

Chapter 6

Increasing Health Literacy to Improve Clinical Trial Recruitment

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ABSTRACT

Health literacy has been found to be linked to healthcare understanding and decision making. Therefore, it makes sense why individuals who do not understand clinical trials will be less likely to want to enroll in one. In fact, three major barriers found in the literature that prevent potential participants from enrolling in clinical trials include a distrust or negative perception, lack of understanding, and lack of accessible and affordable healthcare. Hence, there is a need to increase potential participants' healthcare understanding so that they can make the best healthcare decisions for themselves. Strategies suggested to help increase potential participants' health literacy include revising informed consent forms, utilizing culturally targeted statements, using a variety of material, and training investigative site personnel. These proposed strategies may help increase health literacy, which in turn could improve clinical trial recruitment. Furthermore, these strategies focus on different elements of health literacy and coupled together may bring the most improvement.

INTRODUCTION

Recruitment issues can be costly and lead to overall delays in the clinical trial process. In fact, “every month by which the development process can be shortened is worth US \$25 million in additional income for the average drug” (Marks & Power, 2002, p.105). In addition, these delays can extend the time it takes to get needed medications or interventions to patients. Unfortunately, despite these factors, trials frequently discontinue even in late stage Phase III trials due to failure to accrue (Schroen et al., 2010). Current strategies for recruiting patients can no longer be viewed as the best practice and need to be revised. Health literacy should be considered a vital component to participant recruitment of clinical trials and there needs to be a closer look at its' role in the recruitment process. For example, if an individual does

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not have sufficient healthcare understanding, they will most likely not enroll in a clinical trial. Therefore, improving health literacy could help in mitigating the gap in insufficient recruitment in clinical trials.

A study by Aetna found that only 18% of adults in the United States are proficient when it comes to health literacy (Aetna, n.d.). This considerably small number illustrates the lack of health literacy among Americans. According to Selden, Zorn, Ratzan, and Parker (2000), health literacy is “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (p. vi). This is the ability of individuals to receive healthcare information and then comprehend it in order to make the best healthcare decisions. According to the Kindig, Panzer, and Nielsen-Bohlman (2004), patients who have low health literacy are less likely to have knowledge on how to take care of themselves such as disease management and health-promoting behaviors. Therefore, it makes sense that health literacy is “commonly defined as the skills and abilities needed to gain access to, understand, and use health-related information” (Rudd, 2010, p. 2283). This means that individuals need to be able to obtain the information, comprehend it, and then utilize it when it comes to their own health.

There is now more focus on the health literacy rate of Americans in the United States as it is found to be linked to healthcare understanding and decision-making. In fact, it is a vital component to improving the healthcare of underprivileged populations while at the same time mitigating inequalities related to healthcare (Coulter & Ellins, 2007). More specifically, research has shown that limited health literacy leads to inequalities including having less knowledge of disease management and of health-promoting behaviors, having poorer health status, being less likely to use preventive services, and a higher rate of hospitalization and use of emergency services which in turn will lead to higher healthcare costs (Kindig et al., 2004). Due to these reasons, there is a high need to educate the public and share information on healthcare. Not only does the information need to be shared with the general public, which will increase their healthcare knowledge, but it also needs to be targeted to specific populations such as different minority groups. If individuals do not understand clinical trials or research, they will be less likely to want to enroll in a clinical trial. In addition, with the lack of knowledge or information, they may have misconceptions of what a clinical trial actually entails and thus be less likely to want to enroll in one. More importantly, if patients do not understand healthcare, they will not be able to make the best healthcare decision for themselves.

BACKGROUND

As healthcare research expands, there has been an increase in the number of clinical trials that play an important role in the treatment of many conditions and diseases. As of September 2017, Clinicaltrials.gov noted having an outstanding 254,787 studies listed across 200 countries (Clinicaltrials.gov, 2017). Although they may be different in their disease-focus and study design, similar issues are generally experienced. From a patient perspective, common reasons for not enrolling in a clinical trial or research study include distrust or having a negative perception of research, lack of understanding, and lack of accessible and affordable healthcare, all which are further discussed below. It is important to highlight that the literature presented focus heavily on the lack of minority representation in clinical trials as this is a large contributing factor to the problem of insufficient recruitment. In addition, the literature presented focuses on research in the United States as it represents a significant portion of the literature on clinical trial recruitment; however, similar issues may be experienced globally.

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