Deciding to undergo chemotherapy: how do patients feel about the decision making process at the Edinburgh Cancer Centre?

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Abstract

The aim of this service evaluation conducted at the Edinburgh Cancer Centre (ECC) was to assess how people felt, with hindsight, about the decision to have palliative or curative chemotherapy for lung or gynaecological cancers.

The SURE test, comprising four questions, was adapted for retrospective use with patients who had completed their treatment and had returned to the oncology clinic. A fifth question relating to regret was added (hence the ‘SURE’ test). Questionnaires were completed in conversation with a medical student.

29 patients completed the questionnaire (13 males, 16 females). Patients generally reported high levels of certainty that treatment had been the right choice, both at the time of the decision, and upon treatment completion. Most also reported feeling that they were supported well with the decision. The lowest scoring areas related to understanding of treatment risks and benefits. It is reassuring that most patients felt confident in the decision making around treatment. Others’ work locally has revealed that regret often comes late, and it is possible that findings would have been different if patients had been surveyed later. Poor understanding of risks of treatment could reflect a number of scenarios, and warrants exploration with future work.

Introduction

In non-small cell lung cancer, progression from a small local tumour to metastatic disease causes five-year survival to drop from over 50% to under 15%1. However, studies have shown that patients may be unlikely to recall their cancer stage2, and do not always understand that chemotherapy given during late stage cancer is unlikely to cure their disease3, nor that any extension of life may come with a decrease in quality4. It is these serious issues that suggest effective discussion of treatment choices are essential.

Methods

The questionnaire was designed through adaption of the SURE test5,6, in consultation with specialists from NHS Lothian.

There were five questions (see pie charts above) each answered on a 4-point scale, producing a 20-point score indicating decisional certainty, where 1=not at all, 2=a little, 3=quite a bit, 4=very much.

Patients who had previously undertaken chemotherapy for lung or gynaecological cancers, filled in the questionnaire following their normal appointment, with any clinical information contributed by the patient’s usual oncologist.

Findings

Two areas that scored consistently highly were those reflecting certainty at the time of the decision to undergo chemotherapy, and certainty upon completion, with 92% and 75% of patients answering, “very much” or “quite a bit” to these questions respectively. It appears that overall patients felt sure of the best choice for them when beginning treatment and following it.

Conclusion and Recommendations

There were high levels of certainty regarding patient decision to undergo chemotherapy at the time of treatment, with low levels of regret. However, the extent to which patients felt informed of risks and benefits was contrarily low.

There are several potential reasons for this, including poor comprehension of information, perceived importance of this information and inappropriate consultation focus. However, patients ultimately felt they received enough advice and support and these low levels of understanding seemed to have little to no impact on overall patient certainty.

To further explore the root and effects of this interesting contrast, further study is required in to the methods of patient decision making regarding chemotherapy. A potential area to further the evaluation is performing a similar evaluation for those who declined chemotherapy.

Key References


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