Health Literate Tools for Data Collection in a Lung Cancer Patient Study

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ABSTRACT

Patient preferences regarding adverse side effects of chemotherapy are not typically considered when choosing a treatment for late-stage lung cancer. Our Patient-Centered Outcomes Research Institute (PCORI) funded study addressed this issue. Since most late stage lung cancer patients are older, we adapted data collection tools to meet their health literacy needs. Specific aims:

Aim 1: Determine whether individual patients' preferences, characteristics, and treatment experiences affect the meaning of chemotherapy treatment success.

Aim 2: Determine how to best predict real-life patients' treatment choices based on patients' tolerance of adverse side effects possibly linked with chemotherapy.

Aim 3: Explore whether oncologists are likely to change their clinical practice after receiving information about their patients' treatment tolerance and preferences.

Research Questions

❖ How do patients with advanced lung cancer define treatment success?
❖ Among possible side effects of chemotherapy with about equal prognosis, which side effects would patients most like to avoid?
❖ Will oncologists consider patient preferences when selecting chemotherapy?

Methods

- Mixed method study design includes focus groups, cross-sectional, prospective, and randomized experimental designs, qualitative and quantitative approaches
- Focus Groups of patients, caregivers and clinicians
- Multicenter: 5 cancer centers in Nebraska, 2 in Missouri, 1 in South Dakota, & 1 in Florida (n=9); includes private, state & federal centers as well as large urban and suburban-based and rural sites

Lead Collaborators

➢ University of Nebraska Medical Center (UNMC) College of Public Health, Department of Epidemiology, Omaha, Nebraska
➢ Avera Cancer Institute, Sioux Falls, South Dakota
➢ Callahan Cancer Center, North Platte, Nebraska
➢ Moffitt Cancer Center, Tampa, Florida
➢ Lincoln Community Foundation, Lincoln, Nebraska
➢ Nebraska Cancer Coalition, Lincoln, Nebraska
➢ Saint Francis Cancer Center, Grand Island, Nebraska
➢ Saint Luke's Hospital & Medical Center, Kansas City, Missouri
➢ Southeast Nebraska Cancer Center, Lincoln, Nebraska
➢ UNMC Division of Oncology-Hematology, Department of Internal Medicine, School of Medicine, Omaha, Nebraska
➢ Veterans Administration Health Care Systems in Omaha, Nebraska and Kansas City, Missouri

DISTRESS RATING SCALE

1   2   3   4   5   6   7
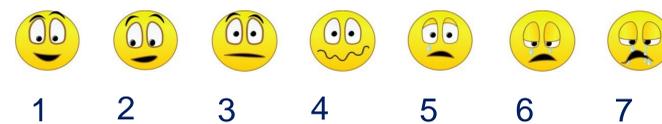
Face 1= almost no distress/highest level of tolerance
Face 7= worst distress imaginable/would hate this the most

Which face best matches your distress level?

Overarching Study Rationale

Lung cancer is the leading cause of cancer-related deaths in the United States and is a major contributor to spiraling health care costs. Traditionally, treatment success for advanced metastatic non-small cell lung cancer (NSCLC) is measured by physicians in terms of survival. It is not known whether individual patients also see success in terms of survival. The idea of patient engagement is based on the principle of working "with" instead of doing "to" or "for" patients. Our study looks at these issues of treatment success and engagement.

Results to Date

➢ Patient, caregiver and clinician focus groups provided suggestions that were used to develop health literate data collection tools that patients easily understood.
- Visual distress scale using faces rather than narrative
- Ranking exercise using laminated cards: 3 header cards and 9 descriptor cards
- Research staff administered the tools in-person, rather than stressed, older persons who may have just learned of their cancer diagnosis having to fill out long, confusing forms

➢ When asked in literate ways, patients are strong advocates for what they want:
- Better patient-provider communication
- Patient navigation and help with new patient orientation to cancer treatment and health literate data collection tools
- Data collection processes incorporating nurse researchers
- Visual tools so that older patients who may have just learned of a cancer diagnosis do not need to focus on reading traditional, complex data forms

Preliminary Conclusions

❖ Patients are willing to participate in research that will benefit others even if it does not benefit them directly; they are more likely to do so when data collection tools are easy to use and the processes meet their literacy needs

❖ Involving patients with treatment planning may improve multiple treatment outcomes including quality of life, patients' satisfaction and family-caregiver satisfaction with treatment outcomes

❖ Patients' definitions of treatment success include factors such as ease of data collection; attention to their personal preferences; effective clinical guidance throughout treatment; help with their functionality and symptom management; and quality of life.

Acknowledgement