Rural Perceptions of Clinical Trials

February 2014

Cancer Health Disparities Initiative

BACKGROUND

Clinical trials have dramatically improved cancer treatment over the past few decades. Most approaches used to treat cancer today would not have become available without advancements discovered in clinical trials. However, only a small fraction of cancer patients have participated in a clinical trial.[i] To increase patient participation, it is important to understand community perceptions regarding clinical trials.

Wisconsin is primarily a rural state. More than 35% of all University of Wisconsin Carbone Cancer Center (UWCCC) patients served annually are residents of rural areas.[ii] There is evidence that rural residents have a higher risk of a late-stage cancer diagnosis. Other studies have documented that rural cancer patients receive lower quality care, and have limited access to cancer support services and clinical trials. In 2011, the Cancer Health Disparities Initiative (CHDI) of the UWCCC launched a cancer education project in Adams County, a rural county in the UWCCC catchment area with high cancer-related disparities.

Most participants said they were willing to participate in a clinical trial.

METHODS

CHDI staff conducted focus groups in Adams County to better understand rural residents' perceptions of clinical trials. Participants were also asked to describe what would support their decision to enroll in a clinical trial and what would be a barrier. Two focus groups were held, each lasting about two hours and moderated by CHDI staff. All focus group participants lived or worked in Adams County. Each group included at least one cancer survivor and one cancer caregiver. Participant groups were as follows: Group 1--Adams County community partners; Group 2--Adams County residents. A total of 15 persons participated in both focus groups.

To begin each focus group session, participants were asked to describe their perceptions of clinical trials. Responses were organized into three major categories: 1) Experimental ("lab rat"), 2) No other alternative available ("last-ditch effort"), 3) Research. Participants were then asked to describe facilitators to enrolling in a clinical trial and to brainstorm barriers to clinical trial participation. Barriers identified were ranked as minimal, moderate or significant barrier.

FINDINGS

Most participants expressed a willingness to participate in a clinical trial. Focus group participants described what would motivate them to participate in a clinical trial as follows:

1. Being treated as human beings, not a "lab rat," by study staff;
2. Witnessing the sincerity of study staff to help establish a trusting relationship;
3. Hoping for an extended life and/or a better quality of life; and
4. Knowing that their participation will make a difference and how it will make a difference.

Common barriers identified by both focus groups included:

Significant barriers

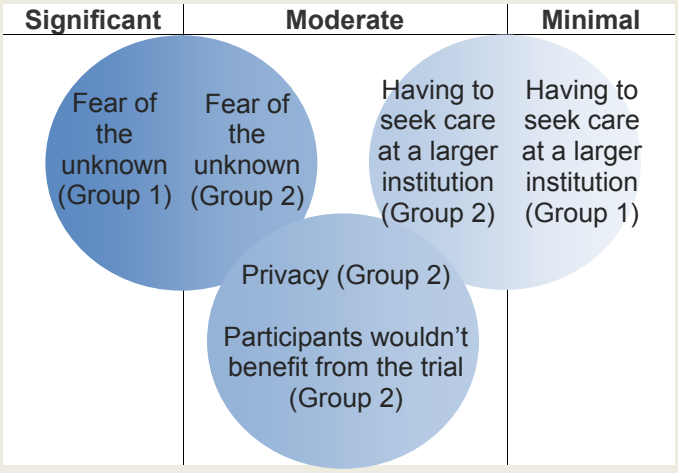
- Transportation
- Additional cost
- Additional time involved
- Feeling like a "lab rat"

Moderate barriers

- Additional side effects
- Loyalty to their current physician and/or health system
- Their physician didn't recommend a clinical trial

Table 1 describes additional barriers identified by one of the groups (but not both).

TABLE 1: Additional barriers identified



DISCUSSION

A dominant theme during both focus groups was the role of the study staff in a patient's decision-making process. Participants underscored the role that study staff and physician-researchers play in the recruitment and retention of clinical trial participants. These individuals were identified as central to establishing trust, rapport and motivation with potential clinical trial participants.

Focus group participants unanimously agreed that relationships with study staff would directly influence their decision to volunteer and their willingness to complete the clinical trial. Participants stated that the physician-researcher needs to offer a friendly face, an open ear and show a high level of concern for potential participants as people, not just "lab rats." Participants emphasized that the physician-researcher, not just the staff, needs to take adequate time to have a conversation with potential participants, thoroughly explain the trial, ensure that all questions are answered and provide user-friendly, easy to understand information. The physician-researcher also needs to convey the benefits for the participant and for future patients.

> The physician-researcher needs to offer a friendly face, an open ear and show a high level of concern for potential participants as people, not just "*lab rats*."

During Focus Group 2, two participants shared their personal stories related to clinical trials. These anecdotes illustrate two different experiences with clinical trials and trial staff:

Jane's son was 12 years old when he was admitted to a large area hospital for an asthma-related problem. Her son was scared and anxious. The hospital staff was very friendly and attentive to her son's needs. After addressing her son's acute needs, the treating physician sat down with Jane and her son. He explained, in very simple language, that he was conducting a clinical trial to explore new treatments for asthma. The physician asked if Jane's son would like to enroll. Jane had numerous questions, which the physician answered thoroughly. Jane never felt like she was in a rush to make a decision. Jane's son elected to participate in the trial. She was very satisfied with her experience and recommended clinical trials to the other focus group members.

Mary had a different experience to share:

Mary's husband was diagnosed with Stage 4 prostate cancer over a year ago. A few months ago, he opted to move his care from a local hospital to a large regional hospital. He felt that he could receive the best care and prolong his life by accessing the larger system's innovative medicine, including clinical trials. Mary explained that during their first visit at the regional hospital, her husband's doctor didn't spend more than a few moments listening to her husband's care preferences. Before her husband could finish his sentence, the physician was recommending a clinical trial. Even though Mary's husband knew that this trial could prolong his life and improve his quality of life, he declined to enroll. He stated that before his disease, he was a person. In order to care for him as a patient, he expected his care preferences to be heard.

> Participants viewed the relationship between study staff and potential participants as crucial – the cornerstone for successful recruitment and retention of rural residents.

CONCLUSION

Rural focus group participants identified a willingness to participate in clinical trials. The participants viewed the relationship between study staff and potential participants as crucial – the cornerstone for successful recruitment and retention of rural residents. Once participants feel that they have established trust with the physician-researcher and associated staff, they are more inclined to participate, as well as to communicate positively with others regarding the research. By demonstrating sincerity, respect and trustworthiness, study staff are more likely to build rapport with rural patients, who will then be more inclined to enroll in clinical trials. Participants also stated that study staff need to help mitigate the significant practical barriers, such as transportation and other additional costs, that hinder rural residents participation in clinical trials.

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[i] Swanson GM, Ward AJ. Recruiting minorities into clinical trials: toward a participant-friendly system. J Natl Cancer Inst. 1995;87:1747-1759.

[ii] University of Wisconsin Hospital and Clinics. Cancer Registry, personal communication; 2013.

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