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Development of a national protocol to screen Dutch cancer survivors on late cancer treatment effects

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ABSTRACT

Purposes: The development of a national protocol to formalize the screening of Dutch cancer survivors on potential late cancer treatment effects and the medical terminology used in describing the patient follow up procedures.

Methods: A combined evidence-based and qualitative approach, the Glaser's State of the Art Strategy, was used to reach consensus on how to screen Dutch cancer survivors on late cancer treatment effects. A core working group set up a first proposal of a screening protocol and a handbook of medical term definitions by incorporating available research evidence (1980–2003), clinical expertise and definitions from Dutch medical dictionaries and textbooks. External experts reviewed this proposal in a cycle of two postal and two discussion rounds. The follow-up procedures and medical term definitions described in the draft screening protocol were to be accepted if consensus among external experts was $\geq 50\%$.

Results: A protocol for screening cancer survivors on late cancer treatment effects was developed describing the follow-up procedures for cancer survivors according to previous therapeutic exposures. Four hundred and twenty one medical terms were used in describing these follow-up procedures. One hundred and fifteen of these terms were classified as multi-interpretable and 101 of these terms were defined. No definitions could be found for the remaining 14 medical terms.

Conclusions: We succeeded in reaching consensus throughout The Netherlands on a protocol to screen cancer survivors on late cancer treatment effects. This protocol is now in use by all Dutch outpatient clinics and warrants that the screening of cancer survivors is consistent across The Netherlands. The screening protocol specifies in detail how screening of cancer survivors should take place and can therefore be used by clinicians who were not involved in the consensus study.

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1. Introduction

Ideally, clinical practice guidelines should be evidence-based, that is based on evidence derived from systematic reviews of scientifically sound studies. Randomized controlled trial studies have been advocated as the preferred source of evidence for clinical guidelines because its design reduces the likelihood of intervening variables affecting the study results. However, not all questions concerning treatment or care can be answered based on evidence from randomized clinical trials. In evaluating 'patients at risk' for example, a prospective cohort study design may provide the best source of research evidence [1]. Besides, in practice there are health care areas where sufficient research-based evidence, from which medical recommendations can be developed, does not (yet) exist. In these cases, results of different studies must be combined with other data and expert opinions, for example concerning current clinical practices, to develop clinical guidelines [2–4]. Formal consensus methods are therefore becoming increasingly popular for health care problems which cannot be answered yet by use of a pure evidence-based approach [5,6]. Consensus studies are mostly used to correct for the lack of conclusive data by linking the knowledge and experience of experts with the available research evidence. The idea is that formal consensus methods structure the decision making process by providing experts in a certain domain with the best available evidence and by asking them to use this information to reach consensus on a issue, mostly in a couple of rounds, during which they are provided with feedback on the group's response.

In The Netherlands, outpatient clinics for the follow-up of Dutch survivors of childhood cancer have been installed some years ago. Though the need for long time follow up of childhood cancer survivors is felt world wide, consensus on how these patients should be screened is lacking [7–9]. The Dutch clinics involved in screening cancer survivors felt that consensus was required on how the follow-up of these patients should take place, first on a national level. Due to the complex and diverse nature of some of the known late cancer treatment effects, it has been recognized that screening for these adverse effects is a difficult task requiring the multidisciplinary cooperation of a variety of medical and paramedical disciplines. In reaching consensus on the screening protocol to be followed by all clinicians involved in screening cancer survivors throughout The Netherlands, we thus acknowledged that cooperation of experts of all these disciplines was essential.

In this study, we used the Glaser's State of the Art Strategy as method to structure the consensus process for creating these patient follow-up procedures.

After a short introduction of formal consensus methods and of research on late effects of childhood cancer, we will describe the set up of our study; the way in which we used the Glaser's State of the Art Strategy to set up and reach consensus on the protocol for screening cancer survivors. Finally, recommendations as to how the impact of consensus studies can be improved are provided.

2. Consensus methods in health care

For the most, the main purpose of consensus methods applied in health care is to define levels of agreement on controversial subjects in resolving issues related to patient management [3,10–12], clinical guideline development [13–15], medical education requirements and learning resources [6,16,17], quality assessment or improvement [18,19], nursing vocabularies [4], information technology and its innovation [20–23], and health professionals information requirements [24,25].

Types of formal consensus methods are: the Delphi-method [5,13,26–30], the Nominal Group (and RAND) method [5,13,26,27], consensus conferences [5,13,26,31], the National Institutes of Health consensus development program—NIH method [5,26,32], and the Glaser's State of the Art Strategy [26,33].

Of these methods, the Delphi and Nominal Group consensus methods have a long history of use in health care. Both describe formal rules of how information should be collected and analyzed. The emphasis of these two methods is on the production of immediate answers to problems. The NIH method and the Glaser's State of the Art Strategy likewise provide a structured environment for finding solutions to problems. These methods however focus somewhat more on getting the results known among other practitioners with the ultimate aim to change medical care on a broad scale. All the consensus methods aim at reaching consensus in a systematic, mostly phased way.

The Glaser's State of the Art Strategy is less frequently used in health care consensus studies than the other methods. This consensus strategy is characterized by a structured process in which a small 'core' group of experts develops a draft consensus proposal first. This proposal is subjected to a series of rounds or critiques by external experts. External experts are invited to participate in the consensus study given their prominent position in the area under consideration. Following the receipt of these outside experts' comments, the core group redrafts the proposal until the experts find it to be generally acceptable [33]. In contrast to the Nominal Group consensus method, the Glaser's State of the Art Strategy requires a facilitator with expertise in coordinating group processes. The person facilitating the consensus process should not be a subject matter expert, nor in favor of any specific outcome of the consensus study [33]. In comparison to the Delphi method, the Glaser's State of the Art Strategy may save time because a core group of experts prepares a first draft for a consensus proposal. Yet, decision making takes place after a couple of rounds, in which the proposal is critiqued by experts outside the core group, which contributes to well-grounded decision making [33].

3. Late effects of childhood cancer

Childhood cancer represents a group of relatively rare diseases. In The Netherlands, every year about 400 children develop cancer [34]. In Western countries, between 70 and 80% of these patients survive their cancer [35,36]. At this moment, 1 out of 750–800 of the young adults in The Netherlands is a

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