

QOL 34

Increasing Medical Alert Devices (MAD) Compliance in School Age Children with Hemophilia: A Quality Improvement Project

Burge, Kara; Wilkerson, Brittany; Crary, Shelley

Submission Group

Quality of Life/Outcomes Research

Abstract

Background: Medical Alert Devices (MAD) are an integral method of alerting first responders of pertinent medical information. It is recommended that persons with bleeding disorders wear MAD to communicate life-saving information. School age children with Hemophilia can be at risk for developing life-threatening bleeding. These bleeds may occur while the child is away from home or from those who are familiar with their bleeding disorder. It was reported that many school age children do not wear MAD for various reasons, including financial barriers and dislike of appearance. Through routine patient follow-up, it was determined that most school age children with Hemophilia at the AR Hemophilia Treatment Center (HTC) were not wearing some form of MAD. Objective: Increase compliance with MAD in school age children with Hemophilia to improve safety. Methods: This study was conducted through qualitative interviewing during comprehensive visits. The HTC social worker met with school age patients with Hemophilia to determine: 1.) Ownership of a MAD, 2.) Compliance with wearing a MAD, and 3.) If not worn/owned, what barriers were present. During the first phase of data gathering that took place over 3 months, of the 13 boys interviewed, 100% of the patients screened did not wear MAD. Through this data we determined primary reasons for poor compliance included financial barriers and dislike of MAD aesthetics. The second phase consisted of developing a plan to address identified barriers. This involved purchasing and distributing personalized MAD for identified patients. Patients were integrated in decision making by selecting their MAD color. During the final phase of this project, we will make 2 follow-up phone calls, 6 and 12 months from the date of MAD distribution to determine if compliance has increased and is maintained. Summary: MAD have life-saving potential and are especially important for school age children with Hemophilia. Compliance with MAD has been poor at the Arkansas HTC for various reasons including cost burden and dislike of aesthetics. Through qualitative interviewing we were able to identify primary barriers for non-compliance and proactively intervene. We anticipate that compliance will improve by decreasing financial barriers and by having a more active role in the distribution of the MAD. Conclusion: Many school age children with Hemophilia do not wear MAD due to barriers including cost and dislike of aesthetics. Although this QI project is still ongoing, it has improved the HTC's understanding of the relationship between those barriers and MAD compliance. By addressing these barriers, we expect to increase MAD compliance by the following year.