

## COMMENT



# Genetic testing decisions in non-western cultures: an opportunity for intergenerational decision making

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Shared decision making is acknowledged as a central tenant of patient-centered medical care. Effective shared decision making involves patients and providers sharing their knowledge, preferences, and values to reach agreement on care decisions. Decision support tools including decision aids have been developed and tested in a wide variety of healthcare contexts. While decision aids improve shared decision making, most theoretical and empirical evidence is based on western ideals such as supporting an individual's autonomous decision making, in a non-directive way, to facilitate informed choice. Shared decision making and decision aids have not been widely researched in diverse communities or non-western populations [1]. The development and testing of decision aids in non-western cultures can help to understand the applicability of shared decision making and associated interventions across a variety of contexts.

In this issue of *EJHG*, Ahmed et al. demonstrate the acceptability of decision aids in a government-funded program to facilitate cascade screening of Beta-thalassemia major in Pakistan [2]. They explored relatives' experiences and acceptability of using a decision aid to facilitate meetings between field officers and family members of children with Beta-thalassemia major who may be eligible for genetic testing. The decision aid used in their study adhered to the International Patient Decision Aid Standards (IPDAS) guidelines, which are predominantly informed by western-based empirical work.

Ahmed et al.'s decision aid differed from traditional decision aids by focusing on decision-making encounters between a provider and multiple family members instead of a provider and an individual. Ahmed et al. found that the decision aid was satisfactory to relatives. Incorporating family members in the encounters may have upheld specific cultural ideals of collectivism and family-based decision making not frequently seen in the decision aid literature. There is growing recognition of the importance of family members in the decision-making process as people rarely make decisions in a patient-provider vacuum [3]. This is particularly true regarding genetic health-related decisions that have implications for multiple family members, often across multiple generations [4]. Future research is needed to explore the application of decision aids to a family-based context as Ahmed et al. demonstrate. Such an application may be particularly pertinent to collectivist cultures that prioritize family decision making, though would likely be applicable across many cultures and countries.

While decision-aid-facilitated family meetings may be an effective way to incorporate intergenerational decision making, it is important to note that some participants in the study raised concerns about the structure of the meetings. Specifically, some

participants felt that women and unmarried relatives may not feel comfortable participating in shared decision making during the family meetings where men are present (either male field officers or relatives). Ahmed et al. noted that currently, the government-funded screening program only employs male field officers. Adaptation of the decision aid for use without the facilitation of a field officer or purposefully including female field officers could remove some of the gender-imbalance-related concerns that participants raised and offers an area for future research.

The study by Ahmed et al. provides promising evidence for the applicability of decision aids and the IPDAS guidelines to non-western cultures. Testing the effectiveness of decision aids in non-western populations will also require an appreciation that desired outcomes may differ from those commonly used in decision-making research among western cultures. More broadly, research around decision making involving multiple family members is an important avenue of future work.

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## COMPETING INTERESTS

The authors declare no competing interests.

## ADDITIONAL INFORMATION

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