

Deciding to undergo chemotherapy:

how do patients feel about the decision making process at the Edinburgh Cancer Centre?

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Aim

This was an NHS service evaluation which aimed to evaluate, using a purpose designed questionnaire, treatment choices made at the Edinburgh Cancer Centre, with a focus on patient experience and perception, as opposed to clinical outcome.

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 'Surer' 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.

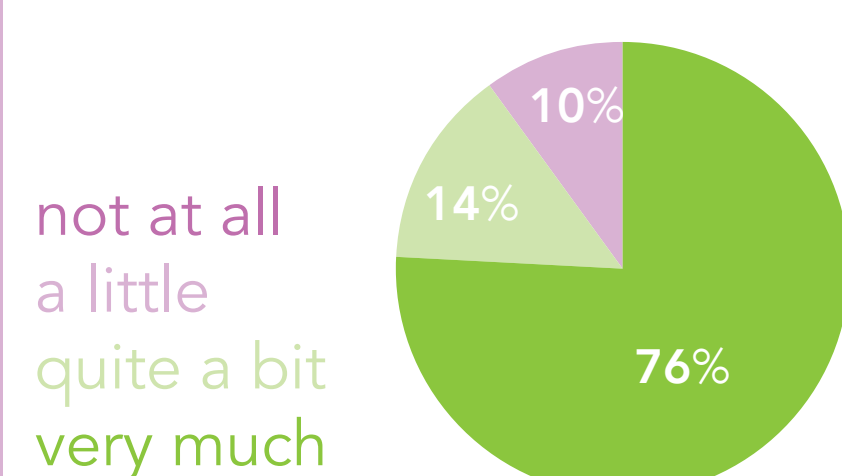
Introduction

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%. 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.

SURER

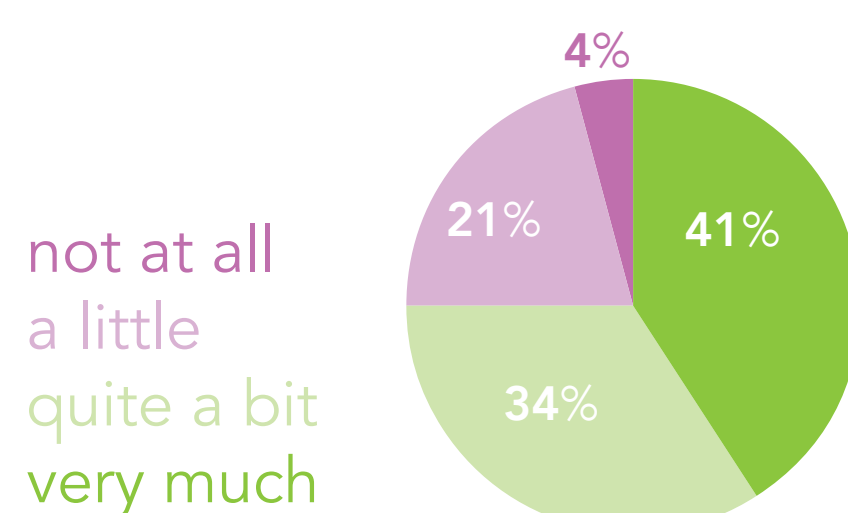
Sure of myself

Q1 Did you feel sure about the best choice for you?



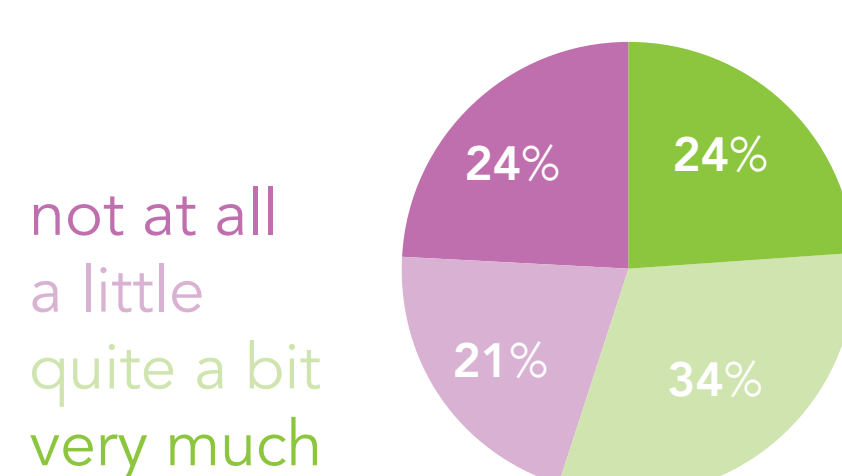
Understand information

Q2 Did you know the benefits and risks of having chemotherapy?



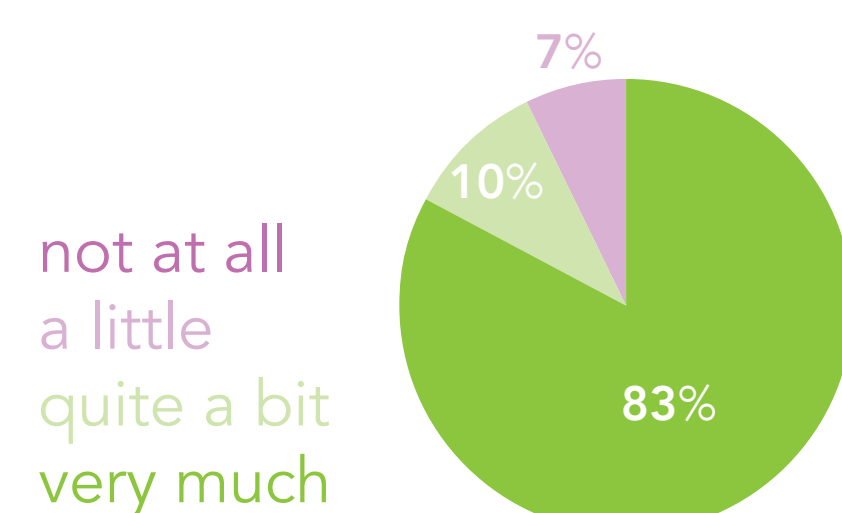
Risk Benefit Ratio

Q3 Were you clear about which benefits and risks matter most to you?



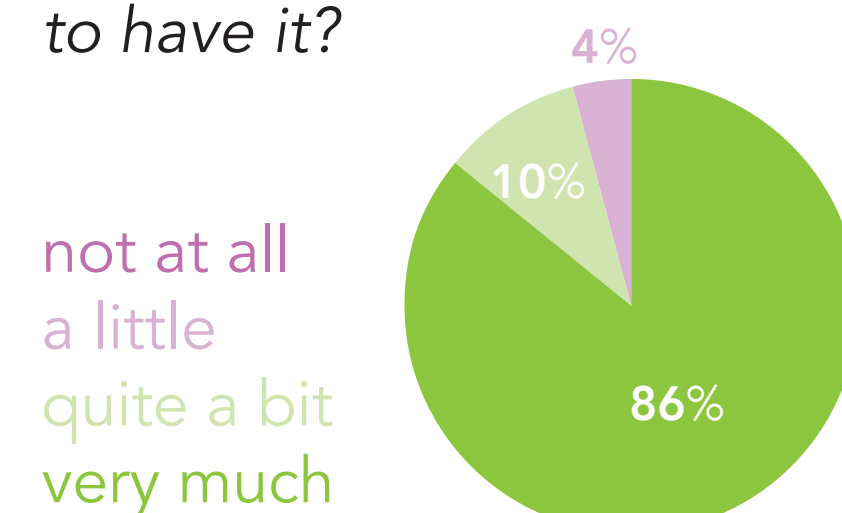
Encouragement

Q4 Did you have enough support and advice to make a choice?



Regret

Q5 Having finished treatment, how sure do you feel now about the decision you made to have it?



Methods

The questionnaire was designed through adaption of the SURE test^{5,6}, 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



overall patients felt sure of the best choice for them when beginning treatment and following it

patient's usual oncologist.

From the 28/06/2017 to the 26/07/2017 29 patients took part in the Service Evaluation.

Approval to carry out this work was granted by NHS Lothian, and UTREC, University of St Andrews.

Key References

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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 90% 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.

Patients felt that they received high levels of advice and support to make their decision, with 83% saying they felt "very much" supported, and none answering with "not at all."

However, there was a relatively large variation in the areas around knowledge and balancing of risks and benefits of chemotherapy, particularly in the question, "Were you clear about which benefits and risks matter most to you?" to which just under half answered, "Not at all" or "A little."

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 contrastingly low.

There are several potential reasons for this, including poor comprehension of information, perceived importance of this information or 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.

The cohort involved in the evaluation were generally positive about their decision to undergo chemotherapy. Thus, from the perspective of these patients, the appropriate treatment choice was made.

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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.



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