

Exploring the Challenges for Nurses in Caring for Patients with Acute

Encephalitis: Lack of Knowledge, Time and Rehabilitation

Abstract

Aim: to explore the experiences of registered nurses providing care to adult patients affected by encephalitis; from admission into hospital through to discharge. *Study Design:* A qualitative phenomenological methodology was used. *Sample and Setting:* Eight registered nurses in a city centre teaching hospital. *Methods:* Data collection took place using in-depth, semi-structured interviews. Data were analysed, and themes identified using framework analysis. *Findings:* Three key findings were identified: nurses felt that they lacked knowledge of encephalitis, they lacked time to give these patients the care that they needed, and they lacked access to rehabilitation for patients with encephalitis. *Conclusions:* This study provides the first evidence on nurses' experiences of providing care to patients affected by encephalitis. It has shown that they often lack the knowledge and time to give adequate support to these patients. They also lack access to rehabilitation for these patients.

Key phrases

- This work adds to the knowledge on the nursing care of patients affected by encephalitis by highlighting how difficult nurses find managing their care if patients become acutely confused.
- This study has shown that nurses often feel they lack the knowledge and time to give adequate support to these patients and their relatives.

- The nurses in this study experienced difficulties in accessing appropriate rehabilitation.
- The findings of this study relate to current literature on the difficulties for nurses when managing acute confusion, particularly when compounded by nursing shortages.

Key words

Encephalitis; acute confusion; nursing care; rehabilitation; challenges.

Introduction

Encephalitis is inflammation of the brain tissue (Solomon et al. 2007), the causes of which in Western Europe include viruses, such as Herpes Simplex Virus (HSV); bacteria, such as *Toxoplasma Gondii*; and auto-immune causes, such as Voltage Gated Potassium Channel-Complex Antibody-Associated Limbic Encephalitis (Granerod et al. 2010). In England, encephalitis has an annual incidence of 5-8 cases per 100,000 of the population (Granerod et al. 2013) and in a significant proportion of patients, no cause is identified (Granerod et al, 2010). Encephalitis inflames the brain tissue, leading to brain injury, and in some cases death.; as such, encephalitis is a neurological emergency. The signs and symptoms of encephalitis include fever, headache, sensitivity to light, memory loss and acute confusion and it can affect any age group. All causes of encephalitis can leave people with significant disability in cases of HSV encephalitis, however, prompt treatment with aciclovir significantly reduces mortality and morbidity (Skoldenberg et al. 1984, Whitley et al. 1986).

Due to the brain damage encephalitis can cause, encephalitis can result in a high economic and social burden to both patients and society (Solomon *et al.* 2012; Easton, 2016).; not only may patients be unable to work at all or to the same level as before, but they may also need long-term care and support with activities of daily living. This can negatively impact their families' economic status, and patients post-encephalitis may also rely directly on family members for day-to-day help and support. In their follow-up prospective study, Hokkanen & Launes (1997) found that six out of 11 adults affected by encephalitis had long-term psychiatric and cognitive impairments. Easton *et al.* (2007) found that although 96% of patients with encephalitis had ongoing complications, 33% were discharged without any planned follow-up. There is a lack of guidance on both where patients with encephalitis should be nursed, and on how to provide appropriate nursing care, and these important points provided the focus for this study.

Mainstream provision of services can struggle to accommodate the complexity of these patients' care, however, Easton *et al.* (2007) state that less than 40% of these patients are cared for on specialist neurological wards, which means that many them are cared for in non-specialist settings. Solomon *et al.* (2012) point out that not only are there no guidelines on the nursing care of these patients, but there is no clear evidence of what settings nursing care should be provided in. Currently, patients tend to be cared for in general medical wards, specialist neurology wards/neurology centres, infectious diseases (ID) wards, and intensive care. Easton (2018) highlights the role of primary care in diagnosing encephalitis, and managing physical sequelae post-encephalitis.

Literature Review

A literature search was carried out to see if there were any original research papers of the nursing care of patients with encephalitis. The databases Medline, Cinahl, Embase, British Nursing Index, and Scopus were searched. The search strategy included the terms “encephalitis”, “nursing”, “care” and “challenges”. No date range was set on this search, as it was already known from previous searches in this area that the number of studies found were likely to be minimal. The inclusion criteria applied as part of the search were that articles had to be written in English; be original research in a peer-reviewed journal; and for the purposes of this study had to concern adults, rather than children. Exclusion criteria were studies on non-acute encephalitis, systematic reviews and literature reviews. No original research papers on the nursing care of patients with encephalitis were found.

Because of this, a second literature review was carried out to set this research in the broader context of caring for patients with other neurological conditions who develop confusion, as this is often the case for patients with encephalitis. The search strategy included the terms “neurological conditions”, “delirium”, “confusion”, “nursing” and “care”. The inclusion criteria for this second search were that articles had to be written in English, published in a peer-reviewed journal, and had to concern adults rather than children. This revealed a broad body of evidence of how confusion is commonly encountered in patients with neurological conditions, and how the care of these patients can be challenging, and how this care can often be hampered by staff shortages. Studies in this field highlighted the importance of nurses in managing confusion to help maintain the safety of neurology patients with confusion, and to help to treat it (Wilson *et al.*, 2020; Zipser *et al.*, 2019, Kristianson, 2019; Baker, 2015; Belanger, 2011). Certain articles that we identified in the literature search also showed how

nurses caring for these patients often feel that their ability to do properly can be hampered by staff shortages or under staffing (Kristianson, 2019; Baker, 2015; Belanger, 2011).

Methodology

Aim

The primary aim of this study is to explore the experiences and perceptions of registered nurses providing care to adult patients with encephalitis; from admission into hospital, through to discharge.

Design

This study was a qualitative exploration, using semi-structured interviews. The theoretical framework that guided the study was a qualitative, phenomenological approach. The key concepts considered for the basis of this study are the traditions of phenomenology: a philosophy and method that focuses on understanding the lived experience (Heidegger 1998, Gadamer 1989, Vandermouse and Fleming 2011, Englander 2012). Despite descriptions of a phenomenological movement, it is generally accepted that there are broadly speaking two traditions of phenomenology, interpretive and descriptive; although Crotty (1996) points out that there is diversity within these traditions. This study followed the tradition of interpretive phenomenology, as it was accepted that the role of the researcher as a research nurse in brain infections at the recruiting hospital site, was likely to have an impact on the research process and interpretation of the findings.

Participants

A sample of eight registered nurses were recruited from one secondary hospital using purposeful sampling. The hospital was a large, city centre university teaching hospital, with a large emergency department, theatres, an intensive care unit, and surgical and medical wards. The hospital also had two infectious diseases (ID) wards. The hospital did not have any dedicated neurology wards or units. The lead researcher approached the participants inviting them to participate. Potential participants were given verbal and written information about the study and were given at least 24 hours to decide on their participation. Before the interviews took place, participants gave written consent.

The inclusion criteria for study participants were 1) being a Registered General Nurse (RGN), employed by the hospital trust being used for the study 2) experience of nursing at least one patient with encephalitis. Participants were recruited by identifying wards commonly involved in acute management of encephalitis, gained through the researcher's role as a research nurse in a multi-centre prospective study looking at the outcomes of encephalitis across the UK.

Subject ID	Sex	Nurse Grade	Area Worked
001	Female	5	ID
002	Female	5	ID
003	Female	7	ID
004	Female	5	ID
005	Female	5	ID
006	Female	5	ID
007	Female	5	ID
008	Female	5	MAU

Table 1: Patient Demographics (ID= Infectious Diseases, MAU= Medical Assessment Unit)

Apart from one nurse who was based on a medical assessment unit (MAU), the nurses in this study had all nursed patients with encephalitis relatively regularly, at least three to five times a year. The hospital was not a specialist neurological hospital, but it did receive specialist referrals for these patients due to its infectious diseases (ID) unit. In the hospital, patients with encephalitis are ideally nursed on the ID unit, unless they require critical care or there are no beds on the ID unit. The nurses all had at least five years of experience, with the most senior nurse interviewed having over 20 years of experience.

The study participants ranged from Staff Nurses through to ward managers, and all but one of the nurses worked on ID wards, with the remaining participant working on a Medical Assessment Unit. Demographic details about the participants are contained in Table One. We aimed to recruit ten participants, but due to time constraints we were only able to recruit eight participants.

Data collection

Data was collected using in-depth, semi-structured interviews, from October 2014 to August 2015. A sample script of these questions can be found in Appendix 1. Semi-structured interviews were used because they are the most appropriate data collection method for the type of data this study aimed to produce. This methodology ensured that data on all the study objectives were covered, as well as allowing responses to be fully explored and the researcher to respond to relevant issues that were raised spontaneously by the participant (Ritchie & Lewis, 2009).

Interviews took place at the hospital site, in a quiet room, away from their work environment and lasted for approximately 60 minutes. This gave enough time for in-depth discussion and for exploration of key issues. Interviews were recorded verbatim using an audio-recorder.

Interview Questions

- 1. Could you give me an overview of your nursing career to date?**
- 2. What kind of conditions do the patients that you nurse in your current work area generally have?**
- 3. Tell me a bit about how often you nurse a patient with encephalitis.**
- 4. Tell me a bit about your understanding of encephalitis.**
- 5. What do you perceive to be some of the nursing priorities for a patient with encephalitis?**
- 6. How do you generally feel about your experiences of caring for these patients?**
- 7. What have you found to be particularly challenging in caring for these patients?**
- 8. What have your experiences been of information giving to relatives?**
- 9. What are the challenges when the patient with encephalitis becomes acutely confused?**
- 10. Tell me about your experiences of caring for patients with encephalitis who have gone on to develop memory loss.**
- 11. What discharge referrals do you feel it's important to make for patients with encephalitis?**
- 12. When discharge planning for such patients, what are your experiences of getting access to neurology services/neurological rehabilitation/neurological psychology?**
- 13. Are there any other issues that we have not yet covered that you'd like to discuss?**

Table 2: Interview Questions

Ethical approval

Ethical approval was gained from the university that was the study sponsor, and local approval gained from the hospital site where participants were recruited from. As this study was interviewing staff members only, NHS Research Ethics Committee approval was not required.

Data analysis

The method of data analysis used for this study was framework analysis. One of the reasons for selecting this method was because it provides a clear audit trail (Flick, 1998).

Interviews were transcribed in full by the researcher. This meant that the researcher was very familiar with the data before the analyses began. Stage one analysis involved immersion by reading and re-reading the transcripts. Stage two involved developing a theoretical framework by identifying recurrent and important themes. The recurring themes identified in stage two were added to a chart on paper as part of the analysis. Stage three consisted of indexing and pilot charting. The draft framework developed in stage two was applied back to the transcripts, and a refined framework devised. In stage four the data were summarised in an analytical framework. The material was reduced into understandable but brief summaries of what was said by each participant. In stage five, the final conceptual framework for the analysis was assembled, which included the merging of some of the over-lapping sub-themes.

Figure One provides a diagram of the analytical framework. Table 3 summarises each stage of the analysis.

Stage	Activity
Stage One	Detailed reading of transcripts
Stage Two	Theoretical framework developed
Stage Three	Indexing of transcript data
Stage Four	Summary of data
Stage Five	Final conceptual framework and merging of sub-themes

Table 3: Analysis Stages

Figure One: Stage Five

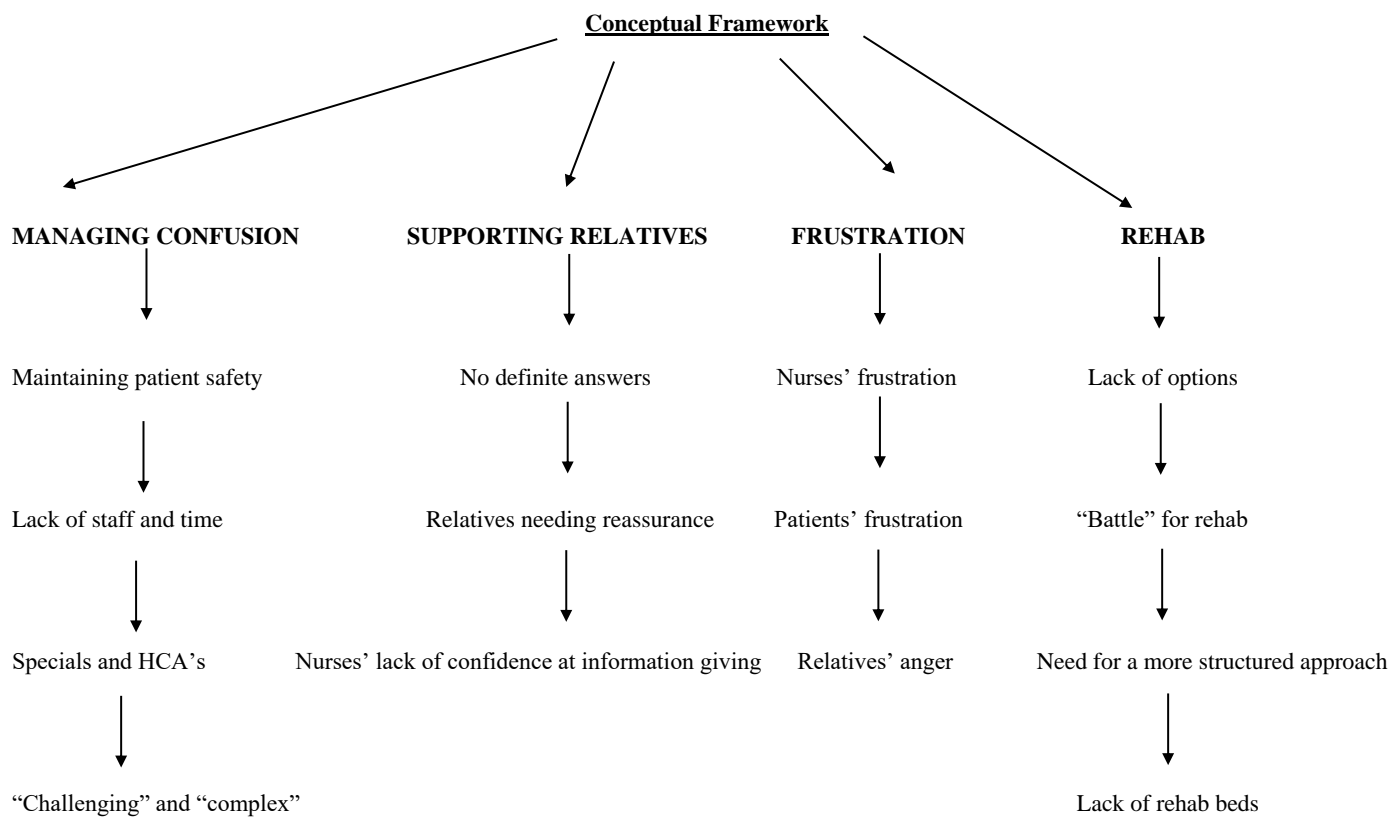


Figure 1: Stage Five Conceptual Framework

Validity and reliability of the analysis

The validity and reliability of the findings was ensured by having two independent researchers experienced in working with phenomenology independently code a sample of the data. These independent analyses produced similar themes. The rest of the coding undertaken by the lead researcher was also reviewed by the second researcher for validity and reliability. The two researchers discussed and reached an agreement when interpretation of the themes differed. The audit trail produced by framework analysis also gave rigour to the work, because it gave a clear written record of the steps taken in the analysis, and the findings and decisions made at each of the five stages.

Results

Key findings

This study found that nurses lacked knowledge of encephalitis in order to care for these patients confidently; they lacked time to give patients the level of care that they required; they experienced a lack of access to specialist neuro-rehabilitation for these patients. These findings are consistent with previous findings in the wider literature on the management of acute confusion and nursing shortages generally.

These three key findings emerged from four primary themes that developed during the data analysis: managing confusion (for example the nursing challenges this poses), supporting relatives (for example explaining the potential for life-long brain damage in their relative), frustration (for example nurses' frustration with staff shortages making it difficult to give

these patients the level of care required) , obtaining appropriate rehabilitation for the patients (for example, lack of beds in neuro-rehabilitation centres) (see Figure One). Each is discussed in more detail below.

Lack of knowledge

It was clear from the interviews that all the participants felt that they lacked knowledge of encephalitis, which hampered their confidence in care and information giving. It was generally recognised, although uncommon, that a diagnosis of encephalitis required rapid diagnosis and the nursing needs required were not always recognised. This is an important finding as it could mean that patients get sub-optimum care if nurses are not aware of their needs.

For example, when subject 001 was describing how much more difficult it was to plan appropriate care for patients with encephalitis when they become acutely confused, she stated that:

“It’s trying to work out what their needs are.....it’s quite challenging.....it’s hard knowing exactly what their needs are....”

When describing her biggest fear in caring for patients with encephalitis, subject 003 describes how scared her lack of knowledge about the condition made her, and how this hampers her communication with relatives:

“....lack of knowledge [is my biggest fear]. I think that scares me. When I don’t know something I don’t like it, I get scared of it. I don’t like not being able to.....if a relative asks me what’s wrong and I can’t answer it or in ward round one of the doctors goes [what sounds to me like] blah blah blah and I’m saying what [does your diagnosis mean]?”

Lack of time

The finding of lack of time arose from the four themes because managing confusion, supporting relatives, and trying to arrange rehabilitation all required significant amount of time, of which the nurses in this study felt they lacked. All the participants in this study highlighted how much time was needed to care for patients with encephalitis, and how short of time they were as nurses. This was often compounded by staff shortages. This is an important finding because it shows how many patients with encephalitis may be suffering because of staff shortages, and by not considering how much time patients require when allocating nurse caseloads.

For example, subject 005 stated how dependent acutely confused patients with encephalitis were on nurses for nearly all activities of daily living, such as feeding, hygiene and dressing:

“In general, these patients take up a lot of time anyway as they require a lot of care. But quite often, when they’re confused they require full care and everything.”

Subject 003 expressed concern over lack of staff and one to one nursing assistants (or specials) for patients that needed one to one care. This appeared to have a strong impact on her perceived ability to provide good quality care to patients with encephalitis on her ward.

“.....our ward is one of the ones we do need staff, so when we get, you know, encephalitis patients it’s frustrating. We don’t get the staff we need.”

Lack of Access to Rehabilitation

The need for patients with encephalitis to have access to high quality and appropriate rehabilitation was strongly identified by all respondents. Paradoxically, each of the participants also felt strongly that patients rarely received the rehabilitation that they needed. This is an important finding because it shows lack of access to appropriate rehabilitation for patients affected by encephalitis to be a common theme that could mean that many of these patients' recoveries are limited due to lack of rehabilitation.

Subject 005 described the general difficulty of getting these patients into rehabilitation facilities by saying that:

"[To get rehab].....it's just too hard."

Subject 007 also echoed previous participants when she described the lack of beds that are available in rehabilitation facilities. This was a recurring discussion point throughout the interview.

"Yeah, it's difficult. There's only so many beds for so many people. Some people can go and do like outpatient clinics. They can go to like centres every day. They can do some stimulation and do stuff with them that they need. But long-term, yeah, it can take a fair while."

Discussion

It is recognised that this study is exploratory in its findings. The study has however produced some tentative new knowledge on the challenges that nurses face when caring for patients with neurological conditions such as encephalitis. It has done this through the identification of four over-arching themes; managing confusion, supporting relatives, frustration,

rehabilitation. However, it could be considered that by helping their patients to become more independent with their activities of daily living, they are playing a part in that rehabilitation, but perhaps the nurses in this study did not recognise this. These four themes led to the three key findings of lack of time, knowledge and rehabilitation.

Although this study focused on encephalitis, it is interesting that the findings are problems that are common to other conditions, such as acute confusion generally and other traumatic or acquired brain injuries. Problems with lack of staff and lack of time to give optimum nursing care are well documented in the literature for many neurological conditions. So is the need for increased knowledge for nurses in caring for these patients, and better access to rehabilitation for patients. The challenges that it presents to nurses when providing care for patients with the condition, has much in common other neurological conditions. There is a misconception that encephalitis is a relatively rare condition. However, it has a higher incidence than other neurological conditions such as multiple sclerosis and bacterial meningitis. This is an additional reason why awareness and training, especially for nurses, is ever more important as this study suggests. Although nurses are likely to have had some training on multiple sclerosis, bacterial meningitis, and acute confusion, they are highly unlikely to have received training in encephalitis, unless they work in a specialist neurology unit.

This therefore poses the question of whether the findings of this study need to be looked at within a much broader picture of other neurological conditions whose nursing care is also challenged by staffing issues, a need for more training and knowledge for nurses, and lack of

access to rehabilitation. The findings of this study are in keeping with other evidence looking at confusion in other neurological conditions (Kristianson, 2019; Baker, 2015; Belanger, 2011).

Therefore, it could be argued that this work has provided some evidence towards new theory on the nursing care of patients with encephalitis. However, it could also be argued that the findings of this study must be considered within a much bigger picture with other neurological conditions, and perhaps any future work in this area could assess these findings in the wider context.

The Findings within the Broader Context of Confusion and Neurological Conditions

It is necessary to relate the findings of this study to the existing evidence on confusion and neurological conditions. The findings of this study relate to existing literature on the need to both screen effectively for delirium, and on the need to manage it effectively (Wilson et al., 2020; Zipser et al., 2019, Kristianson, 2019; Baker, 2015; Belanger, 2011). For example, Lamond *et al.* (2018) highlight the importance of screening for delirium consistently in the intensive care setting. Yevchak *et al.*'s (2012) study has particular relevance to the findings of this study because they ran a pilot focus group with nurses working in acute care settings which found that more needs to be done to promote evidence-based and non-pharmacological approaches to caring for patients with delirium. The findings of this study also have relevance to the literature on nursing shortages generally. Buchan and Aichen (2008) argue that nursing shortages have an impact on clinical practice and health service delivery, and Oulton (2006) highlights nursing shortages as a global problem. The findings of this study therefore have important relevance to the current literature on managing acute confusion and nursing shortages in all clinical fields.

Limitations

The main limitation of this study was its small sample size. This makes it impossible to generalise the findings of the study to the broader population. However, the aims of this study were to identify key themes and topics that are transferable and applicable to the participants under study, and this has been achieved. Another limitation is that due to the need to recruit participants that could provide in-depth data, purposive sampling cannot guarantee how representative the participants were. There is also a lack heterogeneity within the sample in terms of gender, seniority and clinical area worked in.

Conclusion

In conclusion, this study has provided an exploratory start to looking at the challenges of providing high quality nursing care to patients with encephalitis. This study found that the nurses interviewed lacked time, knowledge and access to rehabilitation when caring for patients with acute encephalitis. The findings of this study agree with current literature on managing acute confusion and nursing shortages generally. The implications for practice of this study are that it highlights the need for adequate staffing, training and better access to rehabilitation for patients with neurological conditions such as encephalitis. Although neurological rehabilitation is generally in short supply, it is often the case that specialist neurology centres have better access to this than tertiary hospitals. Future research into the challenges of nursing patients with encephalitis should perhaps be undertaken within the wider context of other neurological conditions, to produce findings that are more widely generalisable.

Reflective Questions

- Are there any other challenges that are common to caring for patients with acute confusion?
- As nurses, how could we work with charitable sectors to help to support relatives of patients with brain infections?
- How have you coped with having to explain to patients and relatives when there is a potential for long-term brain damage?

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