Sharing the diagnosis of dementia: breaking bad news to people with intellectual disabilities

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Background

Existing models for breaking bad news to patients who have a fix-limiting illness are inadequate in meeting the needs of people with intellectual disabilities.

A two-year study into breaking bad news to this group of patients/relatives revealed in the development of a new model for breaking bad news to people with intellectual disabilities (presented at the EAPP Conference 2012 in Köln). SEE LEFT: book and website

The model is based on the finding that bad news situations are usually complex and are made up of lots of different pieces of knowledge and information; the acquisition of these pieces is a non-linear process that can be unpredictable. Building someone’s foundation of knowledge and understanding is central to the model.

It has been used successfully in practice; however, it is unclear how this can be applied to people with ID and dementia. UK and European dementia strategies specify that everyone is entitled that everyone is entitled to know of their diagnosis.

Aim

To explore whether the new model for breaking bad news can be used effectively in sharing a diagnosis of dementia with people with intellectual disabilities.

Methods

The model was applied to people with dementia and intellectual disabilities, as follows:
1. The literature on dementia and breaking bad news was analysed
2. Theoretical assumptions were made based on the model itself
3. The model was applied in real-life situations.

Results

In this real-life case study of Tom, the model was useful for both the clinician and the support staff in helping him understand and cope with his changing situation.

Conclusion

This initial exploration of the use of the model has promising results, but a study is now underway to investigate further how people with ID and dementia can be best supported in their need for understanding.