

SCOPED question-listing improves distress, anxiety and question self-efficacy among hematological cancer patients and may enhance provider-patient dialogue and access to clinical trials

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Introduction

Why question listing?

Many cancer patients feel overwhelmed and do not know what questions to ask their doctor or how to use the information provided to make treatment decisions.

Research suggests that assisting these patients makes them more willing to ask questions and benefit from the information provided.

Decision support and Cancer Support Community

Historically, programs at CSC have been delivered in the form of support groups with multiple participants including patients and caregivers. However, in the early stages of a cancer diagnosis, we know that patients value individual assistance as they explore treatment options.

Thus, there is a need to investigate models of individual support that are consistent with CSC's Patient Active™ Concept, and that can be integrated within CSC's current services.

A Unique Partnership



The three participating sites are local affiliates of Cancer Support Community®, an international non-profit organization striving to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.



ENACCT is a non-profit organization founded in 2004 whose mission is to improve access to cancer clinical trials through education and collaboration with communities, health care providers, and researchers.

Aims

To learn whether question listing is feasible, acceptable and effective in promoting decision quality as part of a one-on-one support initiative for blood cancer patients at CSC.

To reduce emotional distress and anxiety and increase question self-efficacy among blood cancer patients.

Method

The SCOPED model (www.scoped.org)

Situation, Choices, Objectives, People, Evaluation, Decision

The Agency for Healthcare Research and Quality has recognized SCOPED decision support interventions as having a "strong" basis in evidence and includes interventions based on this model in its "Innovations Exchange".



A TWC counselor meets with the patient, helps the patient brainstorm, and types up a list of the patient's questions and concerns. Questions are elicited based on a prompt sheet and review of information about condition and treatment options, including clinical trials.

Participating sites include CSC Centers of Excellence:

- CSC Philadelphia
- TWC Greater Cincinnati/Northern Kentucky
- CSC San Francisco Bay Area

Evaluation study design

- Quasi-experimental evaluation of pre-post changes and at 30 and 90 day follow-up in a convenience sample of patients
- Eligibility criteria: Diagnosed with a new or recurrent blood cancer; Have a scheduled appointment with a health care provider to discuss treatment options

Outcome Measures:

- Emotional distress and anxiety (10-pt scale)
- Question self-efficacy (10-pt scale)
- Patient satisfaction (10-pt scale)
- Use of question list
- Clinical trial participation

Results

Sample characteristics (n=77)

73% female
18% racial/ethnic minority
40% retired; 14% on disability
Income among those not retired: 18% < \$40K
46% diagnosed within last 5 months

Stage of treatment

37% not yet treated
24% considering other treatment options
13% watch and wait
10% disease not responsive to treatment

Feasible

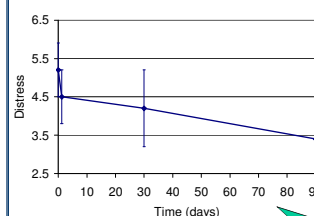
3 facilitators trained
132 patients received question listing support
77 participated in evaluation study

Results, cont.

Table 1. Outcome measures by time

	Pre	Post	30 days	90 days
	Mean			
Distress	5.2	4.5*	4.2*	3.4*
Anxiety	4.6	3.5*	---	---
Question self-efficacy	4.7	8.2*	---	---

* p<0.05, compared to baseline



This figure suggests there was a steeper decrease in distress immediately following the intervention, compared to a gradual decrease at 30 and 90 days.

Figure 1. Level of distress over time.

Effective
The question listing intervention was associated with improvements in outcome measures.

Findings on CCT's

- 48 participants reported making a treatment decision during the 90 day follow-up period
- 4 of 48 (8%) will receive treatment through a cancer clinical trial
- 46% reported discussing cancer clinical trials with their oncologist

Table 2. Use of question list at visit with oncologist

	%
Brought QL to appointment	82
Referred to QL during appointment	94
Showed QL to oncologist	39
QL contributed to a more productive appointment	88
Oncologist answered most questions	88

Results, cont.

What patients say

"This process is wonderful. My husband and I had a very productive meeting with the doctors. We are clear on our next steps. My husband and I are using this technique before all of my appointments. We are clear about our goals and feel more in charge of treatment."

"The question list became the focal point for the conversation; my oncologist was very pleased that I had the list. It helped us both. The conversation was very productive. We made good decisions. There was structure to the meeting; almost like having an agenda."

What facilitators say

"Helping patients make good decisions, including considering clinical trials, is consistent with personal and CSC's missions and goals."

"The SCOPED method is the most worthwhile component of the Open to Options program and the most consistent with CSC's mission."

Acceptable
Satisfaction among participants was high post-intervention (9.1) and remained high at 30 (8.8) and 90 (8.8) days.

Conclusion

Early findings suggest use of question-listing for blood cancer patients may improve coping and decision-making skills and lead to enhanced provider-patient dialogue and access to clinical trials.

Research Implications

The established feasibility and the promising findings of this pilot support a larger randomized controlled trial.

Clinical Implications

Individual support is feasible at Cancer Support Community and a valuable addition to current programs and services.

Funding

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Background: The Open to Options pilot project provides one-on-one decision support to hematological cancer patients in 3 sites nationwide. **Methods:** Facilitators provide support using an evidence-based decision-making model SCOPED (Situation-Choices-Objectives-People-Evaluation-Decisions) to prompt patients to list questions about diagnosis and treatment, including the option of a cancer clinical trial (CCT). Patients complete pre- and post-session surveys, and at 30 and 90 days. Distress, anxiety and question self-efficacy are measured using a 10-point scale. For a subset, outcomes include use of the question list during their oncology visit. **Results:** Three facilitators have used the SCOPED question-listing process with 69 patients (14% ethnic minority). Among patients, there was a decrease in distress ($p=0.065$) and anxiety ($p=0.008$) and increase in question self-efficacy ($p<0.001$). Nearly half (51%) reported discussing CCTs with their oncologist. Currently, 44 have made a treatment decision, and 4 (9%) of these chose treatment through a CCT. At 30 days, 28 of 35 patients (80%) reported bringing their question list to their oncology appointment. Among those who brought their question list ($n=28$), 93% referred to it, 33% showed it to their oncologist, 86% thought the question list contributed to a more productive appointment, and 86% reported their oncologist answered most of their questions. Participants reported the question list: “gave structure to the meeting like an agenda”; “clarified my thoughts”; and “was empowering.” **Conclusion:** Early findings suggest use of SCOPED question-listing for blood cancer patients may improve coping and decision-making skills and may lead to enhanced patient dialogue and access to clinical trials.

Learning Areas:

Conduct evaluation related to programs, research, and other areas of practice

Implementation of health education strategies, interventions and programs

Social and behavioral sciences

Learning Objectives:

Identify design and components of the Open to Options program Evaluate outcomes data of the

Open to Options pilot study Discuss feasibility and effectiveness of the Open to Options program

Keywords: Cancer, Decision-Making