THE BURDEN OF BEING INTERVIEWED: AUTONOMY OR PATERNALISM IN PALLIATIVE CARE RESEARCH?

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Object: participation of patients in palliative care research may be problematic because these patients are both physically and mentally vulnerable. This vulnerability may result in paternalistic behaviour by doctors who are asked to include patients in a study. Our research question was: *how do terminal patients experience being interviewed and what is the opinion of GPs about their patient being interviewed?*
Methods: we interviewed 12 patients and their 12 GPs using open-ended questions in a qualitative design based upon grounded theory.
Results: we found interesting differences between experiences of GPs and patients. Patients did not experience being interviewed as a burden and focussed on positive aspects for themselves and future patients. Doctors did see positive aspects of participation for their patients, but did not ask all patients to participate because they expected the burdens would be too great.
Discussion: in most areas of modern medicine patient autonomy is the most important principle of ethics. This study raises the question in which cases terminal patients need to be protected by their carers and in which cases they can make autonomous decisions.
Conclusion: we conclude that patients receiving palliative care experience being interviewed more often positively than their GPs think