



Wish Equity: English and Spanish-speaking Parent and Wish Granter Perspectives of Wish Granting for Children with Life-Threatening Conditions

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Scholarly

Concentration:

Advocacy (StAT)

Poster available?

***Yes**

Presentation available?

***No**

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RESEARCH STATEMENT/RESEARCH QUESTION: To examine the perspectives of English and Spanish-speaking parents of wish recipients and wish granters in attaining, selecting, and experiencing a wish through Make-A-Wish (MAW) Greater Bay Area.

BACKGROUND: Disparities in pediatric palliative care exist among people of Latino ethnicity and with public insurance. Receiving a wish through the Make-A-Wish (MAW) Foundation has significant benefits including increased hope, improvement in mental and physical health, quality of life, and can even lead to healthcare savings. The Bay Area of California is diverse with a 25% Latino population. There are no published studies examining differences in wish-granting for children.

DESIGN AND METHODS: From January to August 2019 we conducted a qualitative study examining the wish granting experience through anonymous semi-structured one-on-one telephone interviews. We randomly selected (1) English and Spanish-speaking parents whose children received a wish in the last year; and (2) English and Spanish-speaking wish granters from MAW Greater Bay Area. Interviews examined perspectives in attaining, selecting, and experiencing a wish. Iterative team-based inductive coding and theme analysis was conducted and an inter-rater reliability Cohen's kappa of 0.915 was achieved.

RESULTS: Thirty parents (15 English; 15 Spanish) and 16 wish granters (8 English; 8 Spanish) participated. Parents interviewed were 53% female, and primarily self-identified as 50% Latino and 27% Caucasian. The average age of children receiving a wish was 10.5 years. Wish granters were 94% female, 56% Latino, 31% Caucasian, and 13% Asian. Types of wishes included: "to go" (73%), "to have" (17%), "to meet" (7%), and "to be" (3%). Spanish-speaking families were more likely to have shopping spree wishes (33%). Wish granters perceived that families of higher socioeconomic status requested more complex wishes and could afford to pay out-of-pocket for additional amenities. English-speaking families were more like to travel outside of California (79%). Both parents and wish granters discussed Spanish-speaking parents' anxiety regarding documentation status, highlighting the profound and limiting effects on a child's wish selection. The majority of Spanish-speaking parents (93%) had never heard of MAW prior to their child's referral. As such, Spanish-speaking families believed that their child's medical condition impacted the overall wish experience. Spanish-speaking parents were also more likely to recall that the wish referral process took months from initial diagnosis to wish receipt, compared to English-speaking families that reported wishes were granted within weeks. Despite variations in the overall wish experience, it was widely believed that wishes provide respite, distraction, meaningful memories of times of joy, cherished family time, empowerment, and future opportunities.

CONCLUSION: Wish-granting is a powerful form of palliative care and there is opportunity to optimize this process for Spanish-speaking families who encounter unique limitations in wish selection and attainment. Main areas of focus should include increasing knowledge of MAW in this community. Physicians could be key players in elevating the importance of wishes and promoting greater access for Spanish-speaking families. There may be variation in awareness about MAW across families of different races or ethnicities as well.

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