Enhancing knowledge:
the impact of experience and information

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Abstract

Background

The last two to three decades has seen a shift towards patients taking a more active role in treatment decision making. One way of enabling patients to give true informed consent prior to medical treatment is to give them adequate information from which to make a reasonable decision. Research highlights that lack of knowledge or poor recall of information may result in negative consequences for the patient. A plethora of studies have been conducted on improving the type and manner in which this information is given to ultimately improve patient knowledge. Assuming there is a limit to how much information can be imparted prior to treatment, the main purpose of this research was to assess the impact that the experience of treatment in addition to the standard pre-treatment information has on patients' eventual knowledge of chemotherapy treatment information, a unique area of research.

Methods

Part One: A literature review was conducted to determine all possible tools and methods that have been implemented for development of an improved consent process, including their effectiveness and their success in improving patient knowledge of the information given. A large number of studies were identified in assessing the effectiveness of a variety of interventions, in different populations. The main finding of this review suggests that although some of these tools may be beneficial at improving patient knowledge of the information given, patient recall was still poor. Furthermore, a majority of these studies were found to be methodologically flawed, have limited external validity, and were often conducted on small samples questioning reliability of results. Therefore, considering these limitations and the potential cost in implementing such interventions, it is believed that alternative research is necessary. Therefore, a novel area of research would be to assess the impact of treatment experience on patient knowledge of the standard pre-treatment consent information given.

Part Two: A second literature review was conducted to identify studies assessing the impact of patient experience with surgical or non-surgical treatment and its effect on patient knowledge of the informed consent information. Overall, the evidence suggested that despite having experienced treatment, a high proportion of patients still did not recall or recognise aspects of the procedure they undertook. However, scarce data indicated that further research was necessary especially in different patient populations.

Part Three: Gaps identified in part two aided the design of a longitudinal study to assess whether patient knowledge improves when the experience of chemotherapy is added to the standard pre-treatment information used for informed consent. The assessment of knowledge was based on the information given to patients on their information sheet and consent form. Some factors that may be associated with patient knowledge of treatment information given were identified from the literature reviews, either as not being, or scarcely being evaluated. Therefore, the level of patient satisfaction, trust for the physician, and social support were chosen to be measured and their changes over the chemotherapy treatment period were determined. Lastly, particular demographic or psycho-social variables were assessed as predictors of knowledge of pre-treatment information given. Seventy one consecutive men and women due to receive adjuvant chemotherapy treatment for breast or colorectal cancer participated in the study. Eligible patients who consented were visited to complete structured questionnaires at three time points.

Part Four: Six women with breast cancer agreed to participate in the in-depth qualitative interview regarding information given at the time of consent. This additional study was conducted to help triangulate findings from the longitudinal study and provide a richness of responses regarding the topics of interest.

Results

Patient knowledge of the number, name and potential side effects of chemotherapy drugs were evaluated and found to vary greatly. First, patient knowledge of the number of drugs given for chemotherapy was found to be the most highly recalled aspect of consent information

(ranging from 59.6% correct at Time 1 to 68.4% correct at Time 2) although experience over the three time points showed no significant increase in knowledge ($p = .33$). Second, patient knowledge of the names of drugs given, showed a significant increase over the course of chemotherapy ($p = .01$) although the highest proportion of correct recall was still low at only 26.3% at Time 3. Finally, an analysis of patient knowledge of chemotherapy side effects also found participants did not have significantly increased knowledge of potential side effects despite experience ($p = .52$) with the highest proportion of correct recall being 21.1% at Time 2.

Patient satisfaction significantly reduced over time ($p = .04$) although satisfaction remained moderate-to-high. The same result was found for social support with experience ($p = .02$). However, although trust remained high across all three time points, there was a non-significant worsening trend over the course of chemotherapy ($p = .61$). A number of predictors appeared to correlate with variables assessing patient knowledge of the information given. A regression model was found to be significant for the knowledge of the number of drugs [$\chi^2(8, 70) = 30.72$, $p = .000$] with predictors accounting for 47.8% of the variance. The model for the name of drugs received was also significant [$\chi^2(5, 70) = 12.61$, $p = .03$] with predictors accounting for 32.4% of the variance. Being female and being a private patient were found to be significant, individual predictors of knowledge of the name of drugs. However, no other predictors in the two models were strong enough to be individually significant. The patient's age and the extent that they read the information given were the only factors found to be associated with all three measures of knowledge. The most prominent themes of the qualitative analysis included patients having a high level of trust for their physician and that the consent information form given was seen, by patients, as a reinforcement tool which they could refer to if needed.

Conclusion

The experience of chemotherapy treatment in addition to the standard pre-treatment information initially given to patients at consent does not appear to be sufficient at improving patient knowledge of chemotherapy. However findings suggest that different components of

the consent process are predicted by different variables. People differ in their ability to understand information, and have different circumstances and priorities that can influence their memory and interpretations. This leads to recognition of the complexity in improving the consent process and suggests that an individualised or multi-faceted approach is necessary.

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