



Too Ill to Talk?: User Involvement in Palliative Care

Penny Rhodes, Neil Small

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User involvement has become an important part of health policy initiatives during the last decade, but how realistic is the concept and do all users want to be involved? This book brings the voices of people with serious illness, and those caring for them, into debate about how far health and social care services can reflect the views of users.

Providing an overview of the literature on user involvement, the book looks at the policy and professional context within which user involvement is undertaken, in particular user involvement in palliative care. The authors discuss two key concepts - palliative care and empowerment - and analyse the role of self-help groups and new information and communication technologies in this context. The book focuses on the detailed narratives of people coping with three life-threatening illnesses - cystic fibrosis, multiple sclerosis and motor neurone disease - and in this way the views and experiences of the 'user' are brought into play to critique current policy and practice.

Addressing a current health services issue in a refreshingly critical manner the text challenges the assumption that user involvement is either easy to achieve or that it is necessarily welcomed by all parties. It will be valuable reading for students on health studies courses, health professionals and policy makers in health and social care.



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