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Review Article

Towards “Collaborative Ethics” for Translational Medical Research Teams

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Abstract

An increasing focus of public and private funders of medical research is to promote collaborative research teams that translate research findings into community health improvement. Unique collaborative translational research teams are developed to meet this demand from funders and adequately address the complex health needs of diverse communities. These interdisciplinary teams bring together highly educated individuals with varied ethical training and perceptions of the role of ethics in research. This diverse ethical thinking within the collaborative team sets the stage for unique ethical challenges that are faced by collaborative translational research teams. In this article we offer a literature review of key ethical issues that may arise for these collaborative teams that may prevent them from succeeding – namely, conflicts of interest, training competencies, data sharing, and the need to integrate community input into all stages of translational research. Researchers creating collaborative teams can learn from the lessons of the current literature and develop plans to address common ethical challenges for collaborative teams. These teams can also increase research in this area by studying themselves and their responses to ethical challenges. There is also an ongoing need to train researchers to address ethical challenges that arise in collaborative teams since these types of teams are likely to dominate medical research in the foreseeable future.

INTRODUCTION

The field of medicine is comprised of ever increasing silos among fields constructed to address individual diseases in increasingly small, conceptual packages (i.e. molecular genetics of disease) with less focus on the human body as an integrated

system [1,2]. The growing number of specialists is diverse in their languages, behaviors, actions, and culture. Yet, increasingly funders are recognizing that the collective intelligence of these multidisciplinary perspectives and experiences can have a powerful impact on medical and ultimately the health care system. These collaborative teams can yield greater results together by producing strategies

that consider multiple specialty areas that impact medical research, including but not limited to: bioinformatics, bench science, applied science, public health considerations, knowledge about local cultural factors, and ethics.

Such diversity can strengthen teams seeking to maximize available knowledge in the translation pipeline from bench to bedside, but diversity can also hinder ethical decision-making. For example, if half of a team's members favor detailed consent forms for a project and another half favors an implied consent approach, the time to carry out the project could be in jeopardy and the financial resources necessary might also be affected. The amount of ethical training that team members have also varies leaving some to be more judicious with regards to addressing ethical concerns than others [3,4]. For instance, some fields of medicine, such as oncology, have undergone greater ethical scrutiny from bioethicists and the public making their specialists much more aware of ethics as a concern in research. Social scientists who study ethical issues raised by the field of genomics may have a different view on ethical issues than bench scientists or clinician researchers due to robust discussion anticipating the ethical concerns raised by genomics. The National Human Genome Research Institute dedicates 5% of its budget to the study of Ethical, Legal, and Social Implications (ELSI) of the field – a unique approach not matched by any other National Institutes of Health entity [5]. This financial focus has generated a body of literature on this topic and created a group of scholars throughout America's campuses who teach courses to educate future researchers on the ELSI of genomics.

Understanding ethical diversity arising from personal and institutional belief systems and finding compromises are important goals for successful collaborative science teams to achieve [6]. Interdisciplinary ethics training has been discussed to a limited extent in the literature, [7] in addition to other competencies related to collaborative leadership, conflict resolution, and inter-professional/communication [8]. This article reviews key concerns for collaborative science teams arising from this literature.

LITERATURE REVIEW

To identify key ethical issues raised by collaborative science in the field of translational medical research, we searched PubMed (<http://www.ncbi.nlm.nih.gov/pubmed/>) using Medical Subject Headings (MeSH), the US National Library of Medicine's controlled vocabulary for indexing articles. PubMed contains over 23 million citations for biomedical literature from various sources, including life science journals, online books, and MEDLINE. We searched this resource to identify articles on the ethics of clinical and translational research using the following search strings:

- "Interdisciplinary Studies"[Mesh] AND "Ethics"[Mesh]
- "Translational Medical Research/ethics"[Mesh] and "interdisciplinary or collaboration or multidisciplinary"

Using these search terms we identified and reviewed a total of 14 articles. All articles were read in their entirety and key information was extracted from the articles including year of publication, journal name, focus/topic of the article, stakeholders or collaborators

discussed in the article, country of focus, whether interdisciplinary research was discussed in the article, and whether the article was relevant to the review. Three of the articles discussed interdisciplinary research explicitly [9-11]. None of the articles were country specific, but one of them discussed the United States and other countries. The topics covered in these three articles were neurosurgery, health information technology and translational research.

In each of the articles reviewed, the degree of focus on ethical issues varied. One article discussed ethical issues raised by certain types of research such as biomarker research [10]. Two others discussed conflicts of interest and regulation. One of these discussed funding, regulation and intellectual property [11]. Six articles discussed translational research directly. Only three of these also discussed interdisciplinary research [9-11]. Regulations and conflicts of interest were the primary topics of discussion in two of these articles [11,12]. The others discussed IRB review [12], participatory research that included the end users of research results and data sharing topics [9]. Key themes from these articles are discussed below.

Conflict of Interest

Managing conflicts of interest is an essential part of collaborative teams because team members may be motivated by a number of factors, some of which may prevent them from focusing on the problem being addressed by their research and instead focusing on self gain. Conflicts should be known by all team members in order for them to understand the potential reasons for their team members' viewpoints on different issues – especially controversial ones. On the other hand, conflicts of interest guidelines might stifle private-public collaborations as private partners possess a conflict that must be accepted instead of managed. Stossel et al. state that "industry-physicians' collaborations" can be suppressed by what the author labels as a "conflict of interest regulation movement [13]". Lacey and Sutherland point out that the models for translation in industry and academia are different with industry being less interested in the problem at hand and more concerned with a profit margin [11]. For example, if one intervention approach would earn substantially less profit and have marginally greater effectiveness, industry might be less likely to favor it, whereas academia might support it.

Training competencies

While no article clearly provided competencies or a curriculum for training people to deal with ethical concerns in a collaborative science team, one article by Woodward-Kron et al. discussed the use of interdisciplinary perspectives to teach ethical communication using multimedia tools [12]. The authors are aware of an effort underway at NIH that is providing ethical training to researchers from multiple disciplines. This effort stems from NCATS – National Center for Advancing Translational Science [14]. This center is funding awards called Clinical and Translational Science Awards to various medical centers throughout the country. A portion of these awards pay for clinical and translational science degree programs. Most of these programs have some ethical component integrated into their curricula. This effort may provide guidance for similar educational efforts throughout the country.

Data sharing

Data sharing agreements are key for successful collaborative science teams. Ethical challenges that arise here include who should receive the information among the team, who owns the information, whether the information should be shared beyond the team with other researchers, and if the information should be made public. Data sharing issues are growing more important in the age of personalized genomic medicine [15]. Sethi and Theodos discuss the evolving world of electronic health records and how these records are likely to be expanded with genomic information [9]. Multiple researchers would like to tap into electronic health records in order to study various topics that may translate into better care for those included in the electronic health record systems. In the process of translating this information, factors such as the Genetic Information Nondiscrimination Act of 2008 pose unique concerns because the law prohibits any use of this information for discriminatory purposes by health insurers and employers. Such laws can offer protection to patients and also may inhibit some researchers from seeking to use the information. Balancing the needs of communities and researchers is key for successful data sharing especially for community-researcher collaborative teams.

Community versus researcher based research questions

With an increasing focus on the role of community members in research by the National Institutes of Health and other entities, such as the Patient Centered Outcomes Research Institute (PCORI), the development of research questions becomes more challenging, yet potentially more translatable than in the past. Translational research requires looking forward with an eye towards the end users [10]. In most cases these are patients who are likely to benefit from a new innovation, but could also be other individuals – such as health professionals – who are likely to utilize some new intervention.

A community's desire to see an intervention which prevents or treats a disease that impacts them, often leads to an increased focus on ethics for collaborative science teams including community members [16]. Articles reviewed pointed to the need for these end users to participate in all stages of research [10]. This can be difficult because laypeople often lack the requisite background knowledge to understand certain in-depth research questions. Yet, their lack of understanding can motivate researchers to find better ways to communicate. Also, their day to day knowledge of their disease can open the eyes of researchers to new ways of viewing an illness. End users tend to focus on the beneficence that arises from research and can help a collaborative team decrease the harm to their research participants and enhance the benefits. A collaborative team involving end users is best when equitable according to the articles. This results in a shift of the role for research participants from a passive data source to an advisor or co-researcher [16]. Another challenge faced by collaborative teams is that despite an increasing focus on community participation in research, true inclusion is still uncommon, but increasing. Chiu et al. also indicates that the success of translational research projects is much higher with

good participation of the end users [16]. Such perceptions may lead to more community-researcher collaborative teams in the future.

CONCLUSION

Collaborative medical research teams seeking to translate research into practice face numerous obstacles. Here we focus on key ethical issues that may disrupt teams and prevent them from succeeding – namely, the need to integrate community input into all stages of translational research, conflicts of interest, training competencies, and data sharing concerns. These and other ethical issues require more research in the context of collaborative translational research teams and these teams can contribute to research in this area as each team represents a natural experiment in scientific collaboration. In addition to more research in this area, trainees require education in how to address the unique ethical challenges of collaboration with the goal of resolving the conflicts in order to achieve the grand goals that translational researchers have created for themselves – translating research into practice and thereby community health improvement.

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