Recruitment of Participants
Involving Stakeholders Cannot Be Overestimated

Anders Ringnér, PhD, RN and Cecilia Olsson, PhD, RN, ONS

One real challenge in oncology nursing research is participant recruitment. Here, we shall share some of our challenges in recruiting and retaining study participants in our studies, and describe the benefits of patient and public involvement to overcome some of these challenges. Both of us do research in sensitive arenas: sexuality in cancer care and the time frame around a child’s cancer diagnosis, respectively.

There is no single solution to resolve participant recruitment and retention. Many strategies intended to recruit and retain have weak evidence. We emphasize the value of having well-informed and assured nurses responsible for recruitment. As a researcher, one easily thinks that everyone will value one’s research to the same degree as oneself. Nothing could be more wrong. In a busy clinical reality, nurses will naturally give lower priority to recruiting for a research study if there are more urgent tasks waiting. We have experienced nurses favoring studies from local researchers instead of eligible participants enrolling in a multicenter trial. We have also experienced nurses taking actions to protect eligible participants because they believe them to be frail or in a sensitive phase. Such actions and beliefs are contrary to the judgment from the ethical review boards from whom we have clearance to approach eligible participants. Furthermore, during the beginning of the COVID era, studies in general were halted to help prevent collapse of the clinical infrastructure. However, now nursing studies are sometimes postponed in favor of medical studies deemed as more urgent by clinicians. This is a worrying tendency that, in the future, can make recruitment even more difficult. To minimize these potential complications for recruitment, we believe that having a continuous and understanding connection with the recruiting nurses is crucial. For example, Dr Olsson started having monthly telephone meetings with the recruiting nurses to support them in becoming more comfortable speaking with eligible participants about 1 study that was focused on 2 sensitive issues, sexuality and cancer. The enrollment rate increased. Dr Ringnér, in performing a multicenter randomized controlled trial, similarly experienced that working at one of the centers and having a previous personal relationship with the recruitment nurse clearly benefited recruitment at that specific center.

Another common problem in recruiting is that the researchers often overestimate the number of eligible participants and their interest in participating. Researchers must have a realistic view of the number of participants in relationship to the number likely to enroll: participation rates may never exceed 50%, and relevant calculations must be made. If the study has a longitudinal design, even more participants are needed because some are likely to drop out as time goes by. Piloting is crucial here to get a perception of the inclusion rate, but not even a well-planned pilot can predict problems that appear in a larger scale setting such as different conditions at the centers and loss of key people responsible for recruitment.

After a decade, as PhD students and junior researchers, we took our experiences and the evidence regarding planning complex interventions into planning the HeMaSex WebEd-Nurse—a web-based intervention to strengthen nurses’ competence and self-confidence in talking to their patients about sexuality. The HeMaSex WebEd-Nurse is being developed in close collaboration with cancer nurses and patients regarding the content and design of the intervention. The cancer nurses and patients acknowledged the need for the project and confirmed their interest. To our joy, some spontaneously offered to help promote the project to the target group. We also got important input from the cancer nurses to make the intervention more feasible to fit their current work situation, avoid extra burden, and avoid dropouts.

One strategy was to make the intervention as flexible as possible. Instead of a traditional approach with whole course days that would involve traveling for most participants, the training is carried out as a web-based course with short, structured modules, to which the participants have free access throughout the course. Only a few elements such as the introduction to the course (1-2 hours) and weekly reflection seminars (1 h/wk) are conducted at specific times. The course lasts for 5 weeks. The design of the education makes it possible to study both during and outside...
working hours, regardless of location. We hope that these efforts will make the intervention so tempting that the nurses will gladly partake.

To sum up, the value of involving stakeholders cannot be overestimated. It is beneficial to have them promote the project and give it credibility when recruiting participants. They also provide creative input to the design and content of the project. Last, it helps bridge the gap between researchers and clinicians in the long run, creating more clinically relevant research questions.

References