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■ Culture & SDM: Developing a patient decision aid for a multi-ethnic setting- Lessons from the Malaysian Insulin Patient Decision Aid

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BACKGROUND

In Malaysia, one of the main challenges in developing and implementing a decision support technology is how to tailor it to the needs of the three ethnic groups i.e. Malay, Chinese and Indian. There are significant language and cultural differences which the healthcare professionals (HCPs) need to identify and address before shared decision making can take place.

METHODS

In-depth interviews and focus group discussions were conducted in Klang Valley and Seremban in 2010-12 with HCPs who were involved in insulin initiation- including doctors, nurses and policy makers, and patients with type 2 diabetes who were considering insulin initiation. A topic guide was used to guide the interviews and focus groups, which were transcribed verbatim and analysed with Nvivo9 software using a thematic approach. Ethnically, the 41 HCPs were Malays (n=15), Chinese (n=10), Indians (n=13) and other ethnicities (n=3). 21 patients participated and the patients were Malay (n=5), Chinese (n=4) and Indian (n=12). Cultural and linguistic barriers were identified and used to inform the development of an insulin patient decision aid.

RESULTS

Linguistic barriers were common especially when HCPs did not speak the majority language of the practice population. For example, Chinese HCPs found it difficult to communicate with Indian patients who only spoke Tamil and not the more common Malay or English languages. As such, it was necessary to translate the tool into the four main languages using forwards and backwards translation. The cultural perspective influenced patients' values and preferences about insulin and was included in the list of patient concerns. For example, the religious purity of insulin and injections was a concern in both Muslim and Hindu patients. Lastly, use of complementary and alternative medicine (CAM) is widespread in Malaysia, and each ethnic group has different CAM belief systems and practitioners. Despite the lack of evidence on CAM, 'using alternative medication' was included as an option in our patient decision aids to facilitate discussion on the topic during decision making.

CONCLUSIONS

When developing and implementing decision support tools, we must take into consideration the cultural context in order for the tools to facilitate shared decision making.

● Culture & SDM: Who's making the decision? The importance of cultural considerations in globalising shared decision making using Hong Kong as a case study

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BACKGROUND

Most of the research in shared medical decision making (SMDM) has been conducted in English speaking communities. Western cultural and ethical assumptions are implicit in these studies and cultural contexts of other patient populations have received little attention. This literature review of research in shared medical decision making conducted on Hong Kong Chinese patients serves to identify the cultural aspects pertinent in this location.

METHODS

A literature search was conducted in MEDLINE.

RESULTS

Ten studies on shared decision making in Hong Kong were found. Patient autonomy and individual rights, which are assumed important in SMDM research in the west, are viewed less important than family autonomy. For example, 'informed consent' requires the patient to base their autonomous decision on sufficient knowledge. However, studies have consistently showed that Chinese patients in Hong Kong often preferred not to have full knowledge of their condition, even if it pertains to their diagnosis or prognosis. In a culture rooted in the Confucian tradition of familism like the rest of China, patients' family members are often present in consultations and play a key role in decision making. Some family members become the surrogate decision maker even when the patient is fully competent. Where it may be unacceptable for providers in the west to disclose patient information to family members without patient's prior consent and unethical to withhold information from the patient, some studies report circumstances where this is expected of the provider by the patients and their family in Hong Kong. A doctor who delivers grave news to the patient against the family's wishes can be considered inconsiderate and much mistrust and discord in the doctor-patient-family relationship may arise.

CONCLUSIONS

The cultural and ethical assumptions in the current research of SMDM have important implications in implementing SMDM in global settings. These cultural and ethical principles may not be applicable to all cultures and may be detrimental in some. These should be given more consideration and importance in implementing and developing research in SMDM. Given the global increasing trend of cross-cultural doctor-patient relationships, more research on these issues should be conducted.