COULD THERAPEUTIC DIARIES SUPPORT RECOVERY IN PSYCHIATRIC INTENSIVE CARE?

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Conflict of Interest: None.

Abstract

Despite growing literature surrounding the use of patient diaries in intensive care units within the general healthcare setting and the positive effects these may have on a patient's psychological recovery from such an admission; no studies exist examining the effects of similar patient diaries in psychiatric intensive care units when used with people experiencing an acute exacerbation of psychosis. This paper hypothesises the potential positive effects of diaries kept for patients in psychiatric intensive care units. In the development of strategies to help people in psychiatric crisis understand and manage their own distress and psychological trauma, diaries may be helpful for the prevention of further psychological problems and aid recovery post discharge. Research is required to consider the possible effects of therapeutic diaries and the role of the multidisciplinary team in keeping these within psychiatric intensive care settings.

INTRODUCTION

It is internationally recognised that interdisciplinary education and sharing of innovation between specialities, modalities and sectors will shape the future of truly holistic healthcare delivery and drive forward the integrated care agenda (Naylor *et al* 2016, World Health Organisation [WHO] 2010). This paper will discuss one example of an opportunity to break down the silo approach that persists between physical and mental health disciplines when addressing a person's, often multifactorial, healthcare needs. It is proposed that the significant and long-term psychological harm reducing benefits achieved through the use of therapeutic diary keeping with patients in general hospital Intensive Care Units (ICUs), could

be replicable and warrants analysis in those experiencing acute psychosis cared for in psychiatric intensive care units.

A significant proportion of survivors from critical illness treated in the ICU within general healthcare settings frequently suffer from anxiety, depression and post-traumatic stress disorder (PTSD) (Egerod and Christensen 2010, Wake & Kitchiner 2013). Survivors often report amnesia, flashbacks, hallucinations and recurring nightmares post discharge (Roulin *et al.* 2007) and this group are far less likely to return to their premorbid functionality in day to day living (Jones *et al.* 2012). Jones *et al.* (2001) found that delusional memories and large memory voids were a significant factor in the subsequent psychological distress experienced by ICU survivors. The largest multi-centre (26 UK ICUs) study of its kind (n=13,155) examining post critical illness Health Related Quality of Life and psychopathology concluded that over half of the *n*=4943 respondents to a postal questionnaire reported significant symptoms of anxiety (46%), depression (40%) and PTSD (22%) (Hatch *et al* 2018).

In patients admitted to PICU with an acute psychotic episode, comparisons can be made to those surviving a general ICU admission. Whilst PICUs are associated with a reduction in challenging behaviour and incidents of violence and aggression in the short-term – containment, restrictions in movement, sensory deprivation and the organic effects of acute psychosis, can, in the long-term significantly increase a person's traumatic memories of their care and affect their functioning in society post discharge (Vaaler *et al* 2009). A growing body of work in the reduction of restrictive practices is making head way in the reduction of these harmful phenomena (Department of Health 2014.. Clark *et al* 2017) and this has now become evident in the general hospital setting (Hext *et al* 2018, Xrichis *et al* 2018)' To support this agenda, this article considers potential translational benefits of keeping patient

diaries in PICU and argues that teams within the PICU settings could add them to their armoury of therapeutic interventions to enhance management and recovery from an acute psychotic episode.

BACKGROUND

An estimated 30% of general hospital ICU patients are reported to experience anomalous psychological phenomena during intensive care (Ringdal *et al.* 2006, Samuelson *et al.*, 2006). Such phenomena may include dreams, nightmares, delusional memories and even hallucinations which may be more vivid and more readily recalled that factual experiences of intensive care. These experiences can have a profound and long-lasting effect on an individual, potentially impacting the trajectory of their post-discharge recovery (Jones *et al.* 2001, Kiekkas *et al.* 2010). A recognised diagnosis, post intensive care syndrome (PICS) is defined as a long-term physical (neuromuscular), cognitive or mental health impairment as a result of surviving an ICU admission (Rawal *et al* 2017). The effects of PICS also go on to have an effect on the family unit and it's functioning as a whole (Davidson *et al* 2012, Rawal *et al* 2017). If patients only have delusional memories of time spent in ICU, and no factual memories they are considered to be at an increased risk of developing PTSD (Jones *et al.* 2001, Jones *et al.* 2004, Jones *et al.* 2012). Likewise, this delusional state is argued to result in difficulty for patients recognising what they have undergone and how unwell they have been, this may then lead to unrealistic expectations regarding the recovery process (Griffiths and Jones 2001, Roulin *et al* 2007).

Patient diaries were first introduced in 1991 in Swedish ICUs (Akerman *et al.* 2010), to support the patient's recall the ICU stay, which was seen to contribute to better rehabilitation

and recovery, provide a better understanding of what happened, fill in memory gaps and process events and delusional memories (Akerman *et al.* 2010). In a non-randomised controlled study Jones *et al.* (2006) found that ICU diaries might significantly reduce PTSD symptoms in survivors of ICU and continued to make similar postulations in a later study (Jones *et al.* 2009), however, when viewed critically design errors in this study weakened these assumptions due to only a few former ICU patients (n=4) attending the focus group and little was reported regarding the actual content of the diaries. Former patients did however report that the diary alone provided incomplete information. Nonetheless, there is wealth of qualitative evidence that makes a compelling argument for diary use; patients report many of the aforementioned benefits, helping them to piece together fragmented memories and starting conversations with family members in making sense of their shared traumatic experiences (Backman *et al* 2010, Garrouste-Orgeas *et al* 2012).

Diaries are now commonly used in general hospital ICUs across Europe and are increasingly being introduced in ICUs around the UK. The diaries are prospectively written by ICU nurses, other members of the MDT, next of kin and relatives (in the 2nd person). Diaries commence with information pertaining to the reason for admission and the initial support given; subsequent daily entries written by healthcare professionals, in lay terms, detail significant events, changes in condition, routine care that appeared to cause distress or positive landmarks. Families are also encouraged to write in the diaries during the patient's stay, which has subsequently been found to have a significant effect on their own experiences of PTSD and anxiety (Jones et al. 2012).

The Psychological Impact of Psychiatric Intensive Care

Significant psychiatric disorders can impact on the psychological, social and vocational functioning of an individual with recurrent episodes sometimes requiring hospital-based treatment in a PICU (Clark & Cangy, 2016. Clark *et al* 2017). PICUs provide the most intense level of psychiatric care and treatment (Bowers *et al.* 2008. Bowers, 2014. Clark & Cangy. 2016) for patients displaying the highest degree of risk and who are in need of support through containment (Bowers. 2014). These units help reduce symptoms and manage behaviours that may put the patient or others at risk (Pereira *et al* 2005). They are generally small units, usually up to 12 bedded, with higher nurse/staff: patient ratios, usually locked and low-secure in status and often with seclusion facilities (Bowers *et al.* 2008, Clark & Cangy. 2016).

Psychosis is the most common cause of admission to a PICU (Pereira et al. 2005, Clark & Cangy. 2016), diagnostic sub-categories include schizophrenia and delusional disorders, schizoaffective disorder and transient psychotic episodes – often the result of acute intoxication due to street drugs (Pereira *et al*. 2005. Clark & Cangy, 2016. Clark *et al* 2017). PICU patients are significantly younger than other hospital populations (Brown and Bass 2004), but may range from aged 18 to quite elderly, a survey of London PICU's (n=17) showed a mean age of 33 years (Pereira *et al* 2005). The most prevalent reason for transfer to PICU is to contain aggression (Pereira *et al.* 2005. Clark *et al* 2017), thereby, patients are potentially considered more likely to be violent (Bowers *et al.* 2008, Clark & Cangy. 2016). Many PICU patients have comorbidities in addition to their primary psychiatric diagnosis,

including misuse of street drugs, aggressive and/or challenging behaviour, social isolation, homelessness, physical health problems and trauma (Pereira *et al*. 2005, Clark & Clarke 2014). Such comorbidities can affect length of stay and the recovery process whilst in a PICU.

Arguably, in both ICU and PICU patients are exposed to similar psychosis inducing stressors such as noise, light, unnatural environments, disruption to circadian rhythms and physical or even chemical restraint (Clark & Cangy, 2016. Clark *et al* 2017, Hext *et al* 2018. Xyrichis *et al* 2018). Therefore, it is plausible that following discharge from PICU service users may encounter issues similar to those who have had been discharged from a general hospital ICU. That is, whilst ICU and PICU environments have many differences in terms of purpose and function, there remain some fundamental similarities in terms of their approach and psychological impact on the individual (See Table 1 & Table 2).

Table 1: Comparable features of care in an ICU or PICU.

ICU	**PICU**
• Includes multiple intensive and invasive physical interventions and polypharmacy • Often, protracted hospital stays followed by intense rehabilitation • Surrounded by technologies, devices and multiple teams 24/7 to manage life supportive measures,	• Includes intense therapeutic intervention to manage symptoms • Period of stay will vary according to risk of violence & response to treatment but often lengthened by limited stepdown capacity • Enforced containment • Compulsory treatment under the

treated in best interests. • Restricted mobilisation, possible chemical and/or physical restraint in the acute phases of critical illness. • Patients suffering from physical life threatening illnesses, overwhelming sepsis or pre and postoperative care which can contribute to incidence of delirium and psychological distress	Mental Health Act (1983, amended 2007). • Possible restraint and/or seclusion, freedom restricted by virtue of being in a locked unit • Patients suffering from psychiatric illness often confounded by complex psychological and physical health problems.

Table 2: Shared features of ICU and PICU

Shared Features
Unable to freely engage or communicate with friends and family
Being in an unfamiliar/unnatural environment
Treatment given without consent or in best interests
Increased staff: patient ratios
Witness or subject to multiple traumatic stimuli
Often isolated units from other parts of hospital
Limited autonomy of patients in restrictive environments
Traumatic memories post discharge
Increased need for psychological intervention/support
Predisposition to PTSD post discharge
Difficulties interpreting experiences of care
Subsequent familial stress and anxiety

Patient participation in decision making process sometimes significantly reduced

PICU patients often have difficulty recalling the severity of their psychiatric crisis and journey to recovery, resultantly these memory gaps can manifest other psychological symptoms that lengthen or increase recurrence of PICU stays – further exacerbating psychological distress in these individuals (Clark & Cangy, 2014. Clark *et al* 2017). It is posited that PICU patients are more likely to suffer from the effects of their admission, especially regarding experiences of physical restraint and/or seclusion (Clark *et* al 2017). Undetected PTSD may place a person with a diagnosis of psychosis at higher risk of an acute psychiatric crisis and recurrent stays in PICU. Identifying prevalence, treating or preventing PTSD is important because psychological trauma and PTSD are associated with increased risk and severity of other medical conditions, both chronic and acute illnesses (Ford and Fournier 2007).

Diaries and their effects on patients and families

The body of literature supporting the use of patient diaries in general hospital ICU is growing more compelling and has led to significant uptake in the UK. There are well documented therapeutic benefits that appear to help ICU survivors' bridge memory gaps and make sense of confounding delusional memories and flashbacks (Gjengedal 2010, Jones 2009). Despite this, there would appear to be minimal evidence that systematically assesses the potential for using diaries in PICUs to aid meaningful recovery.

The ICU patient diary is typically kept at the patient's bedside with photographs securely stored elsewhere. It is, in effect, a daily record of the patient's ICU stay, significant events in the outside world (e.g. favourite football team wins/loses etc.) written in lay language by nurses, members of the multidisciplinary team or nominated relatives (Jones *et al.* 2012). Following ICU discharge, normally 3 months to a year later patients are offered the opportunity to read and keep the diary. Diaries are non-medicolegal documents that at all times is the property of the patient. If a patient declines to receive the diary it is stored for finite period of time before being destroyed (Jones 2009).

ICU survivors commonly report difficulties discussing their feelings, fears, hallucinations and vivid dreams with others, a phenomenon confounded by lack of insight in to own experiences and fear of being labelled as mentally ill (Engstrom *et al.* 2008). Survivors have further expressed the need to know and understand the events that took place in the ICU (Adamson *et al.* 2004, Hupcey and Zimmerman 2000, Richman 2000). ICU diaries can to afford survivors the opportunity to make sense of fragmented memories and promote open dialogue with those around them, allowing survivors to express what they have and continue to experience (Roulin *et al.* 2007). Diaries, can in this sense be used as a rehabilitation/recovery tool, and are increasingly becoming integral to the care provided to patients in ICUs across the UK and Europe at large (Combe 2005) and there is a growing body of literature supporting this movement (Egerod *et al.* 2006, Engstrom *et al.* 2009, Egerod and Christensen 2009, Knowles *et al* 2008, Löf *et al* 2008, Jones *et al.* 2009).

Studies show that amnesia and/or memory fragmentation developed as a result of critical illness and intensive care can lead to long term/chronic health problems (Jones *et al.* 2001, Scragg *et al.* 2001, Skirrow *et al.* 2002, Vaare *et al* 2009). In this instance diaries may aid

prevention, promote recovery and go some way to reduce incidence and severity of PTSD (Egerod *et al*. 2006; Jones *et al.* 2006). The use of diaries is a simple, cost effective and practical method for the reduction of psychological symptoms and the associated morbidities amongst patients and families having experienced intensive care (Roulin *et al.* 2007).

The Role of the Mental Health Team in the use of Patient Diaries

PICU's continue to have an important role in the care of patients with acute psychiatric disorders and often concurrent complex physical health issues (Clark & Cangy, 2016. Clark *et al.* 2017). High quality assessment from a bio-psycho-pharmaco-social perspective (Clark & Clarke, 2014), treatment and proactive care depends on a competent workforce engaging in continuous professional development (Clark & Cangy. 2016). Research demonstrates that targeted therapeutic activity promotes patient engagement and reduces agitation. Patient-nurse communication and cooperation is invaluable in promoting support, respect, empowerment and recovery (Bowers 2014, Clark *et al* 2017). Unlike the ICU patient, the PICU patient may be able to contribute to their own diary writing at certain times, potentiating wider, yet unknown, therapeutic effects. The writing of a diary may also be incorporated as part of a behavioural support plan, such plans are now a recommendation in the United Kingdom for patients who exhibit challenging behaviour (Department of Health 2014). Clearly the physical and psychological safety of the entire PICU population is central to the nurses role (Björkdahl *et al.* 2010), nonetheless, nurses have great potential and positioning to promote therapeutic culture within the PICU (Bowers 2014, Clark & Cangy 2016, Clark *et al*, 2017). The introduction of diaries may be significant in promoting dialogue between the medical professional, nurse, patient and their families, enabling

opportunities to express experiences and perceptions. Diaries could help to ameliorate the potential negative impacts a PICU admission may present and form a significant step in more personalised behavioural support planning.

As in ICU, PICU diaries could be a cost-effective, non-invasive intervention that may foster hope and recovery and have the potential to promote insight into the patient experience. Staff can be easily trained in the use of diaries which could encourage focused professional/ patient engagement and ultimately reduce conflict and containment. Diaries may provide PICU survivors some meaning and understanding to their PICU experience.

Care in a PICU should aim to ensure freedom from fear as well as from dehumanising and disempowering experiences (Delaney and Johnson. 2007, 2008). Empowering interventions such as discussion, showing interest and encouragement in the patient are important interventions toward promoting person centred recovery (Pitkenen *et al*. 2008), diaries could be a useful tool in this approach. Mental health nurses are essential to the provision of 24 hour intensive care and have the opportunity to facilitate positive experiences for patients during PICU admissions and post discharge. If keeping patient diaries for patients with acute psychiatric presentations became routine in PICUs, there may be a reduction in patient distress, restrictive practices, agitation and challenging behaviour during the PICU stay and further psychological problems following discharge. Of course, further research is needed in this area.

CONCLUSION

Studies report the use of ICU diaries in several European and Nordic Countries including the UK, Sweden, Denmark and Norway. There are many shared commonalities between ICU

and PICU admissions which this paper has highlighted, and yet diaries are not common in PICU practice. The possible impact of PICU diary use should be evaluated as PICU patients may experience similar psychological effects to their ICU counterparts, so it is likely that diaries could contribute towards behavioural support planning, reduce incidents of aggression and violence and be valuable tool towards recovery.

The often unpredictable nature of the PICU environment has the potential to negatively impact on nursing care, and therefore any intervention that promotes patient engagement has the potential to provide a positive impact. This paper aimed to show the positive role of diaries for PICU patients and the intention of the authors to conduct a pilot study focusing this approach in a number of PICUs in order to determine impact and effectiveness over time.

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