Problem

A “CULTURE OF DISENGAGEMENT” IN CANCER RESEARCH?

During their graduate training, cancer scientists spend countless hours with microscopes and petri dishes, but they might never interact with a cancer patient or survivor. This disconnect between patients and scientists is emblematic of a broader trend in STEM education, termed the “culture of disengagement” (Cech 2014). Disengagement likely erodes the quality of graduate research and learning:

CAUSES

- Exclusion of non-technical stakeholders from academic dialogue
- Dismissal of social concerns as tangential to “real” science
- Devaluing social consciousness compared to technical expertise

CONSEQUENCES

- Inability to reflect on the social context of scientific work
- Inability to define and prioritize social problems
- Inability to assess problems, methods, and outcomes from multiple perspectives

OBJECTIVE: USE A COMMUNITY-BASED APPROACH TO DECONSTRUCT THE CULTURE OF DISENGAGEMENT AS WE PERCEIVE IT IN BIOMEDICAL SCIENCE AND ENGINEERING, SPECIFICALLY IN THE CONTEXT OF CANCER RESEARCH.

Methods

THE PATIENT-RESEARCHER PARTNERSHIP AGAINST CANCER

In 2012, we connected with Bob Riter, the executive director of the Cancer Resource Center of the Finger Lakes. The Resource Center is a haven for those who are affected by cancer in Tompkins County. Bob shared our enthusiasm for bringing together scientists and survivors. A synergistic collaboration quickly developed. In 2016, we designed a survey instrument to assess the impact of participation on students’ understanding of cancer.

Learning Outcomes

- INCLUSIVE LEARNING
- TRANSFORMATIVE LEARNING
- SOCIAL RESPONSIBILITY

Broader Impacts

- WHAT DISTINGUISHES THE PATIENT-RESEARCHER PARTNERSHIP FROM “BUSINESS AS USUAL”?

A community-engaged cancer researcher:
- Identifies as a member of the cancer support community and takes actions to support those who are living with cancer.
- Deeply values the social impacts of biomedical research.
- Makes experimental decisions intended to accelerate the rate of scientific discovery and its relevance to public welfare.
- Readily assimilates new disciplinary knowledge apropos of the complex civic structures involved in healthcare and medicine.
- Interprets biomedical evidence from multiple perspectives, and communicates effectively across diverse audiences.
- Critically reflects on the micro- and macro-etiological dimensions of chronic and terminal illness, from health disparities to end-of-life decisions.
- Pursues opportunities to enrich her or his knowledge and skills.
- Receives personal rewards from public engagement, including a greater sense of purpose, intimate friendships, and a stronger social network, access to a wider variety of information, and the encouragement of working together toward a meaningful goal.

Conclusions

It is in graduate education that the attitudes and priorities of future scientists are most firmly shaped. It is here that students formally encounter the profession’s concept of ethical behavior and social values. If patient perspectives are marginalized, emerging scientists will learn to define social issues as tangential or secondary to the practice of cancer research. The patient-researcher partnership deeply affirms the human dimension of biomedical science. Cancer patients are not cells or molecular pathways. They are people first.