
Abstract:

Aim: This article is a report of a study of informed consent in people with a learning disability. The aims of the study were to explore the information needs of people with mild-to-moderate learning disabilities with respect to consent for blood tests and to identify ways of facilitating informed consent.

Background: The recent political agenda for social change in the UK has emphasized the right of people with a learning disability to have more autonomy and make their own decisions. As in other countries, there has also been a shift towards shared decision-making in healthcare practice.

Design: Qualitative study using an ethnographic approach.

Methods: An ethnographic approach was used for this qualitative study. Phase 1 involved observation of six participants with a learning disability having a routine blood test in general practice, followed by semi-structured interviews with 14 participants with a learning disability in Phase 2. Data were collected between February 2009–February 2010.
Findings: The data showed that consent procedures were often inadequate and provision of information to patients prior to a blood test was variable. People with a learning disability expressed clearly their information requirements when having a routine blood test; this included not wanting any information in some cases.

Conclusions: Healthcare practitioners and people with a learning disability need to be familiar with current consent law in their own country to facilitate valid consent in the healthcare context. This study demonstrated the value of qualitative research in exploring the knowledge and attitudes of people with learning disability.