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Using a patient held record for home based palliative care patients: A case study research project

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Abstract

A paper based patient held record (PHR) was introduced by the study region's district nursing service and hospice palliative care co-ordinators to promote continuity of care for home based palliative patients. The inquiry has employed a case study research approach to gain greater understanding of the use, challenges and impact of this initiative from those who had or used the PHR. Through the use of semi-structured interviews and focus groups, patients, lay carers, and clinicians from the main groups providing community palliative services were asked about their views and experiences in relation to use of the PHR.

The research suggests a PHR can bring a positive impact for palliative patients and their lay carers, particularly where used for sharing information with the patient and family, and between clinicians and services. When used for this purpose the PHR can assist clinicians to collaborate and co-ordinate care and to promote patient centred and empowering care. However, the findings also reveal that lack of engagement by clinicians with the PHR can lead to frustration and disappointment, particularly for those most connected to and invested in its use, carrying the potential to disrupt both therapeutic and professional relationships.

The study revealed conflicting goals regarding the purpose of the PHR. Most clinician's appeared to focus their use of it on promoting efficiency, primarily in the direction of value for the clinician and service. In contrast, most lay participants viewed their PHR as a tool to assist self-care and improve their chances to experience continuity. The results reveal that some well embedded ideologies, routines and rituals currently operating within the health sector have the power to constrain or restrain partnership and innovation. However, the position of the patient and family in their home appears to offer a degree of counteraction of power and agency which some patients and family had employed to influence and co-construct the use and function of their PHR with their home visiting clinicians.

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List of Abbreviations

CSFGD	Cancer services focus group doctor
CSFGN	Cancer services focus group nurse
CSR	Case study research
DNFG	District nurse focus group
DNS	District nurse service
FG	Focus group
GP	General practitioner
GPFG	General practitioners focus group
HCP	Health care professional
HFGD	Hospice focus group
HFGD	Hospice focus group doctor
HFGNC	Hospice focus group nurse community
HFGNI	Hospice focus group nurse inpatient
NZ	New Zealand
PCC	Palliative care co-ordinator
PHO	Primary health organisation
PHR	Patient held record