

Establishing patient views of diaries: Altering the boundaries of critical care

Diaries were implemented as part of care delivery in the Critical Care Unit at the Royal Gwent Hospital, Aneurin Bevan Health Board 3 years ago: the first known use of patient diaries in Wales. The diaries are facilitated by an established diary team and as a result of their experiences the need for research into diary use was discussed. In partnership between ABHB and the University of Glamorgan we are currently researching patient perceptions of their diaries to enable the patient voice to impact on this innovative addition to service delivery.

The diary is written on behalf of the sedated and ventilated patient in critical care by nurses, other healthcare professionals & relatives. It forms a chronological insight into the patients critical illness. The diary can potentially form a bridge between a patients' sense of incomprehension of their critical illness journey and the reality of what has happened. Some believe is beneficial in reducing psychological problems and facilitates realistic goal setting & recovery and rehabilitation for some patients (Jones *et al*, 2010, Bäckman *et al*, 2010).



The diary team send the patient an invite to collect their diary 4-6 weeks post discharge from hospital. They send the research study information pack at the same time.

METHOD: Longitudinal Grounded Theory study with participants (n=15) being interviewed at 2, 6 & 12 months after discharge from hospital to capture views over time.

2 months

- Aim to capture the patients experience of critical care
- Prior to collecting their diary
- They don't have to collect their diary. It would be useful to explore views of those who do & do not collect their diary

6 months

- Explore the patients experiences
- Their recovery process
- Their psychosocial wellbeing
- Did they collect diary or not? Why? Explore views

12 months

- A year after discharge from hospital how do they feel about their critical illness
- How would they describe their recovery or ongoing problems?
- What do they feel about diary use and their diary if they collected it?

Constant comparative analysis of critical care survivor stories and experiences over a period of a year following discharge from hospital



Patient Empowerment

Critical care nurses need to ensure that control is handed back to the patient as soon as they are able to make their own choices and their health allows. They may require help in order to regain this control with explanation and communication by nurses. This can change the patients perceptions of the critical care environment into one where 'they feel valued as human beings rather than objects'. (Christensen & Hewitt-Taylor 2007)

Patient diaries may take care beyond the usual boundaries of critical care and enable us to listen to patients, learn from their stories and enhance care.

The use of a critical care patient diary is possibly one way of redirecting the focus of care to a holistic approach that encompasses the physical, social & psychological well-being of the patient, beyond the normal nurse-patient interaction during critical illness & the boundaries of the critical care unit.

Conclusion: Anecdotal feedback from those who return to collect their diary is positive. This research aims to capture a variety of patient views & experiences of critical illness to inform future diary development and service delivery.

References: Bäckman C.G., Orwellius L., Sjöberg F., Fredrikson M. & Walther S.M. (2010) Long-term effect of the ICU-diary concept on quality of life after critical illness. *Acta Anaesthesiologica Scandinavica*. 54:736-743. Christensen, M. and Hewitt-Taylor, J., (2007) Patient empowerment: Does it still occur in the ICU? *Intensive and Critical Care Nursing*, 23 (3), pp. 156-161
Jones C., Bäckman C., Capuzzo M., Egerod I., Flaatten H., Granja C., Rylander C. & Griffiths R.D. (2010) Intensive care diaries reduce new onset post traumatic stress disorder following critical illness: a randomized, controlled trial. *Critical Care*.14(5):1-10 at <http://ccforum.com/content/14/5/R168> Accessed 10/06/11