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Patient Diaries: Survey of Paediatric Intensive Care Units in UK & Ireland

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ABSTRACT

Aim

To explore the incidence, use and scope of patient diaries in Paediatric Intensive Care Units (PICU) in the United Kingdom (UK) and Ireland.

Design

An electronic survey sent to 30 PICUs in the UK and Ireland.

Results

All PICUs (n=30) responded and 43% (n=13) offered diaries. For those units not supplying diaries, the reasons given were concerns around the legal and professional implication of using diaries. Parental/Carer consent to use a diary was gained informally (79%, n=11) and once there was agreement to provide a diary to parents, diaries were usually started immediately (72%, n=12). Parents were the main contributors to the diaries (94%, n=17) and the diaries were populated with photographs (94%, n=15), drawings (100%, n=16) and stickers (94%, n=15). The reasons for offering diaries was to fill gaps in memories, to engage with families and explain what has happened in lay language. The owner of the diary was reported as being the family (82%, n=14) and the child (12%, n=2).

Conclusions

The use of patient diaries is an evolving intervention in paediatric intensive care settings in the UK and Ireland. This national survey has provided a clearer picture of how this intervention is used in the UK and Ireland. PICU patient diaries are used in a significant number of units and how these are used is relatively standardised, although in some different ways from general ICUs.

Relevance to clinical practice

This survey provides a baseline for future exploration, understanding and promotion of patient diaries as a well evaluated tool for the critically ill child and their families.

Keywords:

Children; Diary; Paediatric Intensive Care; Parents; Social Support; Survey Methods

BACKGROUND

Annually, around 20,000 children aged between 0 and 15 years received care in a Paediatric Intensive Care Unit (PICU) in the United Kingdom (UK) and Ireland (PICANet 2018). The incidence of admission has remained steady at around 141 admissions per 100,000 population in the UK (PICANet 2018). Therefore, there are a small but not insignificant, number of children and their families who are exposed to the PICU environment.

Research with children has focused on the impact of hospital admission (Platt 1959, DH 2003). By comparison, the long-term emotional impact of critical illness has been less explored (Renick et al 2004, Colville 2008, Manning et al 2017). A small number of studies, adopting a quantitative approach, provide evidence that the critically ill child and their family can suffer significant and lasting psychological sequelae post PICU admission (Rees et al 2004, Bronner et al 2008, Colville et al 2008). These studies demonstrate that a significant number of critically ill children and their parents may develop Post Traumatic Stress Disorder (PTSD) and that increased parental distress, length of PICU stay, delusional memories and emergency admission are possible predictors of the development of PTSD in children. The impact of PTSD in the child can have lasting deleterious effects: physically, emotionally and socially (Bronner 2008). Studies concluded that the prevalence and incidence of PTSD in the PICU population (Bronner et al 2008, Colville et al 2008) was a concern, however these studies did not explore or consider what interventions could support coping or reducing the risk of PTSD.

A qualitative study using a responsive interview technique and art based, visual approach was used by Manning et al (2017) to explore long-term psychosocial well-being. Nine children were interviewed to discuss their experience of surviving critical illness through

their stories. This study concluded that the children identified many challenges and adversities when attempting to readjust to life following critical illness that both enhanced and impaired their psychosocial well-being.

A conceptual framework to better understand the experience of the child and their family during and post PICU has been developed (Manning et al 2018). The Post Intensive Care Syndrome in Children (PICS-p) framework provides understanding into the phenomena of surviving childhood critical illness. Utilisation of the PICS-p framework will also provide researchers with a guide to measurement future outcomes for interventions.

Although there remains a dearth of literature pertaining to the psychological impact of critical illness on the child, the literature and evidence available does support the negative consequence that this can have on the child's wellbeing.

Interventions to minimise the psychological impact of critical illness

Two studies have focused on the intervention of follow-up post PICU. Bronner et al (2008) and Colville et al (2010) both explored the impact of follow-up of parents post PICU. Bronner et al's (2008) prospective cohort study explored the prevalence of PTSD after an acute admission to a PICU and aimed to determine the risk factors in developing PTSD in parents. Post discharge, 250 eligible patients and family members were invited to attend a follow-up appointment. Of them, 144 (57.6%) parents attended a visit to the follow-up clinic at three months post discharge. This study concluded that an unexpected PICU admission is a stressful event for parents, that psychological support should not end at discharge and importantly that follow-up is warranted.

The randomised control trial of Colville et al (2010) aimed to evaluate the psychological impact on parents of the provision of a PICU follow-up clinic. Families post-PICU (n=77) were randomised to the intervention of invitation to a follow-up appointment with a PICU intensivist, PICU nurse and psychologist at two months after discharge versus the control of no appointment. The study concluded that due to low attendance to the follow-up appointment (25%) it was difficult to justify routine follow-up but suggested that for most traumatised parents, long term distress could be reduced by this intervention.

It is clear from the limited evidence available that the admission of the child into PICU can have significant impact on the psychological recovery of the child and their family. There are no studies looking at what or how interventions can be used to meet the psychological needs of the child post PICU and ways to best identify those at risk or effected and then help this population remains elusive. However, studies exploring the use of patient diaries in Adult Intensive Care Units (AICU) may offer an intervention to meet these unmet needs.

Patient diaries in the critical care setting

Literature emerging from Adult Intensive Care Units (AICU) have explored interventions that may improve the psychological impact of critical illness for both the patient and their relatives. The use of patient diaries is one such intervention, used either exclusively or in combination with follow-up appointments. In the literature related to this intervention, patient diaries used in the adult intensive care environment have been shown to be a low cost, low technological intervention that is valued by patients and their families (Bergbom et al 1999, Backman & Waithler 2001, Johansson et al 2015), which may reduce the incidence of PTSD

(Jones et al 2008), reduce anxiety and depression (Knowles & Tanner 2009, Tomohide 2015) and increase perceptions of quality of life (Backman 2010).

Only a few studies explored the use and impact of diaries in the PICU population. Mikkelsen (2018) explored children's and family's experiences of using dairies after discharge and the role these diaries had in the process of recovery from critical illness. This qualitative study collected data from five children and their families up to six months after discharge from the PICU. The researchers concluded that diaries played a role in making the paediatric intensive care experience meaningful by providing explanations. The diary can also serve as a catalyst for the coping process by "filling in the missing gaps" to support the child's understanding of this experience (Mikkelsen 2018). Herrup et al (2019) undertook a pilot study to determine the feasibility of implementing and the perceptions held by the family members who received the diaries. They surveyed twenty families of children admitted into a PICU in the United States of America and concluded that the use of diaries is feasible and is perceived as beneficial by families. These studies have offered some insights but have only partially contributed to a wider understanding of how diaries are used in PICU.

The use of patient diaries is evolving in paediatric intensive care settings but a clear picture of how this intervention is used is not fully understood in the PICU settings. Therefore, the aim of this survey was to explore the incidence, the use and scope of patient diaries in PICUs in the UK and Ireland.

METHODS

Settings

In the UK & Ireland there are 30-Government funded PICUs. The type of PICUs varied with some providing general intensive care, some designated cardiac intensive care and some that were combined. All 30 PICUs in the UK and Ireland were invited to participate in this survey.

Participants

The survey was circulated to the medical and nursing leads in the PICUs and the aim was to recruit all PICUs and only one response from each unit was required.

Recruitment

102 email invitations to participate were sent to the nurse and medical leads for each PICU unit. Some PICUs had identified more than one lead. Overall, 42 electronic responses were returned, and this were cross checked to identify the units who had and who had not contributed. A reminder email was sent out. Any PICUs who had not submitted the survey were invited to complete a telephone interview using the survey questions. A convenient time was arranged to complete this and again the voluntary nature of participating was assured. The response rate was 100% with all PICUs submitting data for the survey (Table 1).

One Level II Paediatric Critical Care (High Dependency) unit also submitted data. Although this unit had stopped offering diaries due to the time constraints experienced by staff, there was a willingness to continue contributing to diaries started in other settings. Unfortunately, as the aim of this survey was to understand the nature and scope of diaries in the PICU settings, the data of this was excluded.

Table 1: Characteristics of participating PICUs

Type of PICU	Responses % (number) Total Responses 30
General	53 (n=16)
Cardiac	6 (n=2)
Combined	25 (n=8)
Other	16 (=4)

Others included high dependency units (HDU) with PICUs or a standalone HDU.

Data Collection

An online questionnaire using the survey tool, Survey Monkey™ was developed. The survey included 20 questions that asked about: demographics of the PICU, prevalence of diary use, nature of use and if not used, any plans to implement the use of diaries (Electronic Supplement Material 1).

Service user Involvement

The questions were tested and piloted with academic supervisors, internal and external peers until there was agreement on clarity, relevance and ease of use for respondents. Closed questions were used to collect definitive answers and open questions to provide a descriptive explanation where appropriate.

Analysis

Once collected, the data collated was cleaned to include only one entry per responding PICU. The data was exported from a CSV file in Survey Monkey into Microsoft Excel. The

data was analysed primarily descriptively and inferential (Parahoo 2014). Free-text responses in the survey were analysed by thematic content analysis (Green & Thorogood 2009).

Ethical considerations

Local permission was sought and granted by the primary author's Research and Design Department (GSTT/2017/7399) to undertake this evaluation audit.

As this survey was not anonymised, the author was able to identify any PICUs who had either submitted data more than once or had not yet completed a questionnaire. Explicit reassurances around confidentiality were given to respondents. Identifiable personal data was not used in the analysis and then destroyed after the data was imputed into a database.

Data collection was completed before May 2018; the date implementation date of the General Data Protection Regulation (GDPR).

RESULTS

Of the respondents who answered, 43% (n=13) of the PICUs stated that they offered patient diaries and 57% (n=17) did not offer diaries.

Five PICUs commented that they have stopped the practice of offering diaries. The reasons why this has stopped included concerns about the legal implications of writing a diary (n=5), concerns about professional implications (n=4) and financial constraints (n=1).

A written example of why diaries were not used was:

“I think that these are all reasons why diaries have not been introduced - it has taken a while to work through these. I think there are also mixed views from staff about the use of and benefit of diaries”

Of the units who are currently not offering dairies (n=17): 53% (n=9) were “considering introducing or re-introducing” patient diaries and 22% (n=4) “may consider” reintroducing these.

Purpose of diaries

Reasons to use diaries varied amongst the PICUs (Table 2).

Table 2. Purpose of using diaries

Perceived Purpose of the diary (more than one option could be given)	% Responses (n=17)
Fill memory gaps	88 (n=15)
Explanation of what has happened	65 (n=11)
A way of engaging family members in care	94 (n=16)

The purpose of the diary was also described as a communication tool, for example the diary was used as a way of families being able to communicate in a different way with the health care providers caring for their child.

“Enabling family members an alternative tool to communicate key messages about their child’s underlying condition, specific care needs, likes, dislikes, daily routine etc”

The Scope and Use of Diaries

The PICUs who offered diaries to parents (43%) were asked specific questions to understand the processes around how diaries are used. Diaries were offered to all families by 67% (n=8) of the PICUs and the remaining 33% (n=4) offered them once an admission into PICU had been for >24hours. The comments around this question offered further understanding into who these diaries were offered to:

“Also, we tended to focus on families we expected to stay for medium to long term”

“Offered on an individual basis if we think the child/family would benefit. All offered once hit extended stay at 21 days. Too many short stay children to offer all”

It is difficult to interpret two free-text comments on the question of, what guidance is offered on who should not be approached to commence a diary. However, the responses given indicated that diaries are not offered to families who do not understand English or if there are any child safeguarding concerns.

Consent to use the diaries is gained informally and verbally by 79% of PICUs (n= 11) with only 1-unit (7%) seeking “formal consent” and the remainder 7% (n=1) unit sought informal consent and documented this discussion in the patient records. Once agreement to use has been gained from the family or carers, in most cases the diaries were used immediately (72%, n=12). The remainder (28%, n=5) reported commencing the diary within the next 24 hours of the admission.

Parents and families are reported as the main contributors of the diaries (94%, n=17). Nurses and play specialists were the next main contributors (72%, n=13) with a smaller number of units reporting doctors (33%, n=6) as contributors. The diaries are

populated with photographs (94%, n=15), drawings (100%, n=16) and stickers (94%, n=15).

Respondents clarified their answers to this question by including comments such as:

“Families will add photos”

“This is up to the family, but we will offer suggestions (sic stickers)”

The respondents were questioned about who owns the diary and the stated ownership varied. The family (82%, n=14) and the child (12%, n=2) were cited as the owners of the diaries with only one respondent suggesting that the PICU staff owned the diary (6%, n=1)

Understanding of the ownership of the diary was also supported by the responses related to the question: “when does the child and family receive the diary?”. The respondents reported that the diaries remained with the child and family most of the time (84%) although three units (16%) presenting the diaries to the child and family at discharge.

Only two units (12%) currently capture any formal feedback on the value of the diaries, from an additional question in routinely administered parent/carer satisfaction surveys.

DISCUSSION

The prevalence of the use of patient diaries in the PICU settings (43%) was more common than had been expected. As this is the first survey of its type, it was unclear to what extent PICU diaries were offered, however anecdotal evidence would have suggested this was still a rather novel intervention.

There is a predominance of literature pertaining to diaries not only coming from the adult critical care setting but also conducted in Northern Europe where diary usage has been established for almost 30 years. A Swedish survey of the use and practice of patient diaries in the AICU setting found that 75% (n=65/85) offered diaries (Akerman et al 2010). It is positive to see that the potential benefits of using these has been adopted in the PICU settings, but it is clear that this intervention in PICU is still in its infancy.

It was interesting to explore the reasons why the offering of diaries may have been stopped or withheld in some units. The five units who either do not or no longer offer diaries expressed concerns about the legal and professional implications of using these. This is a previously unresearched area of understanding and it would be of value to understand where these concerns have originated from and if these have been grounded in any legal or professional challenge. Other barriers to implementation of diaries such as: lack of time, challenges in constructing content and the attitude of staff, was not reported as a concern by the respondents (Nydahl et al 2014, Johansson et al 2019)

Several PICUs reported providing staff with guidelines regarding who to offer diaries to but not how to populate these. In adult critical there are examples of professional guidelines (<https://icusteps.org/professionals/patient-diaries>, NICE 2009, Beg et al 2016) and also educational videos on how to use diaries. As this has been identified as an area of concern for PICU settings the sharing of good practice and support from professional bodies in the form of a guideline would be invaluable and addressing the concerns raised. Although there was consensus from the PICUs in how consent to use the diaries was sought (verbally 79%, n=11), the legal and professional concerns raised by others who were reluctant to use dairies may be compounded by this informal approach to consent. The process in which

families and in some cases the child is introduced to the idea and value of using a diary, and “consented” could therefore also be captured in professional guidelines and alleviate any apprehensions about usage.

In the PICUs who offered diaries; the ways in which these were used and populated was reported as very similar across the units. In the main, the families were the main contributors to the diaries alongside the nursing team. Although it is not uncommon in adult intensive care settings for relatives to contribute to the diaries, the main authors to the diaries are the nursing team (Knowles & Tarrier 2009, Jones 2010, Tomohide et al. 2015). The ethos of family centred care in the PICU (Latour et al 2009) would naturally facilitate and encourage the contribution of the primary care giver as the main author but this survey has identified a different approach when compared to AICU.

Similarities in how the diaries are populated in the survey was identified between adult and child diaries in the use of text to explain the child’s admission and progress. However, the use of “age appropriate language”, drawings, stickers to decorate and photographs were highlighted as differences in the survey and literature (Mikkelsen 2018, Herrup 2019). The use of photographs to illustrate the child’s stay was also commented on as imperative and this is recognised in the literature as an important tool in supporting the understanding for the child and their family (Mikkelsen 2018, Herrup 2019). The adult literature also supports the use of photographs visual means to explain and fill the memory gaps (Backman and Walther 2001, Akerman et al 2010). Not unsurprisingly, the use of colourful drawings and child friendly stickers to decorate and personalise the adult diaries has not previously been commented on but was reported as a feature of the paediatric diaries.

The reported purpose of the diaries in providing explanations and filling the gaps in memories was similar to the reported purpose and value in the adult literature (Ewens et al 2015). The main finding (94%, n=16) identify that the diaries are used to engage families in the care of their child or loved one with. The AICU literature support this view (Johansson et al 2014, Nair et al 2015) as the diaries are reported as becoming a way for relatives to be present in the critical care area: providing a focus and a task. Mikkelsen's (2018) qualitative study looking at the meaning of diaries to children and their families in the PICU concluded that the diaries were a tool to make sense of the time in the PICU but also offer a tool to support the coping of the family and child.

Who owns the diary also provided some interesting insight. In the adult literature there has been a paradigm shift in recognising that the diary is owned by the patient and not the health care professionals (Engstrom et al 2009, Egerod et al 2011). However, in this survey the parent or family (82%, n=14), not the patient, is viewed as the owner of the diaries. This finding may reflect the legal, cultural and societal status of a child (UNICEF 1989, Children's Act 1989). It would be important to explore this question in subsequent research to understand more fully what the "ownership" of the diary really means and whether the concept of custodianship or "looking after" the diary for the child is more appropriate. Nevertheless, the view that the diary is owned by the family rather than the health care professionals is an important acknowledgement of the relationships within the PICU setting.

There are several limitations to this study that need acknowledgment, including the use of a self-report survey. A limitation of self-reported surveys is that respondents might overstate the responses or provide responses considered to be socially acceptable (social response bias). Further, we did not ask respondents about the guidance given for use of the diary and any professional and

legal guidance, an area of concern raised by several respondents. A question to understand the facilitators and barriers to the use of diaries would also have been important. Despite these limitations, this is the first survey to attempt to explore the intervention of using diaries in PICUs.

Conclusion

The use of patient diaries is an evolving intervention in the paediatric intensive care settings and is still in its infancy in comparison to the adult intensive care settings. This national survey of the UK and Ireland has provided a clearer picture of how this intervention is used. PICU patient diaries are used in a significant number of units and the scope and nature of these is relatively standard. Of those PICUs who do not offer diaries, the concerns around the professional and legal implications was the key determinant of the reluctance to use diaries. The need for professional guidelines to support and address the concerns raised may be a solution to alleviate anxieties.

Those units who offer diaries acknowledged the positive benefits of these for their patients and families and staff. As this survey is the first of its kind, the findings provide a baseline for future exploration, understand and promotion of this intervention for our patients and their families. Further research to explore short-term and long-term impact of diaries from the perspective of the child, their family and the health care professional is warranted.

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IMPACT

a) what is known about the subject

- Critically ill children and their families may experience lasting psychological issues after discharge from PICU.
- Patient diaries are a tool to add communication, fill in gaps in memory and offer insight on their PICU stay.
- The use of patient diaries in PICU settings has a dearth of literature exploring this intervention.

b) what this paper contributes

- This survey is the first to offer insight into the use and scope of patient diaries used in the PICUs in the UK and Ireland.
- The incidence of patient diaries is greater than had first been considered and the scope and usage is relatively standard.
- Concerns around the legal and professional implications of the diaries requires further guidance and advice from professional bodies.

Electronic Supplement Material 1

Abridge version of the questions asked in the survey

1. What is your current role?
2. Tell me about your PICU?
3. Please include the name of your unit
4. Please include your name and email address
5. Do you currently use patient diaries in your PICU?
 - a. If answered No, answered Q.6 to 9
 - b. If answered Yes, answered Q.10 to 20
6. Have you in the past offered patient diaries?
7. If yes, why was this practice stopped?
8. If no, are you considering introducing/re-introducing this tool?
9. Is there anything else you would like to comment on about patient diaries in PICU?
10. Which patient groups are offered patient diaries?
11. Once offered, when are the diaries started?
12. Is there any guidance on whom diaries should NOT be offered to?
13. How is consent gained for the use of the diary?
14. What do you see as the purpose of the diary? (You may answer more than one option)
15. Who writes in the diaries? (You can choose more than 1 option)
16. How is the diary populated? (more than 1 option can be chosen)
17. Who owns the diary?
18. When does the child and family receive the diary?
19. Do you capture any information on the value of the diary ie audit, satisfaction surveys?
20. Are there any further comments that you would like to make in relation to patient diaries?

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