

Addressing Challenges in the Diagnosis and Management of a Rare Disease through Interprofessional Education

Ron Helderma, Maya Doyle, Adam Weinstein, Carolyn Macica

Background:

In the US, 1 in 10 individuals are affected by rare disease and are often further burdened by inaccurate or delayed diagnoses, access barriers to FDA-approved therapies and clinical trials, and limited access to knowledgeable healthcare providers. To enhance team-based collaborative care and health outcomes, an interprofessional education (IPE) event was created for health professional and medical students based on the Interprofessional Education Collaborative's "IPE Core Competencies," mainly interprofessional communication and teams and teamwork (IPEC, 2016). Learning objectives included (1) Recognition of value of rare disease awareness, advocacy, and research (2) Discussion of the challenges associated with rare disease patient management (3) Appraising the value of an interprofessional team in patient management and (4) Appraising the importance of communication between team, patient, and family. The event was organized around the rare disease cystinosis.

Methods:

The IPE event, held yearly for 3 years, focused on the diagnostic odyssey of cystinosis, and includes direct instruction, inquiry-based learning using a case study, and a narrative medicine component through expert patient interview. Pre- and post-event mixed-method survey data were collected to assess the event's success in improving participants knowledge acquisition and competency. Survey answers were quantified and analyzed using grouped and independent T-Tests, and Chi-Square tests (significance of $p < 0.05$). An open-ended question asked participants to list characteristics of effective healthcare providers and trends among the answers were delineated.

Results:

Enrollment included an average of 54 graduate-level healthcare students from nine different degree types. The survey data showed a statistically significant difference between participants pre- and post-event understanding of the importance of rare disease inclusion in educational curriculums ($p = 0.009$) and rare disease research ($p < 0.001$), their confidence working as part of an interprofessional team ($p < 0.001$), and their knowledge of beneficial resources for patients with rare disease ($p < 0.001$). There was no significant difference between pre- and post-event knowledge of how long it takes patients to get a diagnosis on average ($p = 0.307$) or how often patients get incorrect diagnoses ($p = 0.262$). When participants were asked about important qualities of an interprofessional team member, the following characteristics were named the greatest number of times: communicative, empathetic, compassionate, and understanding.

Conclusions:

The use of this interprofessional education model was successful in improving student participant's effectiveness as interprofessional team members and enhancing their confidence and ability to diagnose, treat, and manage patients with rare disease and their families. The inclusion of a narrative approach incorporating patient and family experience was impactful and strengthens case-based learning; partnership with rare disease advocacy groups can support such efforts.