Recruitment problems in psychosocial oncology research

Jacques J.D.M. van Lankveld1 | Joke Fleer2 | Maya J. Schroevers2 | Robbert Sanderman2 | Brenda L. den Oudsten3 | Joost Dekker4

1 Faculty of Psychology and Educational Science, Open University of the Netherlands, Heerlen, the Netherlands
2 Department of Health Psychology, University of Groningen, University Medical Center Groningen, Groningen, the Netherlands
3 Department of Medical and Clinical Psychology, Tilburg University, Tilburg, the Netherlands
4 Department of Psychiatry, Amsterdam Public Health Research Institute, VU University Medical Center, Amsterdam, the Netherlands

Correspondence
Jacques J.D.M. van Lankveld, Faculty of Psychology and Educational Science, Open Universiteit, Valkenburgerweg 177, 6419 AT Heerlen, the Netherlands.
Email: jacques.vanlankveld@ou.nl

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In our professional experience with conducting psychosocial cancer research, we have all experienced problems with recruiting cancer patients and survivors for participation in outcome research. As researchers, we work in a highly competitive environment in which many compete for scarce resources. We sometimes end up submitting ambitious grant proposals whose feasibility, in patient recruitment, may be less than optimal. For instance, in 2013, both van Lankveld and colleagues and Schroevers and Fleer and colleagues received funding for innovative and methodologically rigorous (ie, following Consolidated Standards of Reporting Trials criteria) intervention studies. In both studies, the inclusion rate was disappointingly low (both lower than 1%), even though power calculations were based on prevalence rates of psychosocial problems reported in the recent literature. Similar problems are probably experienced by many fellow researchers, and have also been reported or hinted at in some publications, eg, Fredman1 and van Scheppingen.2 Our goal here is to make a plea for more extensive reporting about this issue, both in the interest of minimizing the risk of publication bias in the field of psychosocial oncology in case study results would remain unpublished, and to allow colleagues to learn from these negative experiences, and thus to avoid wasting additional investigational resources.

We believe that many of the problems experienced in recruiting patients into our studies reflect a lack of awareness among researchers of barriers to recruitment, that result from a mismatch between patient characteristics, the types of intervention that we offer, and the ways we select and approach potential research participants. Patient characteristics include, for example, their felt desire for help, personality characteristics, and their preference for specific treatment type. Types of intervention include, for example, individual vs group treatment and cognitive behavioral vs supportive-expressive approaches. We are convinced that both methodological and patient-related factors contribute here.

Methodological factors include the use of screening instruments that have low predictive validity and do not succeed in identifying those patients who desire supportive psychosocial care, as well as inefficient procedures for approaching cancer survivors. An example of the first factor was provided by van Scheppingen and colleagues2 who conducted an RCT investigating the efficacy of problem-solving therapy for cancer survivors. They reported that screening based on symptom checklist scores and 1 additional question on need for services proved unsuccessful for recruiting sufficient cancer patients in need of care. An example of the impact of procedural characteristics on recruitment rates was published by Fredman and coworkers.1 They investigated a couple-based intervention aimed at relational enhancement for breast cancer survivors. Couples were more likely to participate when they were contacted at home or at a follow-up appointment at the cancer clinic, compared to when they were asked to participate when first diagnosed. Shorter geographical distance between home and treatment facility location also increased the likelihood of participation. Another example of the latter point was given by Rabin and colleagues.3 They
observed significant differences among young adult cancer survivors in
enrollment rates for an exercise intervention study between personal
recruitment at a clinical facility and at cancer-related social events,
and when using nonpersonal procedures via postal mail, telephone,
avertisements on the internet, radio, television, social media, or other
means of contact. Recruitment including personal contact in an
oncology clinic yielded the highest inclusion rates, although the cost-
effectiveness of nonpersonal recruitment strategies was higher.

Patient-related factors are also related to diminished study partic-
ipation in psychosocial oncology research, including patient charac-
teristics, such as both younger and older age, and the perceived
magnitude of burden associated with study participation. Another
important factor that may account for low inclusion rates has to do with
the lower than expected desire for care in patients, despite high distress
scores. Screening for inclusion eligibility in an investigational treat-
ment based on distress level is common practice and is included in several
guidelines for clinical practice, eg, Network. You should only include
patients in an intervention study when screening has shown that their
distress levels are so high that improvement from an intervention can
be expected. However, elevated distress does not necessarily coincide
with patient-perceived wish for help, nor with the desire of patients for
referral to psychological or psychosocial treatment. Thus, instru-
ments that are recommended for distress assessment in psychosocial
oncology, including the Distress Thermometer and the Hospital Anxiety
and Depression Scale, may not be adequate for detecting desire for
care. In sum, both symptom level and emotional distress level are
probably insufficient to identify the actual desire for help and
willingness to participate in intervention research.

A factor that may play a role here is the dynamic coping strategy
of patients and their family. Coping involves the ways that patients deal
with factors such as stigma associated with cancer and with the use
of mental health care, and with the distress experienced during the
diagnostic phase and during primary cancer treatment. Some patients
may already have sought professional help when they are invited for
study participation; others may be convinced that the distress will go
away without professional intervention, or with the help of friends
and loved ones. Patients sometimes report that they want to move on
with their lives, and not focus on their difficulties. Patients find some
cancer-related problems more difficult to discuss with their health care
provider than other problems. For instance, studies addressing prob-
lems with sexual functioning and low sexual satisfaction as a result of
cancer and cancer treatment have met with low participant rates,
possibly because discussing sexual health is a sensitive topic for both
patients and health professionals or because it may not be a high prior-
ity issue for the patient at that time. Thus, more research is needed to
investigate patients’ reasons for reporting (absence of) a wish for care,
as well as the contributions to these reasons of factors such as
(inadequate) problem recognition, knowledge and beliefs, coping self-
efficacy, and social support. Such research provides insight into which
factors need to be targeted to assist patients in making an informed
decision about care uptake.

A possible explanation for the discrepancy between distress and
service uptake is that the presumed link between cancer-related dis-

Key Points
- Patient-reported distress does not necessarily reflect
  the patient’s actual desire for help.
- Distress may be either adaptive and helpful, or
  maladaptive.
- Feasibility studies should assess interest and willingness
  of patients to receive professional psychosocial care.
- Research on optimal recruitment strategies will improve
  enrollment in patient-based research in psychosocial
  oncology.
- Greater reporting of problems with patient recruitment
  in clinical outcome studies in the field of psychosocial
  cancer treatment will help minimizing publication bias.

Dekker and colleagues argued that it is not the intensity but the nature
of emotional responses which determines whether emotions are mal-
adaptive. Using the results of research on the relationship between emo-
tion dynamics and psychopathology, they argued that emotional
responses, reflected in elevated distress scores, often serve an adaptive
purpose. Emotional reactions to cancer and cancer treatment only
become maladaptive when they linger and perpetuate over time, or
when they are extreme and unstable. Emotional responses may also
become maladaptive when they hinder adaptive coping. Dekker and
colleagues further argued that patients’ need for psychosocial care
depends on whether emotional responses are adaptive or maladaptive.
Patients who experience maladaptive emotional responses seem to be
in need of professional mental health care, defined as psychotherapy,
pharmacotherapy, or emergency psychiatric care. In contrast, patients
who experience adaptive emotional responses do not seem to be in need
of professional mental health care. Instead, they may be primarily in need
of support from relatives, friends, and primary caregivers (ie, doctors
and nurses) and low-intensity psychosocial interventions. Further
research on the distinction between adaptive and maladaptive emotional
responses and on tailoring of interventions to the needs of patients with
cancer is needed. Such research has now begun to emerge.

In conclusion, improving the recruitment of patients to psychoso-
cial intervention studies that target emotional needs can be facilitated
by carrying out feasibility studies that assess both the prevalence of
problems in the target population and the interest in and willingness
of patients to receive professional psychosocial care. Estimates of per-
ceived symptom burden and functional impairment alone can result in
serious overestimates of uptake in psychosocial intervention studies.

CONFLICT OF INTEREST

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ORCID
Jacques J.D.M. van Lankveld http://orcid.org/0000-0003-0956-4067
Joost Dekker http://orcid.org/0000-0002-1822-3101
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