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Abstract

Background: The delivery of person centred care is a key priority for managers, policy makers and clinicians in healthcare. The delivery of person centred care in critical care is challenging due to competing demands.

Aim: The aim of this quality improvement project was to understand what mattered to patients on a daily basis within the critical care environment. It aimed to understand personal goals and what patients needed to improve their experience. This paper reports on the outputs from this quality improvement project.

Evaluation Design: During each daily ward round, patients were asked '*what matters to you today?*' Outputs from this were entered into the Daily Goals Sheet which is utilized for every patient in our critical care unit, or in the Nursing notes.

Data Analysis: Using Framework Analysis, prevalent themes were extracted from patient statements documented.

Findings: 196 unique patients were included in this analysis alongside 592 patient statements. Four broad themes were generated: medical outcomes and information; the critical care environment; personal care and family and caregivers.

Conclusion: The analysis of the data from this quality improvement project has demonstrated that by asking a simple question within the context of a ward round; care can be enhanced and personalized and long-term outcomes potentially improved. More research is required to understand what the optimal methods of implementing these requests are.

Recommendations for Clinical Practice: Two main recommendations from practice emerged from this quality improvement project: asking patients '*what matters to you?*' on a daily basis may help support the humanization of the critical care environment. Visiting and access by families must be discussed with patients to ensure this is appropriate for their needs.

Introduction

The delivery of safe, effective and person centred care is a key priority area for managers, policy makers, individual clinicians and patients (Scottish Government 2010, Department of Health 2001). Person centred care is often the most challenging of these goals to deliver. Delivering a healthcare service which is consistent and reliable for every patient on every occasion, is often in conflict with a service which provides individualised care. There are also challenges around how person centeredness and its perceived outcomes can be measured reliably in the clinical environment (Olsson et al 2012).

Patients admitted to the Intensive Care Unit (ICU) are the sickest individuals in the hospital (Niven et al 2015). They are often physiologically unstable and require complex, invasive treatment to manage their care. As such, balancing the delivery of person centred care with the management of intricate and demanding physiology can be challenging for the Multi-Disciplinary Team (MDT) (Jakimowicz and Perry 2015).

With more patients surviving a critical illness, and increasing evidence demonstrating how traumatic the experience can be for both patients and caregivers, there is now a focus on providing person centred care within this environment (McPeake et al 2016a, Zimmerman et al 2013, Wade et al 2012). Over the last decade, there has been a stream of work which has aimed to humanize the ICU environment (Heras La Calle, 2015). Several strategies have been proposed to help achieve this, both pharmacological and non-pharmacological in nature. Most strategies, however, have the same focus: understanding the critically ill patient as an individual and providing comprehensive medical, psychological, and rehabilitation care for both patients and their caregivers (Hosey et al 2018). Interventions to achieve these aims include the implementation of the ABCDEF bundle (Ely 2017). This approach to care has demonstrated that reduced sedation and early mobility, alongside deliberate family centred care can improve outcomes (Pun et al 2018). More recently, Animal Assisted Interventions to reduce anxiety in the ICU have also been proposed (Hosey et al 2018).

The '*What Matters to You?*' movement in healthcare has drawn considerable international attention as a method of understanding what a person values most (Kebede 2016). This

simple question aims to get to the essence of person centred care in a simple way, which helps clinicians appreciate patients' interests, values and preferences (Kebede 2016). Using this simple question as a prompt to engage with patients has been proposed as a vehicle to deliver person centred care across different healthcare systems (Barry and Edgman-Levitan 2012).

At present there is a lack of understanding about how daily, personal wishes and goals could be utilised to deliver improved care within the critical care environment. The purpose of the quality improvement project was to understand what mattered to patients in the critical care environment, with the aim of delivering small scale interventions, which could potentially improve patient experience and care.

Aims

The aim of this quality improvement project was to understand what mattered to patients on a daily basis within the critical care environment. It aimed to understand personal goals and what patients needed to improve their experience. This paper reports on the outputs from this quality improvement project.

Rationale

This quality improvement project reports on what mattered to patients in the critical care environment. The rationale for this evaluation was to understand, from a patient's perspective, what could be done to improve the patient experience. This data would help inform the development of person-centred care practices within the critical care environment. This quality improvement project was part of a national programme of work from the Scottish Government.

Design and Methods

Setting

This quality improvement project took place in one large inner-city teaching hospital in Scotland. This hospital is a tertiary referral hospital for burns, pancreatic care and oesophageal surgery. The critical care unit has 20 mixed medical and surgical beds and admits both elective and emergency patients.

Data Collection

In the UK there are two different patient populations nursed within the critical care environment; Level-Two and Level-Three patients. The term Level-Three refers to the UK Intensive Care Society definition of ICU patients. Level-Three patients require multiple organ support or invasive respiratory support only. Level-Two patients are those patients requiring more detailed observation or interventions, including support from a single failing organ system, or post-operative care and those stepping down from higher levels of care (Intensive Care Society 2009).

This is an evaluation of data collected through a quality improvement project. As part of this quality improvement process, we initially started this project with Level-Two patients in the critical care unit. Thus, this paper presents data from these patients only. Of note, those patients who were Level-Three patients and were 'stepped down' to Level-Two care, are also included in this analysis.

During each daily ward round Level-Two patients were asked '*what matters to you today?*'. Any member of the multi-disciplinary team (MDT) could ask this. Additionally, if for any reason this was not completed during the ward round, it could be completed at another time during that day. Outputs from this were entered into the Daily Goals Sheet which is utilized for every patient, or in the Nursing notes. The responses from patients were often short statements around actions which could be taken or personal goals that they had for the day. For clarity, the data which was analyzed and presented in this paper will be referred to as patient statements.

In response to some patient statements, staff undertook activities to try and support patients and caregivers. If this was documented in the notes, this data was also extracted and reported for the purpose of this evaluation.

Recruitment and Participation

All Level-Two patients were asked '*What matters to you today?*' on a daily basis. The only exclusion criteria was if the patient was unable to communicate, for example, a low Glasgow Coma Scale (GCS) score. If this was the case, person-centred communication tools were

completed by family members. Patients were able to decline if they did not want to share this information, or if they did not want to participate in this activity.

Data Analysis

The Framework Method was utilized for the thematic analysis of patient statements. This method of analysis was developed for use in large-scale policy research (Gale et al 2013). The defining feature of Framework Analysis is the creation and assessment of the matrix output, which provides a supporting structure into which researchers can systematically reduce the data for analysis (Ritchie and Lewis 2003). Due to the large volumes of individual patient statements analyzed, which were often short in scope and nature, and the inability to thematically analyze large sections of text as is traditionally undertaken in qualitative research, this was deemed the most appropriate and effective method for data analysis. There are seven key stages with the Framework Method. These are: 1) Transcription of data; 2) Familiarisation with data; 3) Coding (Labelling important and relevant interpretations of data); 4) Developing an analytical framework; 5) Applying the analytical framework; 6) Charting data into the framework matrix and 7) Interpreting the data.

All patient statements were summarized by two critical care nurses involved in the project (JMcP and LJ). These were listed and entered into an excel spreadsheet. JMcP and LJ then separately analyzed the content and themes of the statements. Thereafter, we sought to deconstruct the statements into individual themes. During this process an audit trail was created, and peer review undertaken by two clinicians (TQ and CC). This peer review analysed the initial coding (Stage Three), the analytical framework created and utilised (Stage Four and Five) as well as the charting of data into the framework (Stage Six and Seven).

Demographic data collected for each patient included: Gender, Age, Admitting diagnosis and the Acute Physiology and Chronic Health Evaluation Score II (APACHE II) (Knaus et al 1985). This demographic data was collected prospectively via the electronic patient record systems utilized in the critical care unit.

Ethical Considerations/Summary of permissions

After discussion with the Chair of the local ethics committee, it was agreed that this work did not fulfil the criteria for clinical research. It was deemed a quality improvement initiative. All data presented in this paper, outwith the daily patient statements, was part of routine clinical data collection; as such ethical approval was not needed for the analysis of this data either. All data presented is anonymous.

Findings

Patient Characteristics

Data was collected between April 2018 and September 2018. 279 Level-Two patients were admitted during this time period; a total of 196 (70% of all patients admitted) unique patients were included in this analysis.

84 patients were male, the median age was 62 (Interquartile range (IQR) 49-72) and the median Length of Stay (LOS) was 4 days (IQR 3-6). The demographics of the patients included in this analysis are shown in **Table One**.

Statement analysis

There were 592 patient statements included in this analysis. Four broad themes were generated (**Table Two**):

1. Medical Outcomes and Information
2. The Critical Care Environment
3. Personal Care
4. Family and Caregivers.

Sub themes were also categorized within these four overarching areas (**Table Two**).

Medical Outcomes and Information

A theme which emerged from the analysis was the need for patients to understand, from a medical perspective, what was happening to them within the critical care environment. This ranged from a basic understanding of what the plan was for the upcoming day, to understanding anxieties and changes related to their care. For example, one patient asked

to have a referral made in order to understand what was happening with their voice as a result of their newly formed tracheostomy:

'To see the SALT (Speech and Language Therapy) team as worried about speaking valve.'

A critical care admission often gave patients time to reflect on drivers for admission to critical care, especially those related to lifestyle factors. Several patients reflected on issues related to addictions and asked for support and input to improve their health:

'Wants to be referred to addictions team to start Methadone programme (Done).'

A prominent theme for patients within this study was pain management. Many patients described that adequate pain management was the most important thing to them. Patients also discussed the need for adequate pain control to support other functioning such as mobilization and sleep.

'Pain under control.'

The Critical Care Environment

The need to humanize the critical care environment was referred to frequently by patients. Many wanted simple interventions, devices and low cost strategies to do this. For example, one gentleman wanted to listen to the football radio show which he normally listened to each evening at home:

'Like to listen to football focus at night time'.

Participants described the noise of the critical care environment and the impact that this had on sleep and rest. Again, low cost and easy to implement equipment was requested to help patients overnight:

'Requesting eye mask and ear plugs which have been given.'

Spiritual care and the need for company and interaction emerged as themes from this analysis. Patients requested support from their own community, as well support available within the hospital setting:

****** asked for visit by chaplain today.'*

Personal Care

Aligning with the theme of improving the critical care environment, patients discussed how they wished for specific personal care. For one patient this was related to the food which they wanted to eat:

'Wishes to eat food that her family will bring up.'

Other simple measures related to personal care were also seen as important to patients- this included:

'Would like a shower and her hair washed.'

Family and Caregivers

The importance of contact with family members and loved ones was highlighted through this analysis. Patients articulated the importance of having loved ones present as they needed:

'She would like to see her partner as he makes her feel safe: achieved.'

Similarly another patient discussed how she missed her children and wanted a visit from them.

'Tearful today as missing children – Nurse in charge will facilitate a visit.'

Discussion

The aim of this quality improvement project was to explore what mattered to patients on a daily basis within the critical care environment. It aimed to understand personal goals and what patients needed to improve their experience. This single centre project has provided unique insights into how staff in critical care can implement small scale change which could potentially improve both patient and caregiver experience. It has demonstrated that by asking a simple question as part of the everyday workload, patients have the opportunity to have questions answered and care provided, which may facilitate improvement in long term outcomes.

Consistent with previous research, the importance of having family members and loved ones present in the critical care environment emerged as a key theme from this analysis (Schnell et al 2013 and Davidson et al 2007). This work would suggest that open visiting times are important to ensure patients feel safe and secure. Concerns are often voiced about this type of policy and can include issues such as interference with workflow, and the adverse impact that this approach may have on staff (Levy 2013). There is little evidence to suggest that this is the case. Indeed, evidence suggests improved outcomes related to delirium with extended critical care visitation models (Rosa et al 2017). However we must recognize the added challenge, especially to bedside nurses, that open visiting hours may bring. Simple recognition of this may help, as well as adequate support from the entire MDT, as well as from healthcare managers (Levy 2013). Further work with caregivers to understand their needs and expectations, and indeed their feelings about this approach more widely, is needed.

When asked '*what matters to you?*' some patients had the opportunity to reflect on drivers for their critical care admission. As a result, a number of patients wanted support with smoking cessation and other addiction issues such as drugs. Previous research, which has explored issues such as alcohol dependence and its impact on the critical care environment (and vice versa), has demonstrated that the critical care environment and/or the critical care stay may present a '*teachable moment*' for some patients (McPeake et al 2016b, Clark et al 2011). It is well documented that those with addiction issues such as alcohol dependence have poorer short and long term outcomes from critical care, compared to those patients who do not (McPeake et al 2015, Gacouin et al 2014). Therefore, clinicians

must ensure that adequate support for addictions is available for patients who request it. More research is required around the potential impact of addiction management in critical care.

Pain management was an important issue for many patients. This may be due to the high number of post-operative patients who were included in this analysis. However, recent data has shown that there is a high prevalence of pain problems in survivors of critical illness (Battle et al 2013, Hayhurst et al 2018), which can have a profound impact on daily activities and long term quality of life (Devine et al 2019). Clinicians in critical care must ensure that all is done within and during the critical care stay to manage pain. This may include the administration of adequate and appropriate analgesia and early mobilization (Devlin et al 2018).

It should be noted that there are challenges with using this approach. For example, when working with patients with communication needs or where English was not the first language, alterations to the tool were required. This was done through interpreters and when possible, electronic devices. This was sometimes time consuming and complex to arrange. However, as this programme of work becomes fully established, these issues should become easier to manage. Further work around these issues and the impact that this approach has on staff is required.

Strengths of this evaluation are that it has described simple interventions which could be provided in most critical care units to help improve patient experience. It has utilised a systematic and structured approach to analysis which has provided detailed information about what matters to patients with a wide range of illnesses. However, it is limited in its focus, in that it provided information from a single centre. Furthermore, it has provided information from patients which met tight inclusion criteria and may not be representative of all critically ill patients. Although broad learning can be cultivated from this project, it is key that those caring for patients think carefully about the individual context for improvement and the staff delivering these interventions. Finally, analysis was undertaken with the summaries transcribed in patient's notes, rather from interviews and direct quotes

from patients. This may introduce bias and limit understanding around the patient experience. Future research must address these methodological limitations.

Conclusion

In conclusion, this quality improvement project has demonstrated that by asking a simple question within the context of a ward round within critical care; care can potentially be improved and long term outcomes enhanced. More research is required to understand what the optimal methods of implementing some of these requests are. More work is also required around what the appropriate, person centered metrics are for this group, to understand if this process can indeed improve outcomes.

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What is known about this topic?

- The delivery of person centred care can be challenging in the critical care environment.
- Clinicians are motivated to deliver more personalised care and humanise the environment, however strategies to do this are lacking.

What this paper adds?

- Introducing a simple question- 'What matter to you?'- during the delivery care is feasible.
- Patients requested both medical and non-medical solutions to enhance their experience.
- The support of family members through open visitation policies and complete information provision was important to patients.

- More research is needed to understand the short and long term impact of delivering this intervention.

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