1997

The Chemotherapy Care Project: comparing oncologists' perceptions and patients' reported physical and psychosocial symptoms

Sallie Newell
Southern Cross University

Rob William Sanson-Fisher
University of Newcastle

Afaf Girgis
University of Newcastle

John Stewart
Mater Misericordiae Hospital, Newcastle

Anthony Bonaventura

See next page for additional authors

Publication details
Authors

This presentation is available at ePublications@SCU: http://epubs.scu.edu.au/educ_pubs/178
Hello. Today, I’m presenting the results from one of three studies conducted as part of the Chemotherapy Care project, a collaboration between the Cancer Education Research Program and the Medical Oncology Department of the Mater Hospital in Newcastle, NSW. You can find an overview of the other two studies in Poster #145. But today I’m concentrating on the study that compared the oncologists’ perceptions with their patients reported levels of physical and psychosocial symptoms.
We conducted this study for a number of reasons. It’s well known that medical oncology patients can experience a wide range of problems, including physical symptoms, mood disorders and reduced quality of life across a number of domains.

More surprising was the literature indicating that both patients and oncologists tend to see such problems as an inevitable part of the disease and treatment process.

Despite this acceptance, there was also evidence that these types of problems can have a substantial impact on patients’ compliance and treatment outcomes. It has been estimated that up to a third of patients will abandon chemotherapy prematurely as a result of such problems.

This highlights the importance of oncologists being aware of their patients’ physical and psychosocial problems and, where possible, helping them to deal with them.

However, there’s very little evidence about oncologists’ ability to identify such problems in their patients.
So, we conducted a study to assess the level of agreement between medical oncologists’ perceptions and patients’ reported levels of:

- physical symptoms
- anxiety
- depression
- perceived needs

So, we conducted a study to assess the level of agreement between medical oncologists’ perceptions and their patients’ reported levels of physical symptoms, anxiety, depression and perceived needs.
This study was conducted in the Mater Hospital in Newcastle, NSW in the academic medical oncology department.

It was based in the outpatients’ clinic, which sees approximately 150 to 180 patients a week and is staffed by 3 medical oncologists and 1 or 2 registrars.

The clinic staff were involved in the design of this study and in the development of the oncologist’s survey.
In order to achieve the desired number of patients, we had to conduct 2 waves of data collection - each lasted for 2 weeks and they were about 4 months apart.

First visit patients were excluded from the study as they would not yet have experienced the impact of treatment and were more likely to be emotionally distressed.

Patients were also considered ineligible if their oncologist considered them too sick or distressed or if they had insufficient English language skills to complete the survey.

All the remaining eligible patients were given an information letter and asked to participate in the study.

Patients attending more than once during the study periods were asked to participate only once.
Consenting, eligible patients completed a survey on a touchscreen computer while waiting to see their oncologist. The survey took an average of 15 minutes to complete and asked the patients about:

- the duration and severity of 12 physical symptoms during the last week
- their levels of anxiety and depression, using the Hospital Anxiety and Depression Scale or HADS
- and their perceived needs, using the Cancer Needs Questionnaire or CNQ, which assesses levels of need in five domains: health information, psychological, physical and daily living, provider care and support and interpersonal communication needs.

Both the HADS and the CNQ scales have been psychometrically tested with cancer patients.
The oncologists completed a brief deskpad survey after each consultation. Their survey asked them to rate their perception of the patient’s current levels of each physical symptom, anxiety, depression and each domain of perceived needs.

The response options shown for each type of symptom correlated with how patients responses were summarised.

A cover sheet on the deskpad survey explained how patients’ answers would be scored and how they would be compared with the oncologists’ responses.

This cover sheet included definitions of anxiety and depression, and example questions from each of the perceived needs’ domains.
At the oncologists’ suggestion, the deskpad survey also asked the oncologists to rate three factors which could be predictive of increased levels of agreement: the oncologist’s familiarity with the patient, their perceived level of rapport with the patient and how pressured they felt by their current workload.
Looking now at the participants’ characteristics, 3 medical oncologists and 2 medical oncology registrars participated in the study - a 100% response rate from the collaborating department.

The oncologists were all male, were aged between 41 and 46 years and had between 7 and 21 years experience in the field.

The registrars were also both male, were aged 28 and 30 years old and had 6 months and 3 years experience in the field.
A total of 288 non-first visit patients attended the clinic during the study periods. Of these, 58 were considered ineligible to participate and a further 12 patients saw their oncologists too quickly to be asked to participate.
So, 218 patients were asked to participate. 204 agreed, giving a 94% consent rate. Of the participants, 122 were currently receiving treatment and the remaining 82 were attending for follow-up visits with their oncologist.
The patients ranged in age from 20 to 86 years, with a mean age of 57.

More than half of them were female.

Colorectal and breast cancer represented the most common primary sites, accounting for almost 60% of patients.

About half of the patients were diagnosed with Stage 3 or 4 cancers.

And almost two thirds were diagnosed more than 6 months before completing the survey.

A very wide range of drugs and combinations were in use, much too varied to attempt to summarise here. But the three most commonly prescribed drugs were fluorouracil, cyclophosphamide and methotrexate.
So, what did we find? The first way we compared the oncologists’ and the patients’ responses was to look at the overall levels of each symptom based on both the oncologists’ perceptions and the patients’ reported prevalence.
As you can see, there was basic agreement about the prevalence of nausea, diarrhoea, skin rashes and pain in the injected limb.

However, the oncologists tended to underestimate patients’ reported levels of fatigue, mouth soreness, constipation, appetite loss, hot flushes, metallic taste in the mouth and of clinical anxiety and clinical depression.

On the other hand, the oncologists tended to overestimate patients’ reported levels of hair loss, vomiting and each of the perceived needs domains.
The second wave of analyses compared each individual patient’s responses with those of their oncologist to assess the sensitivity and specificity of the oncologists’ perceptions, where sensitivity represents the proportion of patients reporting each problem perceived as such and specificity represents the proportion of patients not reporting each problem perceived as such by their oncologist.
Looking first at the physical symptoms, which were asked only of patients currently receiving treatment, we can see that the oncologists’ perceptions of the more stereotypical symptoms, such as hair loss, nausea, vomiting and fatigue, were more likely to match the patients’ reports than their perceptions of other symptoms. Less than half of patients with these other symptoms were identified by their oncologist.

On the other hand, the generally high specificity rates, demonstrate that the oncologists consistently identified those patients with each symptom.

<table>
<thead>
<tr>
<th>Physical Symptoms (treatment patients only)</th>
<th>N</th>
<th>sensitivity (%)</th>
<th>specificity (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• hair loss</td>
<td>122</td>
<td>80</td>
<td>79</td>
</tr>
<tr>
<td>• nausea</td>
<td>122</td>
<td>57</td>
<td>78</td>
</tr>
<tr>
<td>• vomiting</td>
<td>122</td>
<td>57</td>
<td>88</td>
</tr>
<tr>
<td>• fatigue</td>
<td>122</td>
<td>57</td>
<td>56</td>
</tr>
<tr>
<td>• others</td>
<td>62 - 122</td>
<td>0 - 46</td>
<td>87 - 100</td>
</tr>
</tbody>
</table>
Looking at anxiety and depression now, again we can see that the oncologists had trouble identifying those patients with clinical levels of anxiety and depression, but were very good at identifying those without such problems. This makes sense in light of the overall underestimation of anxiety and depression discussed earlier.

<table>
<thead>
<tr>
<th>Anxiety &amp; Depression</th>
<th>N</th>
<th>sensitivity (%)</th>
<th>specificity (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>clinical anxiety</td>
<td>197</td>
<td>14</td>
<td>93</td>
</tr>
<tr>
<td>clinical depression</td>
<td>198</td>
<td>14</td>
<td>94</td>
</tr>
</tbody>
</table>
Finally, in the area of perceived needs, sensitivity rates were much higher than for any of the other problems, suggesting that the oncologists were better at identifying problems in these areas. However, this was largely due to much overestimation of problems in these areas, which is demonstrated by the lower specificity rates.

<table>
<thead>
<tr>
<th>Perceived Needs</th>
<th>N</th>
<th>Sensitivity (%)</th>
<th>Specificity (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>health information</td>
<td>193</td>
<td>96</td>
<td>34</td>
</tr>
<tr>
<td>psychological</td>
<td>200</td>
<td>78</td>
<td>40</td>
</tr>
<tr>
<td>provider care</td>
<td>199</td>
<td>73</td>
<td>53</td>
</tr>
<tr>
<td>physical</td>
<td>202</td>
<td>70</td>
<td>42</td>
</tr>
<tr>
<td>interpersonal communication</td>
<td>198</td>
<td>50</td>
<td>44</td>
</tr>
</tbody>
</table>
The third wave of analyses involved exploring potential predictors of improved levels of agreement between patients’ and oncologists’ responses.

As expected, the level of agreement was significantly higher where the oncologist reported better knowledge of the patient, where they perceived a better rapport with the patient and where they felt less pressured by their current workload.

A number of patient characteristics were also explored but none were found to be related to the level of agreement.
So, to summarise, we confirmed the high prevalence and wide range of physical and psychosocial problems previously identified in the literature.

We also found that there are currently less than optimal levels of agreement between oncologists’ perceptions and patients’ report for many of these problems.

And we identified the existence of predictor variables which highlight the benefit of continuous care with one oncologist and the importance of a good rapport between the patient and oncologist.
Implications for Future Research

- Need for additional data from more oncologists
- Need for improved awareness by oncologists of patients’ physical and psychosocial problems
- Need to trial interventions aimed at improving patient-oncologist communication

The small number of oncologists involved in this study makes it difficult to generalise the results found. However, it does provide the first data in this area. Therefore, further research with more oncologists may be warranted.

However, this study has identified the need for improved awareness by oncologists of their patients physical and psychosocial problems.

Hence there is a need to trial interventions aimed at improving the quality of communication between patients and their oncologists. Any such interventions need to recognise the limited consultation time available in the medical oncology setting.
Therefore, we’re currently planning a randomised controlled trial to test the effectiveness of using a similar touchscreen computer survey to provide computerised feedback to oncologists at reducing the problems experienced by their patients.