

# ON THE RECEIVING END: CANCER PATIENTS' PERCEPTIONS OF THE BURDEN OF CHEMOTHERAPY

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## Abstract

During the 1970s cancer chemotherapy began to emerge from the research environment of leukaemia and paediatric cancer units to become a part of the management of common cancers occurring in adults. Expectations were high that the successes of chemotherapy in leukaemia and lymphoma would be mirrored in treatment of adult solid tumours. The Sydney branch of the Ludwig Institute for Cancer Research, established at the University of Sydney Royal Prince Alfred Hospital in 1977, reported in 1980 that approximately half the chemotherapy given to adults was palliative in intent and that median life expectancy of those patients was 44 weeks.<sup>1</sup> At the time, most chemotherapy was administered to hospitalised patients and the predominant side-effects were nausea, vomiting and alopecia.

In August 1980, Alan Coates was recruited to join the staff of the Sydney Branch of the Ludwig Institute for Cancer Research. He was to remain at Royal Prince Alfred Hospital (RPAH) until he took up his current position as Chief Executive Officer of The Cancer Council Australia (then the Australian Cancer Society) in 1998. His extensive and distinguished clinical and research contributions over these years are reviewed in this issue of *Cancer Forum*. I am reviewing a series of papers presented with the title *On the receiving end* from 1983 to 1996.<sup>2,7</sup> These papers span time during which cancer chemotherapy expanded rapidly, along with developments in supportive care. The papers illustrate Alan Coates' skills in measurement and analysis and also document changes over a 10-year timeframe in patient perception of the relative importance of different side-effects of chemotherapy. These changes mirror changes in cancer chemotherapy and supportive care and the evolution of patient-centred care. Moreover, the co-authorship of these six papers indicates that collaboration with Alan Coates has been a passport to distinction in clinical cancer research.

The first paper in the series reported a survey of 99 English-speaking outpatients who attended medical oncology outpatients at RPAH who had received chemotherapy within the four-week period before study entry.<sup>2</sup> Patients had received a median of three cycles of their current therapy. Two sets of cards were prepared. On each card was the name of one potential side-effect of chemotherapy. Group A cards (45 cards) listed physical side-effects and Group B (28 cards) non-physical side-effects. Patients selected cards from each group which described a side-effect they attributed to their chemotherapy and then they ranked the top five cards in each group. The top five cards in each group were combined and the patient selected the five most severe symptoms regardless of group putting them in order from most to least severe. The median number of non-physical symptom cards selected was seven and of physical symptoms 12, giving a total number of

symptoms selected of 19. The relative severity of side-effects for the entire group ranked the top five side-effects as vomiting, nausea, loss of hair, thought of coming for treatment and length of time treatment takes at clinic. The abstract concludes: "Evaluation of patient perception of the severity of side-effects is an aid to striking the cost-benefit balance when deciding whether to use cancer chemotherapy."

The second paper<sup>3</sup> describes the application of linear analogue self-assessment (LASA) scales to evaluate general well-being and the severity of certain specific problems (mood, pain, nausea and vomiting, appetite, breathlessness, physical activity) perceived by 110 patients receiving therapy for malignant melanoma, small cell lung cancer and ovarian cancer. A number of correlations were observed and it was concluded that LASA techniques provide a convenient method for the assessment of quality of life (QoL) in patients receiving cancer therapy and potentially allows comparison of patient perception of treatment-related morbidities.

The third paper extended the use of LASA scales for eight groups of symptoms identified as important in the earlier studies.<sup>4</sup> These items formed a new instrument (GLQ-8) for measuring aspects of QoL. One hundred and sixty-six patients completed both the GLQ-8 and five previously validated LAA scales, together with the visual analogue version of the Spitzer QL Index. The new scales showed high reliability, with retest correlation coefficients exceeding 0.8 for most items. Correlations were in general higher for the GLQ-8 items than for the five older LASA items. It was concluded that the GLQ-8 and GLQ uniscale were convenient and reliable instrument measuring aspects of patient's QoL in patients receiving cancer chemotherapy. The fourth paper in the series extended cross validation of the GLQ-8 against three established measures of QoL, mood and psychological adjustment to cancer.<sup>5</sup> Correlations were high and it was concluded that the regular inclusion of practical indicators of aspects of QoL in clinical trials would allow improved assessment

of the cost-benefit ratio of treatment to outcome in cancer patients.

The fifth paper replicated the first paper in patients receiving chemotherapy at RPAH 10 years after the initial report. Patients reported experiencing an average of 20 symptoms (13 physical and seven psychosocial). Nausea was the most severe symptom followed by tiredness and loss of hair. Vomiting was now ranked fifth, compared to first in 1983. Differences were detected in the symptoms experienced and reported as most severe between chemotherapy regimens, between older and younger patients, and between males and females. It was concluded that there had been a reduction in the severity of some symptoms experienced while receiving chemotherapy and a shift from concerns about physical to psychosocial issues.

The final paper<sup>7</sup> explored which dimensions of QoL scores carry prognostic information, a theme discussed further by others in this issue of *Cancer Forum*.

### Conclusions

This sequence of papers under the title *On the receiving end* provides insight into Alan Coates' attention to the

needs of patients, the detailed and creative analysis of results and the need to compare new instruments to determine their worth over earlier measures. □

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