

# Patients have a right to know—not a duty to know—their diagnosis, says new research

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The experiences of doctors, patients and carers of initial cancer consultations have informed new guidelines developed at the University of Leicester, in collaboration with University Hospitals of Leicester NHS Trust and Imperial College London, to help patients better understand their cancer consultations.

The research, published today (6 March 2014) in the *British Journal of Health Psychology*, found patients' experiences of being given their diagnosis differed both between participants and within the same participant. This means a doctor's role in communicating information in a patient-centred way can be very difficult.

A variety of defensive mechanisms were found to be employed by patients in order to protect themselves from fully engaging with the knowledge they had been given within an oncology consultation.

Semi-structured interviews were carried out with 36 patients and interpretive phenomenological analysis (IPA) was used to understand participants' meanings of their experiences in their initial consultation. They found patients had a 'right to know' but not a 'duty to know' their diagnosis and prognosis, and as such [doctors](#) face a difficult task in ascertaining how much detail the individual patient wants at any one time.

Research lead Professor Anne Thomas, from the University of Leicester's Department of Cancer Studies and Molecular Medicine, said:

"The accounts from patients of what they wished to know in the consultation could be affected by a desire to protect themselves and/or family members from the distress of bad news.

"With this in mind, the complexity of patients' needs and preferences regarding information means that the doctor's role in communicating that information in a patient-centric way is difficult, especially as we also found that patients' needs varied over time.

Additionally, it is also difficult for doctors to know whether or not the information they disclosed about diagnosis, prognosis and treatments was wanted or understood."

Using information from this analysis and data from a larger study, the researchers have developed a consultation aid for doctors and patients to refer to that will identify the patients' preferences with regard to 'knowing and not knowing'.

Dr Lynn Furber, Senior Nurse Researcher from University Hospitals of Leicester NHS Trust, added: "It was imperative to us to be able to use our research findings to develop a tool based on what patients and doctors told us was important to improve their experiences and provide them with information in a timely and efficient manner.

"This should provide the doctors with better information so that they are able to conduct consultations in a more patient-centred manner. Whilst an oncology consultation that involves giving bad news to patients is likely to be a difficult experience for both doctor and patient, it is hoped that the consultation aid will lead to an increase in patient satisfaction, and help inform doctors on how to meet the individual [patients'](#) needs."

The researchers now hope to expand on this pilot study to explore the acceptability and usability of their consultation support tool.

Once they have proved its effectiveness in practice, it is hoped that it will be adopted into current patient pathways.

**More information:** Patients' experiences of an initial consultation in oncology: knowing and not-knowing, *British Journal of Health Psychology*, 2014.

Provided by University of Leicester

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