A prospective study of patient identified unmet activity of daily living needs among cancer patients at a comprehensive cancer care centre

Karen Taylor and David Currow
Nepean Cancer Care Centre, Kingswood, New South Wales, Australia

Cancer, as a chronic illness, demands a new focus in physical and emotional support. Thus, an assessment of activities of daily living needs among cancer patients was completed. A 1-week, cross-sectional survey of patients was undertaken, by using the Modified Barthel Index, the Eastern Co-operative Oncology Group performance status, a Modified Instrumental Activities of Daily Living Scale and a screening tool. As functional status declined, the number of unmet needs per patient increased. At least one-third of patients who would benefit from assessment were not referred. Without simple screening tools, the needs of this population are not always being recognised or met. Patient identified needs, when analysed by functional level and treatment intent, challenge existing assumptions of service provision. In conclusion, there is an unmet need in this cancer population.

By using the Screening Tool on referral, and with each change in level of function (as measured by the Eastern Co-operative Oncology Group), it would help identify patients who may benefit more from occupational therapy assessment.

**KEY WORDS** activities of daily living, cancer, needs assessment, occupational therapy, palliative care.

**INTRODUCTION**

Cancer is increasingly becoming a chronic illness as treatments improve life expectancy across the population (Coates & Tracey, 2001). Long-term morbidity associated with cancer and its treatment requires evaluation and advice. Those patients who will die from cancer can benefit from adequate assessment of their functional status as their condition deteriorates. Survivors of cancer can be left with functional problems that also require ongoing support. Disability may result from the cancer itself, or from cancer treatment such as subsequent lymphoedema or persistent peripheral neuropathy.

Comprehensive cancer care is, by definition, interdisciplinary, and includes the input of occupational therapists from the time of diagnosis through to cure or death. The needs of the whole patient in such cancer populations need to be studied in order to define:

1. Which patients will benefit from involvement by occupational therapists?
2. When is the ideal time to involve occupational therapists?
3. What screening process will indicate to other health professionals that an occupational therapy assessment may be of benefit?
4. How much contact do cancer patients need with occupational therapists?
5. How does proactive allied health involvement change measurable outcomes such as survival, level of function or unplanned admissions in patients with cancer?

This study is an initial step in the process of optimising resource allocation by addressing points (1) and (3).
Occupational therapists provide services to assist people with occupational performance areas of self-maintenance, productivity, leisure and rest (Chapparo & Ranka, 1997), commonly referred to as activities of daily living (ADL). Many occupational therapists believe that there are unmet needs because occupational therapy skills are not adequately used. Evidence supports the perception that occupational therapy services are under-utilised in cancer services (Soderback & Paulsson, 1997) and needs assessments may be helpful in defining priorities in service provision (Mullersdorf & Soderback, 1998).

The aim of this study was to survey the client-defined unmet ADL needs for patients treated through The Nepean Cancer Care Centre (NCCC), Sydney, Australia. The results are to be used for occupational therapy inpatient and outpatient service planning.

There is a distinction made between ‘expressed’ and ‘unexpressed’ need in the literature (Bunstan, Mackie, Jones & Mings, 1994; Mullersdorf & Soderback, 1998). ‘Expressed need’ involves the patient recognition of difficulties and problems. Expressed needs are classified into three groups: (i) no need; (ii) resolved need (when a need had been identified and met); and (iii) unresolved need (when a need had been identified and not yet met). This definition of expressed need describes the three response categories on the Screening Tool — Activities of Daily Living (ST-ADL; Taylor, 2000 after Cooper, 1997; personal communication, 23 February, 2000).

‘Unexpressed needs’ are difficulties or problems that patients have not yet recognised but others may have identified through observation or measurement. The authors have chosen ‘expressed unresolved needs’ as the measure of unmet need for this study.

The NCCC provides medical, radiation and haematology, and palliative services. Psycho-oncology and allied health staff are employed directly by the Centre. All patients are centrally welcomed to the Centre, for attendance at the outpatient clinic, day ward or for radiotherapy. The NCCC serves a population of 320 000, with 1300 new cancer patients and 25 000 occasions of service annually. A total of 1932 patients attended NCCC in the year 2000; of these, 60% were female and 40% male. Sixty-six percent of patients fell in the age range 51–80 years.

**METHODS**

Approval for the study was obtained from the Wentworth Area Health Service Human Ethics and Research Committee. The study was a cross-sectional prevalence study of 1 week to measure self-reported functional status on four tools: (i) Modified Barthel Index (MBI); (ii) Modified Instrumental Activities of Daily Living Scale; (iii) the Eastern Co-operative Oncology Group (ECOG) Performance Scale; (iv) and ST-ADL. The latter tool measured expressed unresolved needs, which the authors use to define unmet needs.

**SUBJECTS**

The study evaluated the potential needs that could be addressed by occupational therapy intervention in patients (inpatients and outpatients) cared for by cancer or palliative services over a 1-week period. The interviewers were three third-year occupational therapy students, trained for this purpose. Inclusion criteria of the study were:

1. Over 18 years of age.
2. Having a diagnosis of cancer.
3. Being able to speak and write English, or have an adequate interpreter.
4. Being able and willing to complete a written questionnaire.
5. Contact with cancer services during the one-week survey period, 26–30 June 2000.

The exclusion criterion was a score of less than 24 out of 30 on the Folstein Mini Mental State Examination (MMSE), a validated and reliable screening tool for cognitive function (Folstein, Folstein & McHugh, 1975). A normal population will have a score $\geq 24$.

**Assessment tools**

The MBI (Shah, Vanclay & Cooper, 1989) assesses personal care, including mobility. One hundred indicates independence and zero complete dependence.

A modified version of the Lawton Instrumental Activities of Daily Living Scale (MIADL; Abrams, Beers & Berkow, 1995) was used. A maximal score of 24 indicates independence in telephone use, getting to places beyond walking distance, grocery shopping, meal preparation, housework, handyman work, laundry, and taking medicine. This tool is complementary to the MBI, for a broad assessment of ADL.

This study used a modified version of a Screening Tool re Function (Cooper, 1997), the ST-ADL, developed for cancer, HIV/AIDS and palliative care patients. It is a self-administered questionnaire that has a time frame of the past month. Specific categories elicit a wider range of problems than the MBI/MIADL including: work, kitchen activities, writing/using keyboard, leisure and driving (see Table 1 for all listed activities, except eating).

Self-identification of further issues is encouraged by asking for comment on ‘any other areas of life’ (in Table 1 these are shopping for dinner, sitting outdoors, lifting,
A study of ADL needs of patients at NCCC

Table 1. Unresolved, expressed needs or patient identified unmet needs measured on the Screening Tool — Activities of Daily Living (ST-ADL) by patients indicating that they require advice concerning alternative technique/equipment for difficulties they are still experiencing

<table>
<thead>
<tr>
<th>Need Description</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working (e.g., job, profession, volunteer work)</td>
<td>24</td>
</tr>
<tr>
<td>Leisure (e.g., holding cards, gardening)</td>
<td>20</td>
</tr>
<tr>
<td>Driving (e.g., turning key, managing pedals)</td>
<td>16</td>
</tr>
<tr>
<td>Using stairs</td>
<td>12</td>
</tr>
<tr>
<td>Walking</td>
<td>11</td>
</tr>
<tr>
<td>Kitchen activities</td>
<td>10</td>
</tr>
<tr>
<td>Writing/using keyboard</td>
<td>7</td>
</tr>
<tr>
<td>Washing (e.g., bathing/showering/cleaning teeth)</td>
<td>6</td>
</tr>
<tr>
<td>Dressing (e.g., putting on clothes/shoes, transfers (e.g., in/out of bed or bath)</td>
<td>3</td>
</tr>
<tr>
<td>Using toilet, shopping for dinner</td>
<td>2</td>
</tr>
<tr>
<td>Sitting outdoors, lifting, nursing grandchild, sex, walking — going out, running, passenger in car</td>
<td>1</td>
</tr>
</tbody>
</table>

nursing grandchild, sex, walking — going out, running, passenger in a car). This tool measures unresolved expressed need by asking patients to indicate whether they require advice about alternative techniques or equipment for activities in which they currently experience difficulties. The authors are using this as a measure of unmet need.

The ECOG 5-point scale of functional status (Zubrod, 1960) has: ‘0’ as no restriction on predisease performance; ‘1’ as some restriction of strenuous physical activity, but ambulatory and able to do light sedentary work; ‘2’ as ambulatory, capable of self care, unable to work, up and about more than 50% of waking hours; ‘3’ limited self care, chair/bedbound for more than 50% of waking hours; and ‘4’ as chair/bed bound.

**Data collection**

Patients were approached either in their ward or in the waiting areas of the NCCC and invited to participate in the survey. After establishing the patients’ eligibility to participate, the interviewer provided verbal and written information about the survey and obtained the patients’ written, informed consent.

Interviewers administered the MMSE and patients scoring less than 24 out of 30 were not included in the study. Patients whose potential maximal score was less than 30, because of literacy or physical impairment, were included only if their score was ≥ 24.

A count of people who declined to participate, or did not meet eligibility criteria was kept. The number of potential interviewees for the study period was calculated from computerised databases of inpatients and outpatients.

The interviewer scored the MBI and ECOG from patient report at interview. Patients were then asked to complete the self-administered questionnaires (MIADL and ST-ADL), with assistance from the interviewer if requested. Patients were asked to rank their three most pressing concerns on each tool (where results had any impairment in function), together with a preference for the tool that best reflected their perceived needs.

Subjects were stratified into inpatients/outpatients and the categories of oncology, haematology and palliative care using patient identification information. The patient-treating specialist performed further stratification according to treatment intent; curative, adjuvant, life prolonging or palliative.

Outcomes from each of the tools were generated. The service currently provided by occupational therapy was calculated directly from standard allied health data collection.

**RESULTS**

**Participation**

One hundred and four of 236 outpatients and 16 of 34 inpatients seen by the service were evaluated. A further two patients were assessed but not included because of their inability to fully complete the MMSE. Eighty-six patients were not approached in the busiest part of the day. Of the 184 patients approached, eight were ineligible (no interpreter (two) or ‘don’t have cancer’ (six)); 47 declined to participate (too unwell (11), not interested (seven), no time (10), too distressed (two), no reason given (six), other (11)); and seven commenced but were unable to complete the MMSE because of insufficient time.

A comparison of age, gender and treating team characteristics were the same in those assessed and not assessed. The mean age of outpatients was consistent across those assessed during the study week (59 years) and those not assessed during the same period (60 years).

**Mini mental state examination scores**

Fourteen of 120 patients (12%, six outpatients, eight inpatients) initially assessed scored < 24 (median 20, range 13–23) on MMSE. By treatment intent, only patients in the adjuvant setting had no one with impaired MMSE (Fig. 1). In the other groups, treatment with curative (15%), life prolonging (23%) and palliative (14%) intent had MMSE of < 24.
Functional level

Of the 120 initial assessments, only 12 patients (10%) achieved maximal scores on all four tools assessing functions.

Unmet need

Thirty-seven patients (30.8%; 27 females, 10 males) indicated that they had unmet needs and required advice with alternative techniques or equipment on the ST-ADL, for a total of 123 items. The three most frequently indicated items were work (24), leisure (20) and driving (16) (Table 2). Table 1 shows the range of unmet need identified by patients by indicating that they require advice about alternative technique/equipment from the ST-ADL.

As functional status declined, the percentage of patients with unmet needs increased (Table 2). For patients with ECOG 1, 25% had unmet needs around work compared with 40% of people with ECOG 3 or 4. Similar rates were seen with leisure and driving which were the other areas where needs were most frequently identified. The number of unmet needs for each patient increased with the declining level of function (Table 3). Patients with ECOG 0 had an average of 0.06 unmet needs. This increased for each subsequent ECOG level: ECOG 1–0.8; ECOG 2–1.5; ECOG 3–1.4 and ECOG 4–5.0 unmet needs. Analysis of unmet need did not differ dramatically between treatment intent (Table 4, bold section).

Patient’s priorities

Patients were asked to rank their three most pressing concerns on each tool, where results identified any deficit, together with a preference for the tool as that which best reflected their perceived needs.

No specific trend emerged for patient preference for a particular tool. Patients concerns ranged broadly, without any trend emerging, reinforcing the importance of client focused approach.

Table 2. Three most frequently indicated unmet needs versus ECOG

<table>
<thead>
<tr>
<th>Unmet need</th>
<th>Total</th>
<th>ECOG n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working</td>
<td>24</td>
<td>1 (6)</td>
</tr>
<tr>
<td>Leisure</td>
<td>20</td>
<td>11 (18)</td>
</tr>
<tr>
<td>Driving</td>
<td>16</td>
<td>8 (13)</td>
</tr>
</tbody>
</table>

ECOG, Eastern Cooperative Oncology Group Performance Status.

Table 3. Frequency of unmet need on Screening Tool — Activities of Daily Living (ST-ADL) tabulated against functional status as measured by Eastern Co-operative Oncology Group (ECOG) scale

<table>
<thead>
<tr>
<th>Tool</th>
<th>1–2 unmet needs</th>
<th>3–4 unmet needs</th>
<th>&gt; 4 unmet needs</th>
<th>Total</th>
<th>Minimum no. unmet needs by ECOG</th>
</tr>
</thead>
<tbody>
<tr>
<td>ECOG 0 (18)</td>
<td>1 (1)</td>
<td>—</td>
<td>—</td>
<td>1 (1)</td>
<td>1/18 (0.06)</td>
</tr>
<tr>
<td>ECOG 1 (61)</td>
<td>13 (13)</td>
<td>4 (12)</td>
<td>5 (25)</td>
<td>22 (50)</td>
<td>50/61 (0.82)</td>
</tr>
<tr>
<td>ECOG 2 (13)</td>
<td>2 (2)</td>
<td>4 (12)</td>
<td>1 (5)</td>
<td>7 (19)</td>
<td>19/13 (1.46)</td>
</tr>
<tr>
<td>ECOG 3 (8)</td>
<td>2 (2)</td>
<td>3 (9)</td>
<td>—</td>
<td>5 (11)</td>
<td>11/8 (1.37)</td>
</tr>
<tr>
<td>ECOG 4 (2)</td>
<td>—</td>
<td>—</td>
<td>2 (10)</td>
<td>2 (10)</td>
<td>10/2 (5.00)</td>
</tr>
</tbody>
</table>

The estimate of the minimum number of unmet needs in each ECOG group is obtained by dividing the total of the minimum number of needs in that row by the number of patients.
Current service provision: Definition of the gap between existing services and need

Another way to consider unmet need is to compare the current rate of referral to occupational therapy services with the needs identified in this study. Currently, 19% of NCCC patients are referred to the occupational therapy service for assessment. This study identified that 31% of patients have unmet needs. This showed that at least one in 10 NCCC patients had patient-identified unmet need where initial assessment by an occupational therapist is likely to be of benefit.

DISCUSSION

Previous studies have assessed cancer patients’ function or unmet needs for ADL. This is the first study to examine both patients’ functional level and unmet needs in relation to ADL, together with treatment intent in a cancer and palliative population.

A greater number of females than males reported unmet need, which is consistent with earlier literature (Mor, Guadagnoli & Wool, 1987; Mor, Allen, Siegel & Houts, 1992; Newell, Sanson-Fisher, Girgis & Ackland, 1999).

Previous studies found that age is inversely related to unmet need (Guadagnoli & Mor, 1991; Mor et al., 1992). A more recent occupational therapy specific study identified older cancer patients in the active phase of their treatment as more likely to need occupational therapy input (Soderback, Pettersson, Von Essen & Stein, 2000). Our study also found older patients reported higher levels of unmet need (≤ 65 years, 23 of 82, 28%; and > 65 years, 14 of 39, 36%).

Age is reported to correlate with unmet need in personal care (Guadagnoli & Mor, 1991). In this study, few reported unmet personal care needs (six of 120) indicating that these needs were well met in this population. This most likely reflects the quality of integrated community care offered for this region.

Disease progression, age and consequent functional deterioration, relate proportionally to increased needs (Mor et al., 1987). Similarly, severity and duration of the disease relates to an increase in needs (Mor et al.). In our study, functional decline, as measured by ECOG, was clearly related to increased unmet need (Tables 2, 3).

Cognitive impairment is likely to progress with the disease. Twelve percent of our patients had clinically relevant cognitive impairment as demonstrated by a MMSE score of < 24. This compared with another study in the literature using inpatients and outpatients with advanced cancer (8% with a MMSE < 24), despite better function as measured by ECOG (Vigano, Bruera & Suares-Almazor, 1999).

The MMSE scores of < 24 are spread across curative, life prolonging and palliative treatment categories. This confirms that adequate cognitive assessment of all new patients is necessary in this clinical setting no matter what the treatment intent is.

Equally, unmet need when examined by treatment intent (Table 4) demonstrates that all groups have significant numbers of unmet needs. The support that needs to be offered to patients undergoing adjuvant chemotherapy should not be underestimated. In a similar study, it was patients in the active phase of their disease who needed most support (Soderback, Pettersson, Von Essen & Stein, 2000). Another study demonstrated that patients with advancing cancer or those not responding to treatment have higher needs (Newell et al., 1999).

In the United Kingdom, a general health status measure (the UK Sickness Impact Profile) was used to survey cancer patients (Malone, Harris & Luscombe, 1994). Four main areas of impairment were identified, in order of frequency: (i) work; (ii) recreation and pastimes; (iii) home management; and (iv) sleep and rest. This current study had similar areas of frequently identified need (i.e. work, leisure activities, driving and mobility issues).

This current study potentially underestimates unmet need. We excluded patients with poor cognitive function and sicker patients with poorer levels of function who may not have been able to attend clinic for assessment or

<table>
<thead>
<tr>
<th>Treatment intent (no. patients)</th>
<th>Resolved or no needs</th>
<th>1–4 unmet needs</th>
<th>&gt; 4 unmet needs</th>
<th>(Blank)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adjuvant (35)</td>
<td>20 (56)</td>
<td>9 (26)</td>
<td>3 (9)</td>
<td>3 (9)</td>
</tr>
<tr>
<td>Curative (27)</td>
<td>15 (55)</td>
<td>8 (29)</td>
<td>—</td>
<td>4 (15)</td>
</tr>
<tr>
<td>Life prolonging (22)</td>
<td>14 (64)</td>
<td>1 (5)</td>
<td>2 (9)</td>
<td>5 (23)</td>
</tr>
<tr>
<td>Palliative (36)</td>
<td>15 (41)</td>
<td>11 (30)</td>
<td>3 (8)</td>
<td>7 (19)</td>
</tr>
</tbody>
</table>

Values within parentheses are percentages.
participate even if attending the outpatient department. Of the reasons given for not participating, 13 out of 54 (24%) were due to being too unwell or distressed. The possibility of social desirability bias in self-report studies could also apply to this study (Newell et al., 1999).

This patient population in our study is representative of a typical cancer centre population. The line where treatment intent is drawn by clinicians may vary but the proportion in each group is probably representative.

Changing ECOG status should alert staff that ADLs are changing for that patient. It would seem appropriate that any patient with an ECOG of two or less should be considered for assessment. This process could be further refined by the use of the ST-ADL.

Having the medical team routinely screen patients would provide an opportunity for unexpressed need to be identified. Once referred to occupational therapists, realistic goals can be set in the light of that particular patient’s prognosis.

**Future directions**

This study dealt with two of the five questions raised in the introduction regarding the needs of the cancer patient. The questions around timing of involvement, amount of contact and outcomes are areas for future exploration. A comparison of unmet need in the population already receiving occupational therapy to unmet need in the NCCC population as a whole would provide a measure of this service’s effectiveness.

This study identified ECOG as a simple tool that could be used in a busy clinic setting. Prospectively collecting data using ECOG and changes in ECOG with ST-ADL will be the next step in refining this process. As needs change in the setting of chronic illness, it will be important to determine that longitudinal data support these prevalence observations.

Such studies would contribute to an expanded evidence base for practice. Further, this study could be replicated in non-cancer resource scarce areas in patients with progressive diseases such as chronic airways limitation or end-stage heart failure.

**CONCLUSION**

There are a range of unmet needs in the population of cancer patients that we studied that could be addressed by occupational therapy assessment and intervention. Even the unmet needs defined in this study are most likely a significant underestimate given the groups of patients who are not represented in the data.

Patient-stated difficulties with ADL are an indicator for referral to occupational therapy. A screening tool such as ST-ADL, applied when ECOG changes or is 2, 3 or 4, can most efficiently identify this group of patients with unmet need. Active involvement of the nursing and medical teams in this screening process is paramount.

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**REFERENCES**


