



Parental decision making in pediatric cancer end-of-life care: Using focus group methodology as a prephase to seek participant design input

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KEYWORDS

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Summary The ultimate aim of our research program is to provide strategies that facilitate parental decision-making for parents of children with cancer receiving end-of-life care. As a first step to develop this program, we needed insight into parents' reactions and opinions about the research methods planned for a larger study. In particular, we needed their opinions about the general experience of making the decision between palliative cytotoxic chemotherapy and supportive care alone and the factors that parents regard as important when making this decision. In addition, we wished to know whether the methodology proposed for the future study was easy to understand and whether it might cause unnecessary emotional trauma. Finally, we asked their opinions regarding the appropriate target sample of parents to include in the future study. Qualitative data about these issues were collected using focus group methodology involving seven participants. The comments made during the focus group discussions were content-analyzed for common themes. The results from the focus group discussion led to particular modifications in the proposed design and interview strategies planned for the future larger study. We found it was extremely beneficial to include a focus group pre-phase in a study that will interview parents in a high sensitivity area.

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Zusammenfassung Das Hauptziel unseres Forschungsprogramms besteht darin, Strategien zu empfehlen, die den Eltern von terminal krebserkrankten Kindern das

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Treffen von Entscheidungen erleichtern sollen. Bei der Entwicklung dieses Programms mussten wir uns zunächst einen Eindruck darüber verschaffen, wie die Eltern auf die Forschungsmethoden, die für eine umfangreichere Studie vorgesehen waren, reagieren würden und welches hierzu ihre Ansichten waren. Besonderen Wert legten wir auf die Erfahrungen der Eltern mit der Entscheidung zwischen einer palliativen zytostatischen Chemotherapie und einer rein supportiven Betreuung sowie auf die Faktoren, die von den Eltern bei ihrer Entscheidungsfindung als wichtig erachtet wurden. Darüber hinaus wollten wir wissen, welche für die zukünftige Studie geeigneten Methoden leicht verständlich sind und ob sie zu unnötiger seelische Belastung führen können. Schließlich befragten wir die Eltern zu ihrer Meinung über eine für die Studie geeignete Eltern-Stichprobe. In einer Fokusgruppe mit sieben Teilnehmern wurden qualitative Daten zu diesen Fragen erhoben. Die in den Fokusgruppendifkussionen angefallenen Äußerungen wurden in einer Inhalts-Analyse geprüft. Die Ergebnisse der Fokusgruppendifkussion führten zu gezielten Veränderungen des Designs und der Interview-Strategien, welche für die künftige Studie vorgesehen sind. Wir empfanden das Einbeziehen einer Fokusgruppen-Vorphase in das Design einer Studie, in der Interviews mit Eltern auf einem hochsensiblen Gebiet durchgeführt werden sollen, als außerordentlich hilfreich.

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Background

When cure in children with cancer is considered unlikely, the intent of therapy is usually to provide the best quality and quantity of life that is possible, while respecting the preferences of the child and family (Barrera et al., 2002). However, Wolfe and colleagues interviewed 103 parents of children who had died from cancer and concluded that from the parents' perspective, children who die of cancer frequently receive aggressive treatment at the end-of-life and many suffer a great deal during their last month of life (Wolfe et al., 2000). Furthermore, Hinds et al.'s qualitative studies indicated that choosing between the therapeutic options available for children entering the end-of-life phase (particularly between supportive care with palliative cytotoxic chemotherapy and supportive care alone) is an important, but difficult, parental decision (Hinds et al., 1997). Despite this, very little is known about: (1) How parents formulate their preferences regarding aggressive treatment at the end of life and arrive at a decision; (2) what factors influence these decisions; and (3) whether we can make this process easier for families.

Our ultimate research plan is to describe preferences for supportive care with palliative chemotherapy relative to supportive care alone for children receiving end-of-life care using a preference elicitation method called the "Threshold Technique" (TT) (Llewellyn-Thomas, 1995). Generally speaking, the TT proceeds by first presenting the respondent with the relevant hypothetical treatment options and about the key

attributes involved in making a choice. In the clinical context of interest here, at least three therapeutic attributes are potentially important to parental decision-makers; these are the anticipated quality of life, the expected duration of survival, and the probability of cure associated with palliative chemotherapy and with supportive care alone. The situation is particularly poignant for these parents because, although the probability of cure may be relatively small, e.g. 1%, that probability may carry enough significance that parents consider chemotherapy for their child. Then, once the respondent makes an initial choice, the risks of the chosen strategy or the benefits of the alternative strategy are systematically altered until the respondent switches to their initially rejected option. This switch point then represents the relative strength of preference for the initially chosen option.

For the larger study, we plan to interview parents of children with poor prognosis cancer who are receiving palliative care. However, before undertaking this future research, we believed it was essential to seek the advice of parents of children who had died from cancer regarding the study design and data collection methods—including the TT—that we proposed to use. Studies have shown that bereaved parents have found participation in research interviews to be a positive experience (Dyregrov, 2004; Scott et al., 2002). The advice sought from parents would help to augment the quality of the data collected in the larger future study, and reduce the likelihood of inadvertently inducing parental secondary trauma in the future study's participants.

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