and participation was entirely voluntary. The study ran for a period of four weeks commencing October 5 2010 in an attempt to capture a large enough sample and allow for patients on a 28 day cycle of chemotherapy to cycle through the clinic.

Sample

The inclusion criteria were: patients had to be able to read, write and comprehend English, able to complete the questionnaire, have a primary diagnosis of cancer or a haematological malignancy, and be undergoing active treatment either at present or at some point in the last 12 months. No minimum age was specified as the practice is an adult oncology service, in theory this means age 18 and above, however increasing age is the greatest risk factor for cancer and therefore patients in their 20's and below are a scarcity. At the time of the study the youngest patient of the practice was 21 years of age.

Data collection tool

A 40 item questionnaire with a space at the end for any additional comments was used in the study. The questionnaire used was comprised of the 32 item internationally recognised and validated tool developed by the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Group with an additional eight demographic and site specific questions requested by the

Medical Advisory Committee of the day hospital. (See Appendix 2 for a copy of this tool). (51) The EORTC IN-PATSAT 32 questionnaire was designed to assess patients' perception of the quality of doctors, nurses, aspects of care and organisational issues encountered in a facility. It contains eleven multi-item and three single-item scales which include the doctors technical skills, interpersonal skills, provision of information, and availability, an identical set of scales about nursing staff, interpersonal skills and provision of information of other hospital staff, the exchange of information, waiting time, hospital access, comfort and general satisfaction scales. It uses a 'poor', 'fair', 'good', 'very good' or 'excellent' response scale to rate each aspect. Scores for each item are linearly transformed from 0 - 100 with a higher score reflecting a higher level of satisfaction. (51)

Existing literature fails to provide a universally accepted level of satisfaction which can be benchmarked against and previous studies have instead used lowest scoring items to determine areas of need. (6, 17, 19, 40) Based on satisfaction surveys carried out in public hospitals in Western Australia and South Australia, for the purpose of this study and with regard to the high levels of satisfaction usually reported in surveys of this kind it can be considered that areas with scores of 90 or above have achieved a high level of satisfaction, areas which report scores of 80 or above have reasonable levels of satisfaction with room for improvement and areas that score around 70 require immediate attention and improvement. (52)

The first three demographic questions in the questionnaire enquired as to gender, age and primary diagnosis. The principal investigator, practice manager and members of the Medical Advisory Board decided on the final five questions to determine whether they had any effect on satisfaction scores and/or warranted further investigation. These questions enquire as to route of treatment, length of time as a patient of the practice, distance travelled to the centre, mode of transport and

satisfaction with car parking facilities. The questionnaire was pre-tested by ten participants recruited from the infusion centre to determine the interpretability of the questions and to estimate the length of time participants would take to complete the questionnaire. All ten participants of the pre-test study claimed that the questionnaire had been easy to comprehend and complete and all finished it within ten to fifteen minutes.

Instrument reliability and validity

Two studies carried out in 2005 and in 2008 provided support for the psychometric properties of the tool, proving its reliability and validity internationally and cross culturally. (53, 54) Limitations of the tool were recognised, in so much as patients who receive oral therapy only rarely use the infusion centre area and therefore can't answer 11 of the questions relating to the nursing staff working in that area. The EORTC was contacted and asked for advice, and a line advising participants to skip ahead was inserted without threatening the validity and reliability of the tool.

Ethical issues

Participation was voluntary. The information sheet accompanying the questionnaire instructed participants not to write their name or any identifying information on the questionnaire so as to remain anonymous and to deposit the questionnaire once completed into the locked drop boxes located either in the infusion centre or in the waiting room of the main reception area. In accordance with the University of Adelaide's guidelines for the use of questionnaires in research no formal ethics approval was required, however expedited consent for the study was obtained from the University of Adelaide's Human Research Ethics Committee and the Medical Advisory Committee of the day hospital.(55) Informed consent was implied by participants by completion of the questionnaire.

Privacy

Participants were assured that data collected would remain confidential and that only the investigators would have access to the completed questionnaires which were stored in a locked filing cabinet. The questionnaires or results of any individual questionnaires were not shown or discussed with anyone. Electronic data from the survey was stored in password protected files on a computer with password login and firewall protection and backed up to a hard drive in the researcher's home to prevent against data loss. On completion of the study all records will be stored in secure archives belonging to the Adelaide Cancer Centre for a period of five years.

Data entry

All statistical analyses were performed using R, a statistical and computational software program.⁽⁵⁶⁾ Answers from the questionnaires were recorded on a Microsoft Office Excel Spreadsheet using an identifying number. At the completion of the survey a random selection of 50% of the questionnaires were double entered to ensure that no errors had been made during data entry.

Data analysis

The 32 questions that make up the EORTC questionnaire were scored according to the procedure outlined by the EORTC in the scoring manual that accompanied the original downloaded questionnaire. Scale scores are linearly transformed so that all scales range from 0 to 100 with a higher scale score indicating a higher degree of satisfaction. Measures of central tendency such as the mean and the median were calculated to summarise the individual scales. There were 14 satisfaction scales, 13 representing different dimensions of care and one scale for overall general satisfaction.⁽⁵¹⁾ Multivariable analysis was used to determine the effects of demographic variables on satisfaction scores with a p value of <0.001 representing 'statistical significance'. Question 36 of the questionnaire divides respondents into

subsets of the population based on treatment type and analysis of variance (ANOVA) was used to determine whether the mean satisfaction scores of these groups were all equal. Data from the eight demographic questions will be reported using frequency distributions and qualitative data from the open ended comments section at the end of the questionnaire will be coded and categorized using common themes. Exploratory data analysis was conducted to look at potential predictors of satisfaction and generate hypothesis for further study.

Summary

An anonymous self reported questionnaire was used to collect data on patient satisfaction with different aspects of care and services in an outpatient oncology centre. A 40 item questionnaire comprising the 32 item EORTC IN-PATSAT 32, eight demographic and site specific questions and an additional area for comments was used in the study. Expedited ethics approval was sought from the University of Adelaide's Human Research and Ethics department and the Medical Advisory Board of the Hospital prior to conducting the survey, which ran for a period of four weeks and recruited from an adult population of cancer patients. Data analysis was performed using R, a statistical and computational programme.

4. Results

Introduction

This chapter presents the results of the study on patient satisfaction in an ambulatory oncology clinic. The main objectives of this study were to evaluate whether patients were satisfied with the care and services received at the centre, to determine whether patient's needs were being met, to record a baseline level of satisfaction with the service and to identify areas of need as determined by patients in an effort to better inform future service developments. Descriptive statistics such as frequency distributions and measures of central tendency were used to analyse the data collected. The data has been reported in text as well as numerical forms with tables and graphs displaying descriptive statistics and comparison scores.

Return and questionnaire completion rates

Two hundred and nineteen questionnaires were handed out, with 168 questionnaires being returned, an overall response rate of 77%. Only one patient refused outright to participate but offered no reason at the time. Of the 5376 possible answers data was missing from 359 (6.7%). Scales were scored individually and missing values ignored according to the manual for the EORTC as they totalled less than 10% which was considered acceptable. (51)

Patient demographics and clinical characteristics

Five participants failed to identify their gender however those that did reflected a slight preponderance of females (53 % female, n= 86 and 47 % male, n= 77). See Table 2 for demographic and site specific characteristics. Participants were predominantly aged between 51 and 80 years of age (80%) and had quite varied primary diagnoses. Most received their treatment intravenously (72%), however the length of time reported as a patient of the practice varied. The majority of participants

travelled by car to their appointments, with 56% stating that it took them less than 30 minutes to travel to the centre, and 96 % reported being either extremely satisfied or satisfied with the current car parking facilities.

Table 2 Patient sociodemographics and site specific characteristics

Characteristic	Number	% = 100
Age		
< 40 years	6	4%
41 – 50	15	9%
51 – 60	39	23%
61 – 70	62	37%
71 – 80	33	20%
> 80 years	12	9%
Gender		
Male	77	46%
Female	86	51%
Not defined	5	3%
Primary Diagnosis		
Breast	32	19%
Colorectal	25	15%
Lung	13	8%
Lymphoma	19	11%
Prostate	16	10%
Other	61	36%
Not defined	2	1%

Route of treatment

Intravenous	121	72%
Oral	15	9%
Combination IV/Oral	32	19%

Length of time as patient

< 6 months	64	39%
6 – 12 months	30	18%
> 12 months	74	44%

Mode of transport to centre

By car – self driven	66	39%
- driven by someone else	86	51%
- occasionally self & occasionally driven by other	9	5%
By DVA/Leukaemia Foundation or Red Cross Car	1	1%
By plane & then taxi	5	3%
Not defined	1	1%

Travel time to centre

< 15 minutes	30	18%
> 15 mins but < 30 mins	63	38%
> 30 mins but < 60 mins	39	23%
> 60 mins	33	20%

Satisfaction with car parking facilities

Extremely satisfied	122	73%
Satisfied	39	23%
Neither satisfied nor dissatisfied	5	3%
Not defined	2	1%

Satisfaction scores

Mean satisfaction scores for doctors ranged from 90.3 (for the provision of information) to 94.3 (for technical skills). Mean scores for the nurses were lower, ranging from 87.3 (for both availability and information provision) to 91.4 (for interpersonal skills). Overall the lowest mean score was reported for waiting time (86.8) while the highest mean scores of 94.7 were reported for both comfort and cleanliness and general satisfaction. Histograms below graphically depict patients scores for waiting time (Figure 1) and general satisfaction (Figure 2). The observed standard deviations ranged from 9.1 (doctors technical skills) to 15.7 (nurse availability). Measures of central tendency are reported along with 95% confidence intervals and 25th and 75th percentiles for all care dimensions in Table 3.

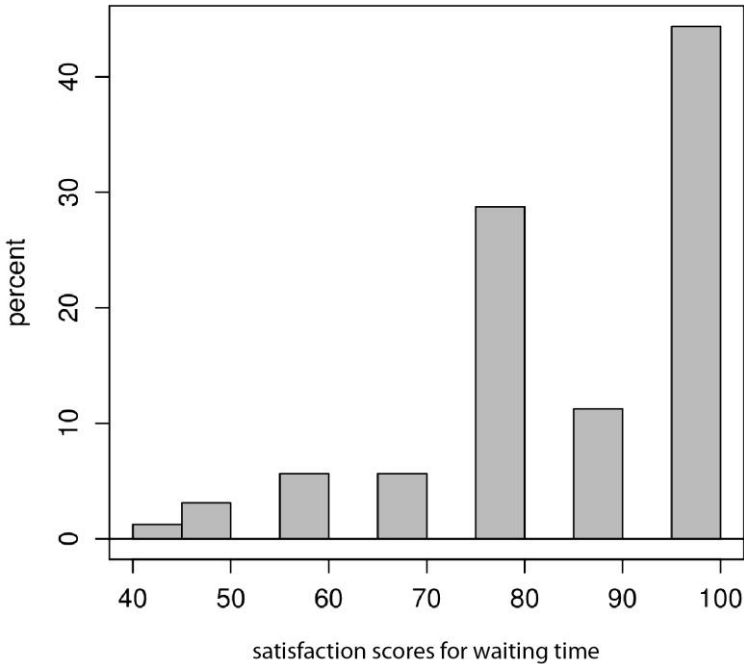


Figure 1: Waiting time

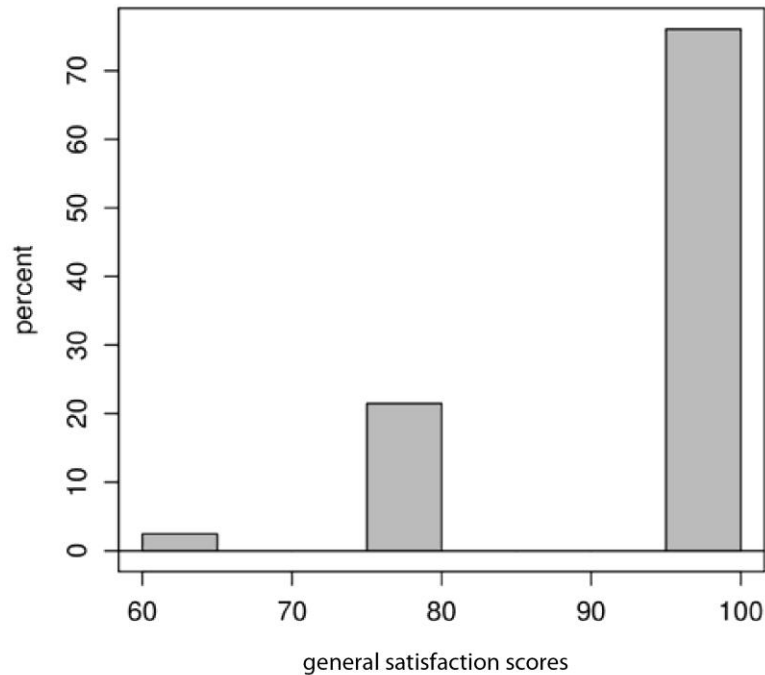


Figure 2: General satisfaction

Mean scores were compared to previously determined baseline levels of satisfaction adopted from inpatient hospital surveys carried out in South Australia and Western Australia that had determined that scores above 90 reflected a high level of satisfaction, scores of 80 or above reflected reasonable levels of satisfaction but with room for improvement, and scores around 70 reflected areas requiring immediate improvement. This showed wait time, exchange of information, nurse availability and nurse information provision to be areas requiring improvement.

Satisfaction scores and demographics

Age, gender, primary diagnosis and length of time as patient did not predict patient satisfaction in this study. Route of treatment scores are discussed separately.

Table 3 Summary of results for descriptive statistics

Dimension	N	Mean (SD)	95% CI	Median (25th – 75th)
Scales				
Drs technical skills	168	94.3 (9.1)	(92.2-95.6)	100 (88.3-100)
Drs interpersonal skills	167	93.1 (10)	(91.5-94.6)	100 (86.6-100)
Drs information provision	168	90.3 (12.6)	(88.3-92.2)	100 (80-100)
Drs availability	168	92.1 (10.8)	(90.4-93.7)	100 (80-100)
Nurses technical skills	141	90.7 (12.7)	(88.6-92.7)	100 (80-100)
Nurses interpersonal skills	141	91.4 (11.8)	(89.4-93.3)	100 (80-100)
Nurses information provision	138	87.3 (14.6)	(84.8-89.7)	93.3 (80-100)
Nurses availability	142	87.3 (15.7)	(84.7-89.8)	90 (80-100)
Other hospital personnel	166	89.8 (12.3)	(87.9-91.6)	93.3 (90-100)
interpersonal skills and information provision				
Waiting time	164	86.9 (14.8)	(84.6-89.1)	90 (80-100)
Access	166	91.3 (12.5)	(89.3-93.2)	100 (90-100)
Single items				
Exchange of information between caregivers	159	88 (13.3)	(85.9-90)	100 (80-100)
Comfort/Cleanliness	163	94.7 (11.2)	(92.9-96.4)	100 (80-100)
General satisfaction	163	94.7 (9.9)	(93.1-96.2)	100 (100-100)

Values are mean. Mean scores range from 0 to 100, with a higher score representing a higher level of satisfaction. Median denotes the point at which half the scores fall above and half below; SD= Standard deviation; 95% Confidence Interval; Values in parentheses alongside the median denote the 25th and 75th percentiles.

Does treatment route predict patient satisfaction?

Question 36 divided participants according to route of treatment. The aim was to determine whether those receiving only oral therapy were more or less satisfied with the care and services at the centre. Analysis of variance (ANOVA) is a statistical technique used to determine whether the means of two or more groups are equal under the assumption that the groups are normally distributed. (57) Treatment route was used as the independent variable for all satisfaction scores with participants being treated with combination therapy used as the baseline group. Results of positive associations are summarised in Table 4.

Table 4: Significant differences between treatment groups (ANOVA)

Factor	Model Strength (R ²)	Coefficient significance	Oral chemo group versus baseline
Nurse availability	0.11	0.0003	-29.5
Nurse interpersonal	0.05	0.0049	-17.6
Nurse technical	0.14	< 0.0001	-27.3
Nurse information	0.07	0.0213	-17.6

Although participants having only oral therapy (n=15) were advised to skip ahead ignoring the questions regarding nurse care dimensions, the majority of these participants did in fact answer them and the resulting answers show that those on oral therapy only ranked the nursing staff considerably lower than the groups who regularly used the infusion centre. Participants having oral therapy only scored the availability of nurses on average 29 points lower than those that had combination

therapy. The same group scored on average 17 points lower for the nurse's interpersonal skills, 27 points lower than the control group for the nurse's technical skills and 17 points lower for information provided by the nurses.

Raw results have not been included but show similar satisfaction scores in all other care dimensions. This demonstrates that satisfaction scores for all other areas are not affected by treatment route but does seem to indicate that patients on oral therapy don't appreciate the nursing staff, which probably reflects their lack of exposure to them. Figure 3 depicts this graphically, showing a plot of mean satisfaction scores by treatment route in relation to the nurse's technical skills.

Figure 3: Plot of means by treatment route

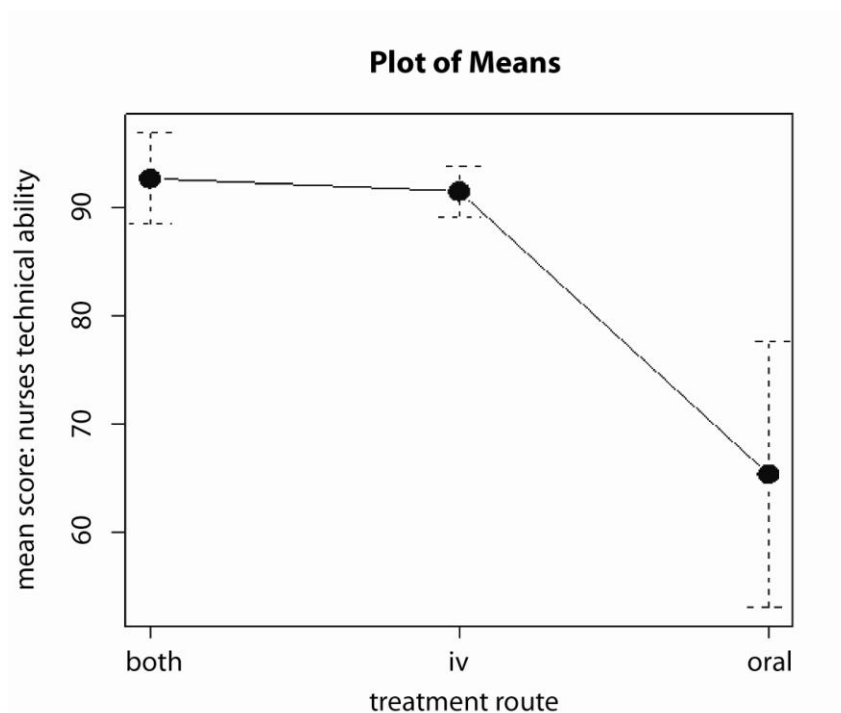


Figure 3 shows that participants who received treatment in the infusion centre rate the technical skills of the nursing staff considerably higher than those having oral therapy only.

Additional comments

Qualitative data collected from the open ended question was categorised into common themes which are listed in Table 6. Participants were asked to comment on anything that they wanted to. Most comments related to staff (30 comments), and referred to ‘their friendliness, care and professionalism’ their ‘efficiency’ or the ‘warm and friendly atmosphere created by the team’. Only one of these was negative and cited ‘inconsistent nursing care’. Nineteen comments related to parking, specifically the issue of introducing paid parking at the centre which one patient referred to as ‘an outrage’. Comments regarding the physical environment were positive and two participants commented on wait times for drugs being made up as ‘too long’. The only new topic commented on was an afterhours phone service for patients to utilise when they required advice (two comments).

Table 5: Qualitative data from open ended comments question. Total no. of comments = 61.

	Number of comments	%
Staff – level of care, professionalism, friendliness, their efficiency and the warm and friendly atmosphere they create	29	48%
Car parking	19	31%
Physical environment	8	13%
Wait time for chemotherapy drug to be made up	2	3%
After hours phone advice service	2	3%
Inconsistent nursing care	1	2%

Summary

This study measured patient satisfaction in a single institution outpatient oncology clinic in an effort to determine a baseline level of service with the centre and to identify any areas of unmet needs with the aim of using the data collected to improve areas found lacking and plan future service improvements. A 40 item questionnaire comprised of an existing, internationally validated tool with additional demographic and site specific questions was used to gather data over a four week period. One hundred and sixty eight questionnaires were returned (77% return rate) showing overall high satisfaction scores with mean scores above 86 for all 14 care dimensions. Scores of 80 or above were noted as areas that could be improved in an effort to increase patient satisfaction. The study found that patients receiving oral therapy only report significantly lower satisfaction scores for nurses in all four areas but report similar satisfaction scores for all other care dimensions. This shows that route of treatment has little impact upon a patient's overall satisfaction but that access to nursing staff increases a patient's appreciation of their role.. Study participants commented favourably on staff in the open ended comments section and also expressed their wish that the car parking remain free of charge.

5. Discussion

Introduction

This chapter explains the findings of the study in relation to the literature on patient satisfaction in cancer care. It begins with a summary of the particulars of the study and its purpose and is followed by a discussion of the main findings of the study and any areas that differ from previous research as well as any implications for practice. Limitations of the study are also discussed along with recommendations for further research.

Purpose of the study

This survey aimed to examine how cancer patients assess their ambulatory cancer care at a private institution with the primary aim of recording baseline satisfaction scores. The data collected will be used to gauge current performance, identify areas of need, drive further service improvements and be used comparatively when evaluating new processes.

Summary of the findings

The findings of this study demonstrate a high level of satisfaction with the centre in all dimensions of care. Mean satisfaction scores for all aspects of care were above 85 with median scores at ceiling for ten of the fourteen care dimensions. The two lowest areas of satisfaction reported were waiting time and the availability of nursing staff and provision of information from the nurses. Treatment route didn't affect satisfaction scores in any care dimensions other than nursing which had been expected since patients receiving only oral therapy rarely if ever see the nursing staff.

Demographic characteristics of the sample

The demographic characteristics of the sample well reflect the population of the practice in regards to gender however differ slightly in age. Study participants were 46% male (n= 77) and 51% female (n= 86) though 3% (n=5) failed to respond. The practice reports 47% of their population to be male and 53% female. The age of the sample differed from the population. Eighty percent of the sample was between the ages of 51 – 80 however the same age range is approximately 57% of the practice population. The main difference is in the over 80 years of age group. The sample had 9% of its total participants in the greater than 80 years range whereas the practice population reports 30% of its patients to be over 80. It is hypothesised that this reflects the fact that increasing age is the biggest risk factor for cancer and that treatment in this age group is dependent upon weighing the benefits versus the toxicity profiles of the intending chemotherapeutic agents with the performance status of the patient. The inclusion criteria of the study required participants to be undergoing active treatment so would rule out any person attending the centre for follow up, monitoring or palliative consultation.

The prevalence of cancer types by primary site marginally differs from the general cancer prevalence patterns as well as that of earlier studies.^(16, 17, 41) Recent figures for the Australian Institute of Health and Welfare list the ten most common cancers by site, in order of prevalence as prostate, bowel, breast, skin melanoma, lung, lymphoma, myeloid, unknown primary, kidney and pancreas.⁽⁵⁸⁾ Whilst prostate, breast and bowel cancer patients represent 44% of the sample population the individual percentages of each are represented in reverse order with a slight overrepresentation of breast cancer and slight underrepresentation of prostate cancer patients. These figures may reflect a patient's disease stage at diagnosis as treatment in all three of these tumour types is highly dependent upon the stage and spread of disease. Screening programs for all three of these cancers may have increased the number of new cases diagnosed through earlier detection however they have also decreased the number of cases requiring multi

modal treatment such as chemotherapy in an infusion centre, by finding the cancers when cure through surgery alone is still possible. The largest percentage of primary site for this study fell in the other category (n=61, 36%), and included renal cell carcinoma, sarcoma, brain tumours, carcinoid, chronic lymphocytic leukaemia, gastric, bladder and hepatocellular. This could be due to several factors; a reflection of the diagnostic and treatment advances that have occurred more recently as most of these cancers previously were often diagnosed in later stages, where intervention was either not indicated or not available, cancers such as hepatocellular that until recently had no effective treatment and the fact that the centre used in this study is a large secondary referral service with medical oncologists who have a special interest in the more diverse cancers such as neuroendocrine tumours, sarcomas and GI tumours.

Previous studies have shown no consistency in the effect of demographic variables such as age, gender, education level and primary diagnosis or stage of disease on satisfaction. Whilst some studies report a positive relationship between demographic variables others report either no association or a negative one. (16, 38, 41) Bredart and colleagues (16) showed age and education level to influence satisfaction whereas gender and disease stage had no impact. Several authors hypothesise that this reflects the higher expectations of those individuals with a higher level of education and the fact that younger patients are often more demanding.(14, 16) This study examined only age, gender, primary diagnosis and length of time as patient and found that patient's satisfaction with the services and care in this centre was equivalent regardless of these variables. Interestingly whilst not statistically significant, patients with lung cancer were marginally less satisfied with access to the centre (p= 0.03).

Whilst this may be a false positive as a result of the multiple testing done in this study, it could also provide support to previous literature that shows that patients with major treatment toxicity or poorer perceived health status reported

significantly lower levels of satisfaction. (5, 47) Lung cancer patients generally report some degree of dyspnoea, ranging from mild shortness of breath on exertion to an inability to complete sentences when speaking. The cancer centre is located on the first floor of the medical centre, the furthest possible tenancy from the front doors. This underlines the need for further research in this area to examine the association between a patient's performance status, their quality of life and their level of satisfaction and to ascertain whether increased satisfaction occurs as a result of any interventions aimed at reducing the impact of their disease upon their physical wellbeing.

Patient satisfaction with outpatient oncology care

Several authors agree that measurement of patient satisfaction has clinical relevance because it not only indicates whether a service meets the needs of its patients but also because evidence has shown that it impacts upon patient adherence to medical recommendations, their compliance to treatment regimens and to improved patient outcomes.(5, 37, 38, 53) Patient goals and values are so individual and reflect great variance, their health status and demographic factors are not necessarily predictive and can change frequently and rapidly, so the only way to accurately determine what patients want from a service and whether it meets their needs is to ask them. Kravitz (8) writes that the issue is no longer about 'whether patient satisfaction is important but whether it can be measured reproducibly and meaningfully' (p. 281).

Assessment of patient satisfaction scores in this study found that participants were more satisfied with the technical and interpersonal skills of the doctors and nurses than they were with their availability and information provision as reported by findings of earlier studies. (18, 37) Comfort and cleanliness scored higher than exchange of information between caregivers and wait times, and recorded higher mean scores than several studies, which most likely reflects the fact that the cancer centre is now situated within a newly designed purpose built medical centre

as opposed to its previous occupancy within an old warehouse with a leaking roof and inadequate heating and cooling. Two of the studies located in the literature search looked at the impact of physical environment on satisfaction and reported that satisfaction with waiting times was improved in each when elements of the environment were manipulated. These included waiting rooms with nature scenes and soft music which have shown to decrease anxiety. The availability of refreshments, a varied magazine selection and pamphlet racks. (7, 20) Gourdjji and colleagues (6) write that psychological factors influence patients perceptions of waiting time, including the perception 'that unoccupied time feels longer than occupied time' (p. 46). In both of the earlier studies wait times had only marginally improved however patients reported greater satisfaction because there was less 'unoccupied time' (p.348). (7, 20)

Existing literature shows a negative correlation between wait time and patient satisfaction with most studies reporting it to be a 'major source of dissatisfaction' (p. 252). (6, 7) Several studies cite wait times to see doctors and waiting for medical tests and results as two of the primary areas of patient dissatisfaction. (6, 7, 20, 37, 41, 43) Lengthy wait times in this study were predominantly associated with waiting for drugs to be made up from pharmacy on the day of treatment rather than wait times to see a doctor and most patients were keen to specify this in the comments section of the questionnaire. This is most likely also due in part to the carefully designed environment of the new cancer centre. The waiting room is a long roomy area with ample comfortable seating, soft music plays through discrete speakers, a water cooler is provided, as are magazines and the daily papers, and pamphlet racks holding information booklets and pamphlets are available for patients and caregivers to take. The waiting area also has a large window overlooking an enclosed garden area with a water feature.

The provision of information has been reported in several studies as an area that many cancer patients perceive as needing improvement. (5, 6, 16, 37) Satisfaction

surveys to date have almost universally reported low scores in this area and most recommend that information regarding a patient's disease, treatment, possible side effects and the management of symptoms of disease and side effects of treatment needs to be informative, relevant, specific and individualised to specific phases of disease and treatment in an effort to inform patients and allow them to be part of the process.(6, 16, 41) Information needs to be provided to patients and their families and caregivers in an environment that allows them to actively engage and question and opportunity for ongoing education and reinforcement of knowledge should be a priority. Several studies have recommended the use of written information to accompany a verbal session and the provision of audiovisual aids to increase knowledge and enhance patient understanding. (6, 7)

Mean satisfaction scores for information provision in this study were above 85 for both doctors and nurses and examination of the raw data reflected lower scale responses to questions regarding management of side effects at home. Oncology patients receiving treatment in a predominantly outpatient setting report high levels of anxiety associated with the management of symptoms at home, the recognition of red flags and their ability to contact health professionals by phone that can answer their health related queries. (18, 20, 37) Educating cancer patients is often a complex issue due to the many topics that need to be covered; patients are often distressed and anxious about their diagnosis and treatment course and may not be able to comprehend what is told to them at the time of initial diagnosis. Whilst some patients want all the details, others want very little, happy to leave their care in the hands of the professionals, whilst others report difficulty in asking questions. Judging the amount and type of information and developing good communication skills with which to build therapeutic relationships with patients is a learned skill, but one that should be encouraged as research shows that it improves patient satisfaction by encouraging patient participation and self care. (6, 43) A Norwegian study agreed reporting that patients who thought they had been well informed were significantly more satisfied with their care. (41)

Literature surrounding outpatient cancer care places enormous importance on the interpersonal aspects of doctors and nurses and the impact that communication has on patient adherence and compliance. Open, empathetic and trusting therapeutic relationships between patients and health professionals encourage patient participation and have shown improved patient outcomes. (14, 17, 37) Patients who report feeling encouraged to discuss health information and ask questions report significantly higher levels of satisfaction in health surveys as described by the Canadian study which utilised nurse navigators who provided additional support, education and symptom management to patients and families improving their access to health professionals throughout their cancer trajectory. (17, 20) The present study reported quite high levels for both interpersonal skills and availability of doctors and nurses; however doctor's scores were marginally higher.

The impact of nursing staff on patients was examined by looking at a subset of the population; those receiving oral therapy only, who rarely, if ever have contact with the nurses. No previous studies were located that looked at patient satisfaction in patients receiving oral therapies only. Satisfaction scores were found to be roughly equivalent in all other areas of care however whilst these patients were asked to skip ahead leaving the questions relating to nursing staff, most did in fact answer and reported lower levels of satisfaction with the nurses. It is hypothesised that this is not a genuine level of dissatisfaction but rather a result of the fact that these patients have almost never had any contact with the nurses and therefore possibly don't have any understanding of their role as evidence suggests that nursing interventions with their patient centred approach lead to higher satisfaction levels. (20) This certainly provides another avenue for further research as the use of oral agents continues to increase and issues of adherence, education and compliance continue to surround them. As the role and scope of nurses are expanded avenues for improving access to health professionals such as the development of

nurse-led clinics require further examination to determine their effects on patient satisfaction.

Qualitative data collected emphasised the impact of patient's interactions with staff which were predominantly related to their efficiency, warmth, compassion, knowledge and technical abilities. This reinforces the importance of ensuring quality improvement measures that support the educational requirements of staff to develop their communicational and technical skills and to provide an environment in which patients and healthcare professionals feel valued and supported. Access to services includes issues such as availability of car parking which has shown to increase frustration and anxiety in outpatients. (14) Car parking was the second most frequently commented on topic in the free text comments section. The medical centre that houses the cancer centre opened in 2009 and provides ample off street parking free of charge. Parking meters have recently been installed and whilst they have so far remained unused their installation has sparked much discussion from a patient population already concerned with financial aspects as a result of their cancer diagnosis.

The EORTC IN-PATSAT 32 questionnaire was chosen because it was designed specifically for the oncology setting had already been widely tested for its validity and reliability internationally and appeared to cover all the dimensions of care that the study required. Previous studies have demonstrated the need to assess several different dimensions of care when measuring patient satisfaction in cancer patients. These patients are often faced with numerous physical and psychosocial issues, and experience lengthy and complex treatments that impact upon their quality of life. Care dimensions found to influence patient satisfaction include interpersonal aspects, technical skills, availability and accessibility of care, continuity of care, communication and the financial aspects of care. (18, 59)

Whilst the importance of measuring patient satisfaction as a quality control measure has gained universal acceptance, it is not without its criticisms. As noted earlier by Ware and colleagues and cited by Goldzweig and colleagues (38) a patient's personal preferences, their perceived health status, their expectations and the reality of the care they receive all influence this construct. Patient expectations are usually determined by a multitude of variables which include cultural and societal norms, previous experience and current knowledge and are therefore often quite intricate. (14) Literature to date recognises the difficulty of defining patient satisfaction when it is in fact quite complex and can be influenced by many different factors and aspects of care. Draper and colleagues sum this up best by stating that 'satisfaction is not something pre-existing in the patient, waiting to be measured, but a judgement people form over time as they reflect on their experience' (p. 464).(32)

One of the key flaws in patient satisfaction measure stems from the theory that dissatisfaction is a result of negative experiences. In other words it is theorised that patients usually express satisfaction unless a negative experience has occurred.(14, 38) Goldzweig and colleagues (38) suggest that because of this positive satisfaction scores should not be taken to mean that patients have received exceptional care but 'simply that nothing extremely bad has occurred'. (p.1564). Another flaw noted in patient satisfaction surveys is that patients generally report greater satisfaction with care and services than they actually feel. Most studies report high levels of satisfaction which creates doubts over the sensitivity of the measures and their ability to discriminate between satisfied and unsatisfied patients. Inflated scoring can be due to several reasons, the fear of social desirability bias and therefore the fear that patients will receive a lower standard of care, their reluctance to express a negative opinion when they feel that they are reliant on the healthcare system, their genuine gratitude for individual staff and the wording of questions in some surveys and/or interviews.(14, 38, 39)

Cohen, Forbes and Garraway (60) undertook a study that looked at the impact of negative versus positive statements in satisfaction surveys. Using two separate surveys, one designed with negative statements such as 'I was not encouraged to ask questions', or 'I was not provided with enough information' and the other with positive statements such as 'You were given enough information', patients were asked to circle a 5 point scale indicating either their agreement or their disagreement with each statement. Results of the study showed a large and statistically significant difference in satisfaction scores, supporting the idea that 'substantially different conclusions can be obtained if patients are presented with a negative statement about care and asked to agree that something "bad" happened, as opposed to presenting them with a positive statement and asking them to disagree that something "good" happened' (p.843).

Literature on measuring patient satisfaction supports the idea that general satisfaction questions usually receive positive responses whilst questions on specific aspects of care warrant more variation in satisfaction scores and are often criticised for their resulting high scores.(14) Ford writes that general questions can often mask the consumers concerns with specific issues which may cause dissatisfaction for patients as they only record one aspect of the total experience and fail to determine the impact of a person's expectations or their needs. He further writes that 'there is little evidence that expressions of satisfaction are the result of fulfilment of expectations' (p. 22), and cites a limitation of satisfaction surveys in so far as they fail to explain why people are either satisfied or dissatisfied with their care. (61)

Significance of findings

Response rate

The high response rate (77%) indicated that patients were happy to provide feedback however the total amount of questionnaires given out was less than the researcher's expectations. With an estimated 150 – 250 patients utilising the

infusion centre each week it was hoped that a larger sample would be achieved though it was noted that dissemination and return rates were dependant on individual staffing of the reception desk.

Implications for practice

This study provides several starting points that can be developed in an effort to improve patient's experiences. Firstly a better, more sensitive tool may need to be located or developed which specifically addresses the institutions questions. Several healthcare facilities have found it necessary to use several tools and adopt different methods with which to gather data on a patient's total care needs to determine fully the impact of the disease on individuals and gauge their priorities for change. (6, 16, 41) Lowest scoring items from the questionnaire should be reviewed to evaluate what improvements can be made to increase patient satisfaction in these areas and methods such as focus groups and complaints analysis can be used to better plan patient centred interventions. Several areas highlighted by previous literature provide avenues for investigation.

A nurse practitioner candidate employed in the practice has an interest in oral chemotherapeutic agents and supportive care and one of her primary responsibilities is the provision of a business hours telephone enquiry and triaging service for disease and symptom management however the role is relatively new and had not been completely established at the time of the study so evaluation of this service during the study was thought to be too premature. Future role development also hopes to include several nurse-led clinics for patients on oral agents, a pain clinic and a formal survivorship program. Literature supports the patient centred benefits of nurse led clinics however most have been developed in areas where medical staff shortages and overcrowded outpatient clinics have driven their establishment and further investigation is required to determine the impact of this in private practice. (29)

Study limitations

The present study has some limitations. Firstly, the primary aim of the study was to record baseline data for the service that could be used to direct and evaluate future service developments however time constraints of the Masters program didn't allow for development and piloting of a tool that would meet the specific requirements of the service. Therefore the findings of this study are limited to the instrument used. The use of the existing tool whilst proven to be valid and reliable is quite structured and because the format is predetermined restricts responses. It also comprises a response scale with more favourable than unfavourable options, which may have lead to some scoring bias. The response scales also have limited variability due to ceiling effect, (a large percentage of participants scoring at the upper limit) and whilst lowest scoring items may provide clues as to where service fails to adequately meet patient needs the tool includes no specific measure of which aspects of care patients are most dissatisfied with and want improved.

Previous studies have reported lower levels of satisfaction from participants with a poorer perceived health status. (5, 47) The questionnaire used in this study did not ask patients to rate their health status however it was noted to be an obvious admission during the course of the study.

The sample used in this study was not a random sample so could contain some degree of selection bias on the premise that patients who choose to participate may be different from those who choose not to. Missing data represented 6.7% (n=359) of all data collected. Most of this was in the section enquiring about nurses (n= 310, 86%) which possibly reflects that patients didn't comprehend the additional line advising them to skip ahead if they were only receiving oral therapy or that it had been somehow misleading.

Conclusion

In summary, this study aimed to examine patient satisfaction in a single institution ambulatory oncology setting for the purposes of quality improvement. A new

facility, it is hoped to utilise the information collected to gauge current performance and direct future developments to meet the needs of patients more adequately. The increasing incidence of cancer and the growing number of cancer survivors will continue to place demands on services where resources are already limited. Pharmacological and technological advances will extend current service delivery beyond that which is already provided allowing patients better choices in the way they approach and manage their illness and treatment plans.

Whilst existing research acknowledges the difficulties associated with the patient satisfaction construct it widely accepts its ability to be used as an important outcome measure to determine whether a service meets the needs of its patients and to provide patients' perceptions on areas requiring improvement or service development.(39, 62) It can be used to monitor performance and to evaluate the effectiveness of new procedures or developments and to direct expenditure into areas that most benefit patients' needs. The results of this study showed that overall patients were highly satisfied with the care and services received however issues such as information provision, wait times for drugs to be made up and issues of paid parking require further investigation in an effort to improve services and increase patient satisfaction with the centre.

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Appendix I



PARTICIPANT INFORMATION SHEET

STUDY NAME: Patient satisfaction in the ambulatory oncology setting: Are patients needs being met? A cross-sectional survey.

INVESTIGATORS: Ms Deborah Hoberg RN, Grad Dip Ns Sc Onc.
Professor Alison Kitson RN, BSc(Hons), DPhil, FRCN, FAAN
Ms Liz Zwart RN, Onc Cert, STN, Grad Dip Ns Sc Onc, MNsSc
Dr Brian Stein MBBS(Hons), FRACP

Dear Recipient,

I am a Master of Nurse Practitioner student at The University of Adelaide, and would like to invite you to take part in a research study while you are here today at the Tennyson Centre.

Purpose of the study

This study aims to assess patient satisfaction within the outpatient cancer care setting. The purpose of this research is to allow us to measure our current performance, to highlight areas that may require further improvement and identify ways in which we might improve our patients care by addressing any unmet needs. This information will allow future service development to better reflect the needs and expectations of patients.

What is involved in this study?

Participation is voluntary, and you are free to withdraw at any time. If you agree to take part in this study you will be asked to complete a 40 item questionnaire. The questionnaire consists of the validated European Organisation for Research and Treatment of Cancer inpatients satisfaction questionnaire (EORTC IN-PATSAT 32) and a section with questions aimed to collect data on gender, age, diagnosis and access to the centre. The questionnaire should take approximately 15 mins to complete.

Confidentiality / Privacy

All of the information you provide will be securely stored and kept confidential. In addition, this research will form part of my Masters degree and the information collected may be used in publications about the study, however your name will not appear in any publications.

You may choose not to take part or you may withdraw from the study at any time.

Refusing to participate or leaving the study will not affect your current or future medical care

Thank you for taking time to consider this study.

If you are willing to take part in the study, please complete the attached questionnaire during your visit today and return it into the marked drop box located at the reception desk. This information sheet is yours to keep.

Contact Information

If you have any questions about the study or would like to speak with my supervisors, please contact:

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Complaints

This study was reviewed and approved by The University Of Adelaide's Human Research Ethics Committee.

Any persons with concerns or complaints about the conduct of a research study can contact the secretary of the Human Research Ethics Committee, Ms Sabine Schreiber, Tel: 08 83036028 Email: sabine.schreiber@adelaide.edu.au

Appendix II

Patient Satisfaction Survey –

We are interested in some things about you and your experience of the care received and the services available during your visits. Please answer all the questions yourself by circling the number that best applies to you. There are no ‘right’ or ‘wrong’ answers. The information that you provide will remain strictly confidential.

During your visit how would you rate doctors, in terms of:	Poor	Fair	Good	Very Good	Excellent
1. Their knowledge and experience of your illness	1	2	3	4	5
2. The treatment and medical follow up provided?	1	2	3	4	5
3. The attention they paid to your physical problems?	1	2	3	4	5
4. Their willingness to listen to all your concerns?	1	2	3	4	5
5. The interest they showed in you personally?	1	2	3	4	5
6. The comfort and support they gave you?	1	2	3	4	5
7. The information they gave you about your illness?	1	2	3	4	5
8. The information they gave you about your medical tests	1	2	3	4	5
9. The information they gave you about your treatment?	1	2	3	4	5
10. The frequency of their visits/consultations?	1	2	3	4	5
11. The time they devoted to you during visits/consultations	1	2	3	4	5

If you are currently on oral medications for your cancer treatment and have not at any time in the last 12 months received treatment in the infusion centre please go directly to question 23.

During your visits, how would you rate nurses, in terms of,	Poor	Fair	Good	Very Good	Excellent
12. The way they carried out your physical examination (took your temperature, pulse and blood pressure...)?	1	2	3	4	5
13. The way they handled your care (gave your medicines, performed injections...)?	1	2	3	4	5
14. The attention they paid to your physical comfort?	1	2	3	4	5
15. The interest they showed in you personally?	1	2	3	4	5
16. The comfort and support they gave you?	1	2	3	4	5

Please go on to the next page

During your visits, how would you rate Nurses, in terms of,	Poor	Fair	Good	Very Good	Excellent
17. Their human qualities (politeness, respect, sensitivity, kindness, patience.....)?	1	2	3	4	5
18. The information they gave you about your medical tests?	1	2	3	4	5
19. The information they gave you about your care?	1	2	3	4	5
20. The information they gave you about your treatment?	1	2	3	4	5
21. The information they provided about side effects and when and whom to contact after-hours?	1	2	3	4	5
22. The time they devoted to you?	1	2	3	4	5

During your visits, how would you rate services and care organization, in terms of	Poor	Fair	Good	Very Good	Excellent
23. The exchange of information between caregivers?	1	2	3	4	5
24. The kindness and helpfulness of the reception staff?	1	2	3	4	5
25. The information provided on your arrival?	1	2	3	4	5
26. The information provided to you before you left?	1	2	3	4	5
27. The waiting time for obtaining results of medical tests?	1	2	3	4	5
28. The speed of implementing medical tests and/or treatments?	1	2	3	4	5
29. The ease of access (Parking, means of transport...)?	1	2	3	4	5
30. The ease of finding ones way to different areas?	1	2	3	4	5
31. The environment of the building (cleanliness, spaciousness, calmness, lighting, décor..)?	1	2	3	4	5

In general,

32. How would you rate the care received during your visit	1	2	3	4	5
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Please go on to the next page

To help us with collating the information and using it to determine your needs we also need to collect some general information about you and how you access our centre, **for the following 3 questions circle only the answer that applies to you.**

33. Gender

Are you Male or Female?

34. What age range are you in?

< 40 years of age

41 – 50

51 – 60

61 – 70

71 – 80

> 80 years of age

35. What is your primary diagnosis?

Breast

Prostate

Colon or Rectal (Bowel)

Lung

Lymphoma

Other, please specify _____

36. How do you receive your treatment?

Intravenous (via a cannula, PICC or Infusaport)?

Oral (by mouth)

Combination of both

For the following four questions please circle the letter that best applies to you.

37. How long have you been a patient of ours?

a) 0 – 6mths

b) 6 – 12mths

c) more than 12 months, please specify _____

38. How do you get to the Centre for your visits and/or treatment?

a) Car – drive yourself

b) Car – driven by someone else

Please specify who, i.e. Wife, husband, sister, father, uncle etc. _____

c) Bus

d) Taxi

e) DVA, Red Cross or Leukaemia Transport

f) Other, please specify _____

39. How long does it take you to get to the Centre?

- a) less than 15 mins
- b) more than 15 mins but less than 30 mins
- c) more than 30 mins but less than one hour
- d) more than one hour, please specify _____

40. How satisfied are you with the car-parking facilities at the Centre?

- a) Extremely satisfied
- b) Satisfied
- c) Neither satisfied nor dissatisfied
- d) Dissatisfied
- e) Extremely dissatisfied

Is there anything you would like to comment on? Please write in the space below, but for privacy reasons please do not write anything that may be used to identify you.

Thank you for taking the time to complete our survey.