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Preserving the Integrity of Studies and Clinical Trial Participants in the Social Media Era

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Introduction

Compared to just 5% of Americans in 2005, nearly 70% use social media today. New opportunities for interacting with others have emerged as a result of the rise of social media, which is broadly defined as content posted by Internet users on sites like Facebook, Twitter, and blogs. Social media use has significant advantages for prospective and enrolled research participants, including the creation of a forum for information exchange and fostering a sense of community and social support. The use of social media by participants, which can be an effective recruitment tool, can also benefit trials. Participants' online sharing of trial-related information carries risks in addition to these benefits. First, their use of social media might harm the integrity of the study. If information is shared online that is incorrect or unclear, it may lead to compromised eligibility criteria, unblinding, slowed recruitment, or participant dropout. These issues may be exacerbated. This, in turn, may impede the creation of the precise data required to advance patient care, waste trial resources, and diminish the contributions of other study participants. Second, participants may be at risk from online trial participation communication. Coaching to game safeguards provided by eligibility restrictions or adverse event monitoring, as well as the dissemination of inaccurate or misleading health and safety information, are examples [1].

Discussion

These concerns are far from hypothetical, according to a 2012 review of online material posted by self-identified participants in clinical trials. Even though more research is needed to figure out how much discussion there is online about current clinical trials, it is likely that problematic communications have become more common as more people use social media. Numerous clinical trialists and funders have taken note. For instance, the National Cancer Institute has shown an interest in this matter by holding a public conference in June 2018 on how to use social media to raise awareness of cancer trials and how to properly manage online communications after enrolment [2].

It is essential to acknowledge that participants already communicate about trials. In any case, virtual entertainment emphatically up the ante by working with correspondence that can contact enormous crowds at low or no expense without regard to geographic limits. Social media can facilitate communication between individuals who otherwise would not be likely to meet, whereas in-person or local communication between participants is more accidental and limited in scope. As a result, social media make it harder to deal with issues caused by participant communication. The interaction of social media with traditional clinical trials has received less attention in the ethics literature, despite the fact that research on data collected using social media platforms and Internet-related research in general have received significant attention [3].

The Social Media ADEPT framework we present here is designed to help researchers and patient partners address the concerns raised by participants' online trial communication. The following steps are included in the framework to encourage a structured and systematic approach: Design studies to minimize these risks, educate participants about their responsibilities to promote study success and avoid harmful social media use, Preempt problems by offering alternative mechanisms for participants to have their concerns addressed, and Take additional steps if necessary. Assess when and how social media are likely to pose risks for a study. In what follows, we depict the advantages and cutoff points of this methodology, reasoning that this is a promising model to safeguard members and preliminary trustworthiness from the disadvantages of online entertainment correspondence while holding the advantages [4].

Consider CLEVER, a phase 2 pilot trial of hydroxychloroquine, everolimus, or the combination for prevention of recurrent breast cancer; this is an ongoing breast cancer trial at our institution for patients who are free of disease but at risk of recurrence due to having disseminated tumor cells. NCT03032406) is the identifier on clinicaltrials.gov. Participants in the trial are assigned to one of four arms, each consisting of two oral medications that have been approved by the US Food and Drug Administration for use in other indications but are currently being evaluated for their capacity to eliminate these remaining tumor cells when used separately (arms 1 and 2), together (arm 3) or in conjunction with a delayed start (arm 4). The approach's viability serves as the primary endpoint, and toxicity and preliminary efficacy serve as secondary endpoints. The trial is open-label for cost and practicality reasons. After six months, participants have their bone marrow tested again to determine the best treatment duration and to avoid potentially unnecessary treatment. The study treatment is ended if there are no more cancer cells in the bone marrow. Participants, regardless of their previous assignment, receive the two study drugs together for six months if it is not.

Early on, a number of participants shared information about the study on an open Facebook page for breast cancer patients, which helped recruit people from all over the country and was welcomed by the researchers. Hence, a few members made a shut Facebook bunch only for preliminary members. The participants informed the investigators of the existence of the closed group, but they did not invite them to join. If participants shared information about study assignments and test results, they became concerned about potential harm to the trial as a whole. Investigators were concerned that participants might develop anecdote-driven theories about whether or not the drug regimen to which they were randomly assigned "worked" and share those theories online because they are aware of their study assignment and whether or not their results indicate bone marrow clearance. Such data sharing could lead current members to be unglued about their treatment tasks and to reexamine whether they need to forge ahead with study or potentially look for the drug(s) that they accept to be "winning" from another source. The peer-to-peer advice given to individuals considering trial enrollment regarding whether they ought to agree to be randomized to a "losing" arm may also be influenced by the sharing of such information. There could be significant repercussions for participant interests and scientific integrity if either or both of these things took place [5].

Conclusion

The researchers were cognizant of the fact that cancer patients, who

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are already dealing with the burdens of study participation and the anxiety of a cancer relapse, naturally want to maximize their individual success and avoid taking on unnecessary burdens. However, they were also aware that participant speculation and theorizing during a trial based on personal experience anecdotes could lead to incorrect and premature conclusions that would be detrimental to participant interests and would improperly bias personal decision-making. This is due to the fact that careful procedures and safeguards against bias, in addition to robust aggregate data from an adequate sample size, are required to make valid judgments. Furthermore, participants may be subjected to research risks and burdens without sufficient countervailing social benefits as a result of such speculation and theorizing, which could jeopardize the larger objective of advancing therapy for potential patients. As a result, the investigators sought advice on how to proceed after determining that the Facebook group could not be ignored. While the difficulties they face illustrate a broader issue, their specific solution is discussed below.

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