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Optimizing language for effective communication of gene therapy concepts: A qualitative study

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Abstract

Objective: For communities of persons living with hemophilia and other genetic conditions, gene therapy could represent a paradigm shift in treatment strategies. As therapeutic modalities become increasingly complex, there is a critical need for all stakeholders (patients, physicians, patient advocates, nurses, caregivers, reimbursement agencies, drug developers, and regulators) to communicate with a lexicon that is intelligible, accurate, and consistent. In doing so, expectations can be more carefully managed and potential risks, benefits, and limitations can be better understood. In recognition of this need, a first-ever study of gene therapy lexicon was conducted. Here, we report findings that identify a recommended language set for effectively communicating information about adeno-associated virus (AAV)-based gene therapy for hemophilia, between and among stakeholders. Methods: Structured screener interviews were used to identify a total of 84 suitable participants representing five individual countries (US, UK, Spain, France, Germany, Italy) and audiences (hematologists, nurses, caregivers, patients, and patient advocates). Then, a series of in-depth interviews, face-to-face focus groups, advisory board meetings, and online group interviews were held to collect, refine, and test language and image concepts. Sessions were conducted in local languages with detailed discussion guides. Across multiple topics, preferred words, phrases, and pictorial representations were developed and agreed upon through an iterative and adaptive process. Undesirable, disagreeable, or confusing language was identified. Preferences were largely consistent across audiences and countries; however, where differences existed, country-specific recommendations were made. Summary: Study results show that the hemophilia community has preferences around consistent lexicon used to describe hemophilia and its therapeutic approaches. Further, outcomes suggest that the use of preferred language can increase understanding and comfort during discussions of novel and complex therapeutic modalities such as gene therapy. Conclusions: This study suggests that consistent use of community-informed lexicon can minimize miscommunication and facilitate informed decision-making regarding potential future treatment opportunities. *Authors listed alphabetically