<table>
<thead>
<tr>
<th><strong>Title</strong></th>
<th>Patients’ satisfaction with a nurse-led oncology service</th>
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<tr>
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<td>Egan, Mary; Dowling, Maura</td>
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Abstract

This study reports the findings of a quantitative study determining the satisfaction levels of patients attending a nurse-led oncology day ward. A random sample of one hundred patients was surveyed using an adapted version of the Leeds Satisfaction Questionnaire (LSQ) (Hill, 1997) to ascertain the satisfaction levels of patients attending the unit. Satisfaction levels were found to be favorable in general. However, the study did highlight that some aspects of patient information required attention. Moreover, issues with the use of the questionnaire emerged as the inclusion of both positive and negative statements in the Likert style questionnaire presented contradictory findings.
Nurse Led Cancer Care

Nurse-led care can be loosely described as to encompass roles at the interface between nursing and medicine; these include roles previously performed and in some instances still are being performed by doctors (Miles et al, 2003). “Nurse led care” as it applies to the unit where this study was undertaken is defined as providing a service to the consumer in a unit, which is managed and staffed solely by nurses. In this unit, an oncology consultant conducts a clinic once a week in conjunction with the nurse led service, where all patients receiving treatment are reviewed.

In cancer care an approach in relation to follow up care used frequently is the use of telephone support, and according to Cox (2003) this is a feasible and effective way of providing support to cancer patients. It is also argued that follow up by nurses is efficient, cost effective, gives greater satisfaction to patients and also reduces investigational procedures as well as reducing overload on outpatient resources (Moore et al, 1999). Furthermore, Koinberg et al (2002) found that nurse led follow up at breast clinics had high patient satisfaction ratings and good medical safety. In addition, Moore (1997) reports that a nurse led service provided a wide range of therapies for patients with cancer, from conventional treatments to massage and exercise programmes. Moreover, a comparison study between nurse led care and conventional care, revealed a reduction in costs by as much as 31%, as well as increased satisfaction levels with nurse led intervention (Faithful et al, 2001).

Other studies too, have been carried out where satisfaction levels were higher among
patients who were treated by nurses. For example, an increased throughput of patients was noticed at a nurse-led breast clinic at Glouster Royal Hospital (Earnshaw & Stephenson, 1997). Moreover, Corner et al (2000) examined nursing interventions for patients attending a lung clinic and they revealed a higher level of acceptance among patients in the nurse led follow up.

There has been an increasing trend to treat patients with cancer in an outpatient or day unit setting because this decreases hospital stay, resulting in improved patient outcomes and reduced cost to the community (Wallis, 2003). However, Scott (1997) maintains that while patients might be receiving these treatments in an out patient setting, they require as much support as patients receiving intensive inpatient therapies. For these patients their disease and treatment cause as much anxiety and distress to them as to those in inpatient units.

A model of cancer nursing, which focuses on the out patient and ambulatory care of clients, will depend heavily on the nurses having the skill and expertise to develop their roles (Loftus, 2001). The emphasis of nurse led care according to Parrish (2000) has shifted from disease surveillance to the physical, social and emotional needs of patients and their families, with rapid communication between the hospital and the patient’s General Practitioner, and also includes close liaison links with the Community Palliative care team. Nurses who operate in a nurse led cancer service bring a different perspective to the patient. They change the environment of care and provide patients with support that enables them to cope with their illness both physically and psychologically (Moore,
The outpatient day ward where this study was carried out, allows for the post diagnosis treatment of patients requiring chemotherapy and other related products. In addition to the administration of these treatments, the care of patients visiting the oncology day unit includes ongoing comprehensive assessment by nursing staff in relation to side effects of the treatments and their management. Available also is supportive psychosocial care for the patient and their families, which includes education, and development of coping strategies, to help minimise side effects of treatment. The unit also offers symptom management and the provision of other relevant information to help at this difficult time, such as information regarding transport arrangements and availability of wig clinics. Information is also provided regarding the location of voluntary support groups, which some patients often may find helpful to visit.

In addition, nurses at this unit must recognize when it is appropriate to seek medical intervention for the side effects, and subsequently refer the patient to the appropriate medical team. Therefore it is essential for the nurse to demonstrate knowledge, skill and expertise in this respect.

**The measurement of patient satisfaction**

Patient satisfaction is a significant factor in the patient's well being and so must be included when evaluating health care service provision (Hill, 1997). Also, patient satisfaction is a fundamental requirement for a hospital’s success (Mustard, 2003).
Data on patient satisfaction with nursing care are routinely collected as an indicator of the quality of service being provided. However, even though there are numerous studies being compiled on satisfaction levels with nursing care there is no clear theoretical indication of what patient satisfaction really is (Avis et al, 1995; Schmidt, 2003). Therefore, research findings are of questionable validity without the clear definition of what constitutes patient satisfaction (Schmidt, 2003). Mustard (2003) suggests that the simplest and most accurate method of analysing and improving patient satisfaction is to elicit comments from the patient while the patient is still in the hospital receiving the care. In this way flaws in the service can be corrected before the patient leaves the building (Mustard, 2003). However, such an approach has potential difficulties in a nurse-led oncology unit where patients are often anxious to complete treatment and return home promptly.

Another consideration regarding the measurement of nurse led care for cancer patients relates to the reality that every patient with cancer may not be suitable to being reviewed by nurses. Researchers cannot be certain how the attributes of care selected for measurement are related to patients’ expectations (Avis et al, 1995). In addition, the expectations and preference of patients vary with the experience they have of the health service, the extent of their disease, and the belief and value system that they have.

**Data collection**

This study adopted a descriptive cross-sectional survey design, where the aim is not to
understand or explain the underlying causes but to obtain a description of the situation (Burns and Grove, 1995). A literature search was carried out which revealed the Leeds Satisfaction Questionnaire (LSQ) (Hill, 1997), as the most suitable as it was specifically designed to study patient satisfaction with a nurse-led rheumatology clinic.

The LSQ comprises of forty four questions on a 5-point Likert type rating scale, and has been tested and found to be both reliable (Cronbach’s alpha 0.96) and stable (test-re-test r = 0.83) (Hill, 1997). For the purpose of this study, some minor adjustments were made to the questionnaire in order for questions to be related to an oncology unit rather than a rheumatology clinic. In the adapted questionnaire, there were questions with regards to the cancer itself, the treatment being administered, side effects, coping mechanisms, as well as information relating to medications and other tests and x-rays being carried out. In addition, it was decided to also add in ten demographic questions to ascertain other aspects in relation to the population that was attending the oncology unit. It is common to collect demographic data such as age, gender, educational level or medical diagnosis and these variables when analysed provide key characteristics of the population being surveyed (Burns and Grove, 1997).

Approval for the study was granted from the hospital’s research ethics committee prior to the study commencing. Also, when patients were invited to complete the questionnaires it was highlighted to them in a letter that by their returning the completed questionnaires would be considered as consent for their participation. Following approval, a pilot study was conducted with eight patients not included in the study sample. The questionnaire
was then sent by post to a random sample of one hundred (drawn from a sampling frame of the population all those who attended the oncology unit in 2003).

The response rate was seventy two percent (72%), which was considered adequate and therefore follow-up with a phone call reminding the remaining patients to complete the questionnaire was not necessary. Also as it was not fully known what state of health they might have been experiencing, subsequently it was felt that they should not be bothered about the questionnaire when they did not return it at the outset.

**Data Analysis**

The questionnaire data was analysed using SPSS. Demographic data were at a nominal level of measurement with the remainder of the Likert style questions at ordinal level. Data analysis was subsequently organized under the forty-four categories or variables on which the patients were questioned following which the questions of similar nature were grouped together in order to form themes. For example, variables on communication and information giving were grouped together, as were explanation about disease and its side effects. Access to care and waiting times were also compiled into another group, as were negative and positive aspects towards staff. Two tables were constructed for each grouped theme; one table-representing positive worded statements on the Likert scale, and the other for negative worded statements (Tables 1 & 2). Non-parametric statistical tests were then carried out on the data in the tables of each group with the significance level set at 5%. The Mann-Whitney U test was used to compare differences between tables. The Chi square test was used to access the statistical significance of any
differences between the variables.

**Results and Discussion**

89.5% of patients were satisfied with staff in the unit (Chi square: $p = 0.871$, Mann Whitney: $p = 1.0$), and 79.4% were satisfied with the unit itself (chi square: $p= 0.933$; Mann Whitney: $p= 0.916$). Furthermore, regarding questions relating to how the patients felt they were treated, 86.3% said they were satisfied with the unit with respect to themselves as patients (Chi square: $p= 0.91$; Mann Whitney $p = 1.00$).

Some issues of interest arose during data analysis which warrants some discussion. Question 13 makes the assumption: “I’m satisfied with the care I receive in the unit”, and 94.4% of patients responded with strongly agree/agree. Question 36 states: “My care is just about perfect”, and 86.1% responded with strongly agree/agree. However, on closer examination, question 5 states: “There are some things about my care in the unit that could be improved”, and only 56.9% strongly disagreed/disagreed with this statement, and 22.2% were not sure. This is the largest score for the category “not sure” seen in the entire questionnaire. Perhaps if the question read: “My care in the unit could be improved”, then patients may have answered more positively as the words “some things” may have entered doubt into the patient’s mind and made them uncertain how to answer the question.

The response to Question 5 does seem to display dissatisfaction with the care received in the unit. This is at odds with the answers to questions 13 and 36. The frequency responses
to question 5 and 13 and 36 show significant statistical difference (Chi square, \( p = 0.000 \)) in each case. It was initially concluded that respondent fatigue may have been an influence on the response to some of the questions, but it would be more expected towards the end of the questionnaire rather than at the beginning. As this was only question five it was highly unlikely that the difference was due to fatigue. Therefore, it was thought that the setting of the questions in the negative and positive stance could somehow confuse the respondent, 8\% of whom were over 76 yrs and 29\% had only primary education.

Likewise, questions 37 and 43 ask about continuity of care. 81.9\% of patients disagree/strongly disagreed with the statement: “I hardly ever see the same person when I come for my appointment” whereas only 65.3\% strongly agree/agree with the statement: “I see the same person nearly every time I come to the unit”. However, 23.6\% and 9.7\% disagreed and were not sure respectively. The responses show a disparity (\( p = 0.037 \)). Respondent fatigue is believed to be a factor here, which is a possible explanation for the disparity the two variables. These questions are towards the end of the questionnaire which has fifty four questions, and respondents may have experienced fatigue and were therefore not paying attention to the way the made their responses. The wording of the questionnaire may confuse less informed clients where they would feel they already answered a similar question, and give the same answer to both questions. This highlights a possible limitation to the use of such a Likert type questionnaire in this study.

In this study it was also found that 25\% disagree or strongly disagree that they see the
same person each time they attend the unit with 9.7% not sure, thus leaving 65% agreeing that they do see the same person when they attend. However, when this question is posed in the negative stance it showed again that respondents are both satisfied and dissatisfied at the same time, with 82% disagreeing that they hardly ever see the same person in the unit and only 15% agreeing with this statement. The range of differences found in relation to these two questions is also significant (p <0.013). This finding leaves an inconclusive result regarding satisfaction with this aspect of the patients’ care.

Lecoutourier et al (1999) found that patients and families have a greater level of satisfaction when they have a higher degree of understanding of the patient’s condition and treatment and available services and entitlements. Poor communication and lack of information are the most frequently reported reasons for dissatisfaction (Carr-Hill, 1992).

In this study, a very high percentage of respondents were satisfied with the care they received. However, in some aspects, notably information and education, a lower scoring of satisfaction was noted especially regarding new prescriptions. This finding concurs with that of Carr-Hill’s (1992) where lack of information was also the reason for patient dissatisfaction.

In keeping with other studies (Hill, 1997; Byrne & Richardson 2000), the overall satisfaction with the amount of information and explanation provided by the staff in this oncology unit was comparable. Over 80% of patients felt fully informed in general about their cancer and its side effects. Nevertheless, it was disappointing to find that 23% of
respondents felt they got no explanation about their disease or its treatment and 12% were unsure if they did or not receive information. However, it must also be taken into account that the diagnosis of cancer causes an emotional reaction that limits the ability of the patient to assimilate new information (Hughes et al, 2000). With regard to the information needs of patients who have diagnosis of cancer, Wilson et al (2002) found that while some needs were met by staff in the hospital setting, many more came to the fore when the patient was discharged home, and these were then met by the community nurse. Wilson et al (2002) also reports that it was often very important also to provide information to the carer, as patients sometimes were not able to remember all the information that was relayed to them initially.

Information is needed in order that the patient can make both mental and physical adjustments to his life. This provides a challenge for the nurse in the oncology setting. However, McCaughan (2000) argues that the informational needs of cancer patients change over the duration of the illness, from the time of being first diagnosed to them receiving treatment, and that it was important to gauge the level of understanding that individuals had as some patients would require more information than others. Fallowfield & Jenkins (1999) believes that very often doctors fail to inform patients regarding their informational needs and underestimate both the amount and kind of information that the patient requires. It is often perceived that medical staff delivers only the information that they feel is adequate. In the present technological age patients often resort to the Internet to gain information regarding their illness or its treatment, and while this may be an advantage in some instances, it is the interpretation of this information that is important.
Whilst it is acknowledged that every effort is made to provide information and education to all cancer patients’ efforts are not always fruitful. For nurses working in oncology units perhaps it may be a matter of reiterating the information and explanation time and time again, and also making sure that a relative or carer also has access to the information being delivered.

In this study it was also found that the patients surveyed had an overall satisfaction rating 91% in relation to attitudes and skill of the nurses. However, some patients (n = 12) felt they had no confidence in the person who was treating them at the time they were in the unit. Many of these patients are already compromised facing huge dilemmas as regards the state of their health. Therefore, the need to boost their morale, give positive encouragement and respect their individuality is paramount. Even though stress levels were reported as being small (8%), not having confidence in their carer could undoubtedly increase the level of anxiety for those relevant.

In order for patients to have confidence in the carer, the oncology nurse needs to be professionally prepared for their role. The Calman Hine report (Department of Health, 1995) recommends that nurses who work in the area of cancer care should have postgraduate education. Such preparation of oncology nurses ensures that staff has explicit theoretical and practical knowledge in relation to specific situations when involved in the care of cancer patients.
A positive or empathic approach to patients relates to several aspects such as courtesy friendliness, being treated pleasantly and ones situation being understood (Arthur, 2004). There was no indication in this study to support the belief that nurses did not spend time with their clients. Considerable emphasis is placed on the amount of psychosocial support that is needed by those who have a diagnosis of cancer (Moore, 1997; Kearney, 1999).

It is well documented that receiving a cancer diagnosis brings psychological distress, an emotional burden and a feeling of loss of personal control that is a threat to survival and self-image (Walker et al, 1999). In order to avoid unnecessary delays in responding to the needs of patients, while they are receiving treatment, an oncology service must operate an open and friendly referral system whereby the patients can contact the nursing staff at any time either by themselves, through another health professional or a family member. Awareness of the support available to those who attend an oncology service is part of the informational education programme that each should patient receives prior to them embarking on their chemotherapy regime. This is ensured in this unit by not alone verbal information, but also by an information booklet, which contains the hospital numbers along with a number for the direct line to the oncology unit staff. The written documentation about the problems that might arise during a treatment is shown to the patient in the booklet, and the patient is encouraged to ask questions regarding any aspects of the treatment. Telephone information regarding out of hours service e.g. (the middle of the night) are also given to the patient on their first visit. Nevertheless, in this study, 13% of patients felt that they were unable to access staff and 15% were unsure if
the could or not but 70% felt it would be easy to contact the nurses in the unit if the need arose. It is therefore apparent from this study that although 90% of patients agreed that they were encouraged at the outset to contact the staff if problems arose, there nevertheless appears to be a problem in their ability to remember that throughout their programme the same principle applied. However, it is accepted that a diagnosis of any long-term, chronic or life-limiting illness is associated with a burden of emotional, physical and mental distress (Costello & Nelson, 2004).

The provision of nurse led care can reduce waiting times (Mackie, 1996; Loftus, 2001). In this study with regard to waiting times, 93% felt it was worth the wait and this was a high level of satisfaction, which concurred with others (Mackie, 1996; Loftus, 2001). However 16% felt they were waiting a long time in the day unit before being attended to. In the event of patients being kept waiting, it is imperative that they are informed at all times the reason for the delay. Providing reasonable explanations to patients about the nature of their wait for services increases patient satisfaction significantly (Nielsen, 2004). The implementation of a more streamlined appointment schedule could perhaps rectify some of the problems causing the long waiting times. However, it would be important to allow for some flexibility, as patients may not always be in a position to adhere to strict appointments due to the nature of their illness.

**Limitations**

The study presents findings from one hospital setting in a rural area and therefore is not representative of the population as a whole. Furthermore, the length of the questionnaire
may have contributed to response fatigue in participants who may already have been experiencing fatigue from their illness and treatment. The mental effort required to cope with the intense and competing demands imposed by a diagnosis of cancer can cause attentional fatigue (Richardson, 1995). Therefore, even though all the questions were relevant to the care aspect being provided, patients may have experienced fatigue answering the questions towards the end and responded without giving any real thought to whether they were satisfied or not with the care being provided. This would then have an influence on the outcome of the study.

Moreover, as the survey was carried out almost a year after some patients attended the unit, there may have been some inaccuracies too due to memory distortion, memory gaps and selective memory. Cancer patients’ memory distortion can happen for example, when a past event is seen to be worse or better than it was, and time has put a different perception on it (Burns and Grove, 1997). Despite the limitations outlined above, 94% of patients were satisfied with care that was provided. However, it must be acknowledged that patients’ expressions of satisfaction may also be subject to their belief that it may be impolite not to express satisfaction (Avis et al, 1995; Avis et al, 1997). Furthermore, the uniformly high levels of satisfaction from surveys has resulted in doubts over the sensitivity of the measures used and their ability to discriminate between satisfied and unsatisfied patients (Carr-Hill, 1992). Also, patients may express satisfaction with a service when they are relieved that their expectations of care are not as bad as it might have been (Avis et al, 1997).
**Conclusion**

Further research is needed on the role of the oncology nurses in nurse led ambulatory day care units, and also to ascertain the expectations of patients who attend such facilities for treatment. Patients’ expectations need to be addressed, as it is often not known at the outset what expectations or preferences oncology patients have. Therefore, it is recommended that qualitative approaches are the most suitable to investigate patient satisfaction as the consumer is involved in identifying their views of satisfaction and not those laid down by health care professionals (Avis et al, 1997). Approaches such as observation and interviews allow patients to provide a deeper, richer and contextual description of their experiences and researchers to clarify patients’ responses (Tasso et al 2002).
**Key Points**
Patient satisfaction is an important element of health care service provision
This study reports overall satisfaction with a nurse led oncology service.
Respondent fatigue may occur with oncology patients completing satisfaction questionnaires
The use of likert scale questions with positive and negative worded statements may result in confusion for some respondents

**Key words:** Patient satisfaction, oncology, nurse-led service.
Table 1: Questions concerning staff presented in a positive manner

<table>
<thead>
<tr>
<th>Question</th>
<th>SA/A</th>
<th>NS</th>
<th>D</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>2: I feel that I’m in good hands when I come to the unit</td>
<td>98.6</td>
<td>1.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4: I’m always given a clear explanation of why tests are done</td>
<td>94.2</td>
<td>4.2</td>
<td>1.4</td>
<td></td>
</tr>
<tr>
<td>9: The person I see in the unit really knows what she is talking about</td>
<td>93</td>
<td>1.4</td>
<td>5.6</td>
<td></td>
</tr>
<tr>
<td>25: The person I see in the unit seems to know how it feels to have cancer</td>
<td>75</td>
<td>12.5</td>
<td>6.9</td>
<td>4.2</td>
</tr>
<tr>
<td>38: The person I see at the unit appears skillful at their job</td>
<td>91.7</td>
<td>1.4</td>
<td>2.8</td>
<td>4.2</td>
</tr>
<tr>
<td>41: When I attend the unit I’m told everything I want to know about my cancer</td>
<td>84.7</td>
<td>6.9</td>
<td>4.2</td>
<td>4.2</td>
</tr>
<tr>
<td>Mean</td>
<td>89.5</td>
<td>4.2</td>
<td>2.8</td>
<td>3.1</td>
</tr>
<tr>
<td>Question</td>
<td>SD/D</td>
<td>NS</td>
<td>A</td>
<td>SA</td>
</tr>
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<td>-------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>16: My questions are answered in words I find hard to understand</td>
<td>86.1</td>
<td>5.6</td>
<td>4.2</td>
<td>4.2</td>
</tr>
<tr>
<td>21: The person I see in the unit sometimes appears uncertain about what they are doing</td>
<td>87.5</td>
<td>2.8</td>
<td>5.6</td>
<td>4.2</td>
</tr>
<tr>
<td>22: The person I see in the unit is not as thorough as she should be</td>
<td>90.3</td>
<td>5.6</td>
<td>4.2</td>
<td></td>
</tr>
<tr>
<td>24: The person I see in the unit does not understand what it feels like to have cancer</td>
<td>73.6</td>
<td>16.7</td>
<td>5.6</td>
<td>4.2</td>
</tr>
<tr>
<td>27: I have no confidence in the person who is caring for me</td>
<td>81.9</td>
<td>1.4</td>
<td>6.9</td>
<td>9.7</td>
</tr>
<tr>
<td>39: The person I see in the unit does not always talk sense</td>
<td>93</td>
<td></td>
<td>4.2</td>
<td>2.8</td>
</tr>
<tr>
<td>40: Sometimes the person I see in the unit is too busy to spend time with me</td>
<td>81.9</td>
<td>6.9</td>
<td>4.2</td>
<td>6.9</td>
</tr>
<tr>
<td>44: I’m always kept waiting a long time before being attended to</td>
<td>73.6</td>
<td>9.7</td>
<td>8.3</td>
<td>8.3</td>
</tr>
<tr>
<td><strong>Mean</strong></td>
<td>83.5</td>
<td>7</td>
<td>7.1</td>
<td>5.8</td>
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</table>
Table 3: Results of differences between tables.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Percentage</th>
<th>Chi-square significance</th>
<th>Mann Whitney significance</th>
</tr>
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<tbody>
<tr>
<td>Satisfaction with staff in oncology unit</td>
<td>89.5%</td>
<td>0.871</td>
<td>1.0</td>
</tr>
<tr>
<td>Satisfaction with unit itself</td>
<td>79.4%</td>
<td>0.9333</td>
<td>0.916</td>
</tr>
<tr>
<td>Satisfaction with how patients felt they were treated</td>
<td>86.3%</td>
<td>0.91</td>
<td>1.00</td>
</tr>
<tr>
<td>Satisfaction with respect to themselves as patients</td>
<td>86.3%</td>
<td>0.91</td>
<td>1.00</td>
</tr>
</tbody>
</table>
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