

Disseminating Information to Culturally and Linguistically Diverse Patients and Their Families: Clinician and Parent Perspectives

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Objective:

The purpose of this project was to review the state of best practice guidelines for the dissemination of information to culturally and linguistically diverse (CLD) patients and their families.

Methods:

A single subject design was implemented. A review of personal experience, best practice solutions, and one parent's perspective of current patient-provider outcomes were reviewed.

Subject:

- *Female mother of a teenage son diagnosed with Autism Spectrum Disorder*
- *Ethnic Background: Guatemalan*
- *Primary Language: Spanish*
- *Limited English proficiency at the time of diagnosis*
- Data collection was obtained using a qualitative research methodology. A behavioral study with a semi-structured, construction was used to allow the single subject respondent to express in her own words, with minimal hold on the respondent's responses.
- A check list of questions was developed to be asked during the interview. Questions were related to the respondent's experiences navigating the health care system for her son with Autism.
- The four targeted topic areas included:
 1. Cultural Responsivity
 2. Communication with Health Care Providers
 3. Collaboration with Health Care Providers
 4. Knowing your Rights

Results:

A review of the literature outlined best practice guidelines for patient-provider communication, specific to the dissemination of information to culturally and/or linguistically diverse populations.

Findings Include:

- Eliminating language barriers by:
 - Developing an awareness of one's own cultural beliefs, values, attitudes and practices.
 - Increasing one's knowledge and understanding of specific cultures, cultural beliefs, values, and attitudes.
 - Using bilingual health care providers and/or an interpreter, which is optimal.
 - Developing an awareness of the patient's low literacy or English proficiency levels are key.
 - Using shared decision-making is essential.
 - Best practice includes:
 - Clinicians who use culturally sensitive communication can demonstrate an understanding of patient and family beliefs, goals and values.
 - This approach includes family-centered care, which involves respectful and supportive interactions with the family, fostering partnerships and promoting continuity of care

The following key experiences were overlooked by health care practitioners for this family despite best practice guidelines.

Experiences that were difficult:

- Religion and its implications for CLD families—assisting families in balancing and understanding the importance of medication use and its implications over or coordinated with prayer. (Cultural Responsivity)
 - Recognizing that some cultures may view disabilities as an act of God for punishment of something the family did or did not do. (Cultural Responsivity)
- Families may experience shame due to their cultural beliefs. (Cultural Responsivity).
- Management of the disability may be non-existent in certain communities due to such beliefs. (Cultural Responsivity)
- Suggested management strategies may be rejected as success for individuals with disability may be foreign in certain cultures. (Cultural Responsivity)
- A belief that the child is “crazy.” (Cultural Responsivity)
- Resources (e.g., handouts and websites) helped the subject understand her son's diagnosis, but they were all in English so they were difficult for her to comprehend. (Communication)

Experiences that were valued by this family:

- Use of an interpreter was crucial to the subject's ability to understand and process her son's diagnosis and plan of care. (Collaboration)

- Acknowledgement that each culture is different, and it is important to give each family opportunities to voice their concerns and ask questions (i.e., open dialogue). (Collaboration)
- Involving family in the plan of care, respecting their decisions, and valuing their input. (Collaboration)

Experiences this family would suggest for others:

- Resources (e.g., handouts and websites) helped the subject understand her son's diagnosis but they were all in English, so when possible, resources should be translated to the family's primary language. (Communication and Knowing your Rights)
- Education of patient and family rights as related to health care delivery and access to resources/support. (Knowing your Rights)

Conclusions:

Findings suggest the need for establishing trust between the family and provider is crucial, and the need to educate families about their health care rights cannot be overlooked. More research should be conducted to identify factors that improved CLD patients' and family satisfaction with healthcare services.