Abstracts of presentations

Bridging the gap between research and practice: patient pull or clinician push?
Concept Mapping to Elicit Men's and Partners' Views of Active Surveillance vs Active Treatment for Early Stage Prostate Cancer

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BACKGROUND

There is no consensus on the best option for men facing a diagnosis of early stage prostate cancer; active treatment often causes side effects, e.g., incontinence, and does not extend life. Active surveillance is an option that is not currently included in decision aids. Methods

Using concept mapping, a qualitative, participatory method, we produced a framework for viewing active surveillance and active treatment: 54 statements about what men need to make a decision were derived from focus groups with African American, Latino, and white men and partners in Houston and El Paso who had screened negative (n=80) and from journal articles; 86 similar participants (55 from the focus groups and 31 new participants) sorted the statements and rated their importance.

RESULTS

Multidimensional scaling and cluster analysis yielded an 8 cluster map based on the data for the 3 ethnicities. Clusters were labelled Doctor-patient information exchange, Finding out about active surveillance and active treatment, Weighing the options, Seeking and using information, Spirituality and inner strength, Access to active treatment, Side effects of active treatment, and Family considerations. There is a major cluster, rated somewhat more important overall, concerned with obtaining information and weighing options in decisions. The other major grouping concerns family, faith, and considering the side effects of active treatment. Average cluster importance ratings varied in Finding out about active treatment and active surveillance (less important by Hispanics), Access to active treatment and Spirituality (more important for African Americans). Women saw weighing options and seeking information from physicians active surveillance more important than men. There were no differences by gender in clusters about family considerations or spirituality.

CONCLUSIONS

Our next step is interpretation by participants and advisers. The results are contributing to the development of educational messages that include active surveillance.


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BACKGROUND

Patients, family and healthcare professionals are the main stakeholders in decision making. Traditionally in Asia, family units are close-knit and are often actively involved in the care of the patient. However, their role in making healthcare decisions has not been studied. Using insulin initiation in Type 2 diabetes patients as an exemplar, this study aimed to explore the healthcare professionals' views of the stakeholders' roles in decision making in Malaysia, a multiethnic Asian country, which has a public-private dual healthcare system.

DESIGN AND METHODS

In-depth interviews and focus group discussions were conducted in 2010 with healthcare professionals consisting of general practitioners (n=7), diabetes nurses (n=3), government policy makers (n=1), family medicine specialists (n=1) and endocrinologists (n=1). A topic guide was used to guide the interviews which explored healthcare professionals' views about healthcare decision making roles. The interviews were transcribed verbatim and analysed using Nvivo software using a grounded theory approach.

RESULTS

This study found that the key stakeholders in making decisions about insulin initiation included the patients, their families and doctors. In this study, healthcare professionals viewed the patients as the main decision maker.

The families had a significant influence on the decision making process. In some instances the decision was made solely by the spouse or the children, in particular amongst patients who were elderly or visually impaired, requiring assistance with insulin injections. There was an observed trend that domestic helpers were becoming the main caregivers and this might influence the decision making process.

Doctors' role in decision making varied widely. Some would make decisions for the patients while others would leave it to the patients to decide. Their preferred role was influenced by the clinical settings of their practice (Private vs Public) and doctor-patient relationship. Nurses and diabetes educators were less involved in the decision making process.

CONCLUSION

In Malaysia, doctors and patients' families played an important role in making decisions about insulin initiation. The role of domestic helpers in influencing the decision making process needs to be further explored.