

Predictors of Change in Distress, Anxiety and Question Self-Efficacy Following a Community-Based Treatment Decision Support Program for Hematological Cancer Patients

Miller MF¹, Belkora J², Buzaglo J, Coyne K¹, Crawford B¹, Stauffer M¹, Blakeney N³, Michaels M³, Golant M¹

¹Cancer Support Community, ²UCSF Breast Care Center, ³Education Network to Advance Cancer Clinical Trials

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

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.

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:

- TWC 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=69)

72% female
14% racial/ethnic minority
41% retired; 16% on disability
Income among those not retired: 21% < \$40K

Clinical factors

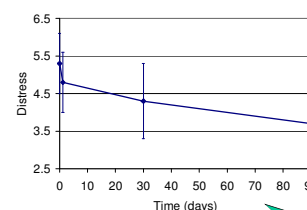
46% diagnosed within last 5 months
37% not yet treated
25% treated but now considering other treatment options
14% watch and wait

Feasible
3 facilitators trained
69 patients received question listing support

Results, cont.

Table 1. Outcome measures by time

	Pre	Post	30 days	90 days
	Mean			
Distress	5.3	4.8	4.3*	3.7*
Anxiety	4.6	3.5*	---	---
Question self-efficacy	4.9	8.1*	---	---



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

- 4 of 44 (9%) will receive treatment through a cancer clinical trial
- 49% reported discussing cancer clinical trials with their oncologist

Table 2. Use of question list at visit with oncologist

	%
Brought QL to appointment	80
Referred to QL during appointment	93
Showed QL to oncologist	33
QL contributed to a more productive appointment	86
Oncologist answered most questions	86

Factors associated with change in outcomes

Lower income (p=0.005) and higher baseline distress (p=0.011) were associated with a greater decrease in distress. Higher baseline anxiety was associated with a greater decrease in anxiety (p<0.001). White race (p=0.041) and lower baseline QSE (p<0.001) were associated with a greater increase in QSE.

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, etc..."

"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."

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.

To identify factors associated with greater change in outcome measures.

Conclusion

Early findings suggest use of question-listing for blood cancer patients may improve coping and decision-making skills and may lead to enhanced provider-patient dialogue and access to clinical trials. Several factors (income, race, baseline levels of distress, anxiety and QSE) predicted greater response to the question-listing program.

Research Implications

The established feasibility and the promising findings of this pilot support a larger randomized controlled trial. Further research is needed to evaluate the value of targeting and/or tailoring treatment decision-making programs for blood cancer patients.

Clinical Implications

Individual support is feasible at CSC and a valuable addition to current programs and services.

Funding

Centers for Disease Control and Prevention

Geraldine Ferraro Blood Cancer Program

(#DP07-709 U58/DP001111)

Predictors of Change in Distress, Anxiety and Question Self-Efficacy Following a Community-Based Treatment Decision Support Program for Hematological Cancer Patients

Miller M, Belkora J, Buzaglo J, Coyne B, Crawford B, Stauffer M, Blakeney N, Michaels M, Golant M.

Purpose: Open to Options is a pilot project that aims to enhance treatment decision making and improve well-being among blood cancer patients in three communities nationwide with an emphasis on enrolling ethnic minority participants. Trained facilitators provide one-on-one patient support using an evidence-based decision-making model entitled SCOPED (Situation-Choices-Objectives-People-Evaluation-Decisions) to prompt patients to list questions about diagnosis and treatment. Evaluation data indicate a decrease in distress and anxiety and increase in question self-efficacy (QSE) following the program. The present analysis examines factors associated with greater change in outcomes.

Methods: Distress, anxiety, and QSE were measured on a scale of 0-10, with 0 being minimum and 10 maximum. Multiple regression analysis was used; the dependent variable was the difference between pre- and post-intervention values.

Results: To date, three facilitators have used the SCOPED question-listing process with 64 patients (16% ethnic minority). Among patients, there was a decrease in distress ($p=0.058$) and anxiety ($p=0.026$) and increase in the patient's question self-efficacy ($p<0.001$). Lower income ($p=0.005$) and higher baseline distress ($p=0.011$) were associated with a greater decrease in distress. Higher baseline anxiety was associated with a greater decrease in anxiety ($p<0.001$). White race ($p=0.041$) and lower baseline QSE ($p<0.001$) were associated with a greater increase in QSE.

Conclusion: Early findings suggest one-on-one decision support for blood cancer patients may improve coping and decision-making skills. Several factors (income, race, baseline levels of distress, anxiety and QSE) predicted greater response to the question-listing program.

Research Implications: The established feasibility and the promising findings of this pilot support a larger randomized controlled trial. Further research is needed to evaluate the value of targeting and/or tailoring treatment decision-making programs for blood cancer survivors.

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