Working with People Affected by Cancer in Food Safety Research: Recruitment Considerations from a Transatlantic Collaboration

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SUMMARY

In July 2022, a memorandum of understanding was signed between food safety researchers from the ZERO2FIVE Food Industry Centre at Cardiff Metropolitan University, UK, and the College of Education and Human Ecology at The Ohio State University, USA. The transatlantic agreement relates to behavioral food safety research most often focusing on vulnerable consumer groups that is being conducted by the two institutions.

Despite recruitment procedures being described in the methods sections of food safety behavioral studies, the challenges faced by researchers in recruiting participants are seldom shared. Because issues experienced with recruitment and solutions to overcome such issues are not shared, it can be difficult for researchers to foresee challenges and predict recruitment obstacles when building study design, which can negatively impact research progression.

As researchers that have experienced such issues, we acknowledge the importance of sharing the lessons learned in this research area. Therefore, in this general interest article, we share our experiences of recruiting people receiving chemotherapy for the treatment of cancer in the United States and the United Kingdom for food safety behavioral research, we describe the participant recruitment challenges that we have faced, and we share the approaches that we have used to overcome these challenges.

OVERVIEW

Recruitment of vulnerable consumer groups for research

Recruitment of human subjects is critical to success in all behavioral and intervention studies. Recruitment refers to the process of enlisting the study participants and includes several interactions between the researchers and participants before the initiation of the consent. Such interactions involve identifying potential participants and providing the participants transparently with the information about the project in a way that motivates their support of the study. The goal of successful recruitment is to enroll a sample representative of the target population and to enroll a sufficient number of participants to meet the power requirements of the study *(7)*. With these two main goals in mind, there are many potential challenges in enlisting human subjects for food safety studies and intervention, especially from vulnerable populations.

Vulnerable populations, such as cancer patients, are often difficult to recruit into studies due to the acuity of their health status *(13)*. Research in food safety behaviors during cancer treatment requires access to the patients during the times when they are highly vulnerable. The recruitment process occurs in a clinical setting while cancer patients and their caregivers may be experiencing acute stress from diagnosis and treatment. Common barriers in recruitment of the cancer population may include mistrust in research and science, patient demographic, and lack of time commitment *(6)*. Therefore, familiarity and collaboration with the clinical team are crucial to identifying optimal recruitment times and approaches and for overcoming the trust challenges between the researchers and the patients. It is also essential that researchers ensure that patients are not overburdened with involvement in research. Additional barriers may be imposed by the socioeconomic status of the patient population, leading to underrepresentation of low-income populations in studies and the widening of health disparities gap *(9)*. Integrating recruitment approaches appropriate for patients in treatment can improve recruitment rates and retention. Suboptimal recruitment may result in sampling bias or insufficient sample size, both of which are detrimental to the quality of studies and can contribute to lack of replication, low generalizability, inadequate statistical power, and reduced validity of conclusions.

Therefore, it is critical to understand the challenges and barriers related to food safety behavioral research among cancer patients and predict such challenges that may arise during the research. However, in published research, the recruitment procedures often negate to report problems that arise during recruitment; furthermore, there is no published information on how to solve these problems. Consequently, new research studies only benefit from anecdotal evidence from previous studies shared informally between researchers. We believe this to be a missed opportunity to improve the knowledge base in food safety behavioral research and we provide an in-depth account of our experiences in these areas of recruitment.

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Research with U.K.-based chemotherapy patients and family caregivers at the ZERO2FIVE Food Industry Centre

We undertook a series of studies at the ZERO2FIVE Food Industry Centre with chemotherapy patients and their family caregivers that incorporated telephone, in-person, and online interviews *(2)*; an online questionnaire *(3, 5)*; and in-person focus groups *(4)*. Numerous methods of recruitment were used, including posting online adverts, distributing posters in the local community, and liaising with cancer support groups.

Recruitment from cancer support groups involved one of the researchers attending cancer support groups in the local vicinity, however, we found that those attending the support groups were often not eligible to participate, having completed treatment >3 years ago. Indeed, some were 10, 15, and 20 years posttreatment. Access to support groups when asking to attend in-person was generally not restricted; however, when requesting for project information to be shared with support group members via email, some support groups declined to do so stating that they would not want to put an additional burden on those they support during treatment: "they've got enough on their plate without having to fill in your questionnaire." When recruiting freely online (using Twitter) and on community notice boards, target sample sizes were achieved, whereas involvement with cancer support groups did not result in many participants.

To aid recruitment of patients and family caregivers for focus groups and interviews, supermarket vouchers were provided as incentives; however, on occasion, some participants declined the offer of vouchers stating that because the research was funded by cancer research charity they "couldn't take it": they wanted the money to be used in the project for something more worthy. They were happy to participate without the incentive; others indicated that they would have happily participated without the incentives but that it was a welcomed gesture.

Although it was not captured or analyzed as part of our research, some participants discussed their motivation to participate in the research. The statement "to give back" was frequently used: many felt thankful for the support and healthcare that they had received during their treatment. Others indicated that they wanted "some good to come out" of their "bad experience." There was often a sense of wanting to "help others" going through cancer treatment and to "benefit society."

Family caregivers discussed that they wanted to take part in our research because their spouse or partner had the opportunity to get involved with clinical trials and they could not be involved with such research; family caregivers discussed that they had not seen the opportunity to participate in any other cancer research that involved the patient's family caregivers, which motivated them to participate.

Lessons learned and personal perspectives resulting from research at the ZERO2FIVE Food Industry Centre—Dr. Ellen Evans

Talking to people during in-depth interviews is always interesting and a pleasurable part of the work that I do. I always feel extremely privileged when people choose to participate and openly share their experiences with me for the benefit of others. It can sometimes be an emotional experience for participants because it can relate to a traumatic experience, which is something we always consider when applying for ethics approval at the university. However, the emotional impact of interviewing upon the researcher is seldom considered and is an experience that we must consider, particularly when Ph.D. students are undertaking research in this area. Indeed, the impact of undertaking in-depth interviews on the interviewer has been described as a "roller coaster ride" *(1)*. It is acknowledged that researchers involved in interviews of sensitive topics may experience emotional reactions; therefore, it has been suggested that formal debriefing mechanisms should be integrated into the qualitative research processes to ensure the wellbeing of researchers *(1)*.

There are several interviews that I've undertaken with people affected by cancer that remain with me to this day, and they probably always will. One interview participant described how the impact of cancer treatment resulted in a failed suicide attempt. A parent described desperately trying to feed their child who was undergoing treatment. A person my own age described being given a "food safety in pregnancy" leaflet shortly after being told that the cancer treatment would likely result in infertility. I also recall a participant realizing the importance of food safety during our discussion and becoming upset that their spouse had not been told of the risks and stated, "it's just not right, is it?" They then went on to thank me for wanting to do research in this area. Since commencing in food safety research with vulnerable patient groups, it has become standard practice to provide participants with debrief information that not only signposts participants to relevant food safety information but also to relevant sources of support and guidance.

As researchers, we must always be mindful of the situations and experiences of patients who participate in our research. Interviews often provide a safe and confidential one-on-one setting in which participants become comfortable to discuss sensitive or difficult topics. They may digress and discuss some topics that seem not entirely relevant to the research aims; however, we must be respectful of their decision to participate in research at a challenging time and we must show them the empathy, respect, and compassion that they deserve.

Research with U.S.-based chemotherapy patients and family caregivers at The Ohio State University

At The Ohio State University, we have conducted several studies focusing on cancer patients who were in different

cancer treatments, including chemotherapy, radiation, immunotherapy, and combinations of treatments. We have conducted in-person surveys *(11)* with the combination of online and paper questionnaires *(8)* and researcher-assisted digital surveys *(12)* with the patients receiving treatment and have used several recruitment methods. These recruitment methods included online flyers, flyers in the hospital waiting rooms, clinical dietitian and nurse liaison, and in-person communication with cancer patients while waiting for an appointment or during a treatment.

During the survey data collection in 2018, we collaborated with clinical dietitians and nurses to initiate the recruitment process. All researchers were introduced to the nursing staff and explained the patient flow and the basic house rules in the waiting room in each hospital location. The clinical dietitians and nurses were distributing study flyers and scripts. We have relied on nursing staff to indicate the patients that were likely to agree to participate in the study. The researchers were present in the hospitals, and they had a desk assigned to them on the treatment floor. The surveys were paper based and consisted of two self-guided questionnaires—a food safety and food security questionnaire and a food frequency questionnaire—taking a total of from 90 minutes to 2 hours to complete. On-hand researchers were there to help with participants' questions and logistics. Participant recruitment was steady, and the obstacles that we encountered were mostly related to the patients' vulnerabilities. For example, the patients had difficulties staying awake, or they were experiencing nausea and fatigue due to medication. The patients who received longer treatments were often visited by friends and family, thereby interrupting the survey completion. Many patients were overwhelmed by the length of the survey. We have adjusted the approach by splitting the survey completion into two parts and allowing the patients to take the survey during two consecutive visits. To avoid the increased attrition, we offered two incentives to participants upon the completion of each questionnaire. The data collection delays were minimal, and survey was completed in 13 months from obtaining institutional review board approval.

The findings from the study were published *(11)* and used to develop a food safety intervention targeting identified knowledge gaps *(10)*. We used the findings from the most recently published study from the ZERO2FIVE Food Industry Centre *(4)* to inform several appearance features of the intervention study at The Ohio State University *(10)*. The study had initially intended to undertake in-person recruitment; however, it was adapted for digital recruitment to avoid increased risk of patient exposure to COVID-19. Flyers were distributed with both QR codes and HTML links, for ease of access, but digital recruitment numbers remained low. One of the possible reasons for this low recruitment is that patients are given many flyers and pieces of information when they begin their treatment. With so much to manage, it is likely that patients would be overwhelmed and any flyer not indicated to be highly important would not be prioritized.

In addition, our typical participants were >50 years old. Although many people in this age population are adept at using technology, they are more likely not to own a smart phone, tablet, or laptop than those in younger age groups. Not having a researcher on-hand to guide and assist with digital material access may have deterred potential participants who felt that the process of accessing the content was difficult or inconvenient. Once again, we had to adjust our approach and revert to in-person recruitment. The materials were amended, and researchers were trained to safely approach the patients in hospitals. After the first week of in-person data collection, it became apparent that shifting the approach increased engagement, despite the finite pool of patients. Potential participants were able to be approached when they had time (i.e., during infusion treatment), rather than being expected to make time later. They were also supported throughout the surveys and educational module by researchers who could troubleshoot technical difficulties and answer questions. Furthermore, researchers provided iPads to participants to complete the surveys and engage with the intervention, so they were not limited by whether their personal devices were sufficient to access the study nor by personal limitations of knowledge pertaining to QR codes or HTML links.

Once we overcame the barriers presented by COVID-19 pandemic restrictions and digital recruitment shortfalls, the recruitment rates improved; however, there were several noteworthy trends in the recruitment process. In the first 3 weeks of in-person recruitment, the majority of patients were willing to participate in the study. We estimate that approximately 6 or 7 of every 10 patients consented to participate and finished the surveys. Because of the treatment rotation schedule, we reached saturation and the participation rate dropped to 25%.

We have learned that the chemotherapy patients with longer treatments (≥2 hours) were more willing to take the survey. Patients who agreed to do the survey often stated that they had "nothing better to do." The majority of patients we interacted with were amicable and pleasant. The patients who were eager to complete the survey seemed to have additional motivation and often displayed the sense of obligation to provide data for educational purposes. Some patients shared that they saw the survey as a fun challenge to see what they knew about nutrition and cooking. Others shared that they worked in food service, had a background in agriculture, or had a deep passion for cooking and food. However, the patients who are in treatment often experienced acute vulnerabilities. For example, they would fall asleep or experience extreme fatigue due to the treatment and the disease progress, which resulted in incomplete attempts and decreased recruiting numbers. Some patients explained

that they did not want to finish the survey because they were overwhelmed and found the survey to be too long and strenuous. One patient said, "it was just too many questions."

Lessons learned and personal perspectives resulting from research at The Ohio State University—Dr. Sanja Ilic

When developing the study design, a thorough understanding of the patient flow and the treatment logistics is critical for successful recruitment. For example, the duration, cycle, and timing of the treatment slots were important factors affecting the recruitment rates during our studies. In our study targeting the patients receiving chemotherapy, patients with longer treatment (≥2 hours) were more likely to enroll in the study than those with shorter treatment times. It was beneficial to have the indication from nurses who understood the situation of each individual patient and were able to tell us which patients were likely to participate in the study. Although technology is evolving, cancer patients are predominantly older adults and the digital recruitment approaches were appropriate.

Finally, it was apparent that each participant is an individual in a unique situation and that personal contact was critical to ensure adequate recruitment. Communicating with the patients when they are the most vulnerable was challenging but rewarding. During the study, we witnessed the devastation that cancer causes to whole families. We were inspired by unmatched hope and enthusiasm among individuals affected with cancer. I felt privileged that our participants gave us the time in their day when they had daunting priorities and uncertainties to deal with.

RECOMMENDATIONS

The challenges faced by researchers when undertaking research are seldom shared, and we believe that it is important to be open about such issues and how they were overcome. Resulting from our experiences in the United Kingdom and in the United States, we have created a list of recommendations for improved recruitment of participants from vulnerable populations in food safety human behavioral research:

- Understand the population and associated caregivers and where they are in the treatment process; be mindful that diagnosis and treatment can impact people in different ways
- Work with health providers who understand patient schedules and individual situations to ensure that an approach is ethical
- Make more solid study design, develop appropriate recruitment methodology, and build in protection against recruitment bias to prevent or overcome recruitment bias
- Integrate strategies for inclusion of marginalized groups and ensure an appropriate recruitment approach for the population in question
- Use an appropriate level of technology for demographic characteristics of the target population and provide inclusive incentives
- Consider appropriate monetary incentives or reimbursement based on the amount of time and effort involved with participation
- Ensure the provision of appropriate training and suitable support mechanisms to ensure researchers involved in interviews of sensitive topics do not overburden participants or result in participants or researchers becoming emotionally overwhelmed
- Be mindful of the impact of researcher presence on participant engagement with data collection and interventions
- Consider the value of working with a patient advisory group to ensure research protocols, recruitment approaches, participation, and intervention delivery methods are appropriate for the target audience and location

CONCLUSIONS

In this general interest article, it was important for us to share our experiences of working with people affected by cancer in food safety research. We believe that as researchers we have a responsibility to be transparent about the recruitment issues that we have faced and document how these issues were overcome so that future researchers can benefit from the lessons that we have learned. Although the challenges and experiences discussed in this article are specifically relating to two transatlantic research groups working with cancer patients receiving treatment, we hope that our reflections provide fellow consumer food safety researchers with valuable insight into the challenges faced in recruiting vulnerable groups to participate in food safety studies.

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