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The experiences of rural and remote families involved in an inter-hospital transfer to a tertiary ICU: a hermeneutic study

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Abstract

Background: Inter-hospital transfers are necessary for critically ill patients to improve their chance of survival. Rural and remote families experience significant disruption to family life when critically ill patients are required to undergo a transfer to a tertiary hospital. What is not known is how ICU staff can assist these families who are involved in an inter-hospital transfer to a tertiary ICU.

Purpose: To gain an understanding of rural and remote critical care families' experiences during an inter-hospital transfer to a tertiary ICU.

Method: A hermeneutic phenomenological approach was adopted informed by the philosophical world views of Heidegger and Gadamer. Data collection occurred by in-depth conversational interviews from a purposeful sample of seven family members. Interview transcripts, field notes and diary entries formed the text which underwent hermeneutic analysis.

Findings: Being confused, being engaged, being vulnerable and being resilient emerged as significant aspects of the rural and remote family members' experience during a transfer event.

Conclusion: A better understanding of the experiences of rural and remote families during an inter-hospital transfer journey can inform the practice of ICU nurses. This study highlights the specific experiences of rural and remote families during an inter-hospital transfer journey to a tertiary ICU. It also informs nurses of the meaningful ways in which they can support these families with the uncertainty and chaos experienced as part of this journey.

Key Words

Critically Ill; Inter-hospital Transfer; Hermeneutic Phenomenology; Intensive Care; Critical Care; Families; Relatives; Rural and remote areas.

Introduction

Inter-hospital transfers (IHT) for medical treatment are necessary to improve the chance of survival of critically ill people.¹ People in rural or remote areas who become critically ill or experience trauma may need to be transported to a tertiary intensive care unit (ICU) for treatment.² In 2011, more than 21,000 patients (16% of all Australian ICU admissions) were initially admitted to one of 43 regional ICUs³. In 2006, an audit of the three Queensland tertiary ICUs estimated the number of incoming ambulance IHTs of critically ill patients at 450 per annum. It is evident that the number of rural and remote patients involved in an IHT within Australia is significant.⁴

Rural and remote family members (RRFM) experience significant disruption to family life when critically ill relatives move to a tertiary hospital.⁵⁻⁷ Families make a significant contribution to both the acute and ongoing illness recovery of critically ill patients.^{8,9} For critically ill patients, an IHT typically occurs with limited time to fully inform and involve the family. Consequently, the relatives of these patients are likely to have specific care needs that require appropriately targeted nursing and health service responses. Limited research has been undertaken to inform ICU staff how to assist families who are involved in an IHT. Hence, the aim of this study was to gain an understanding of rural and remote critical care families' experiences during an inter-hospital transfer.

Method

Study Design

A hermeneutic phenomenological approach was chosen as it provided a sensitive mode of inquiry for revealing the everyday practical experience of being a RRFM involved in an IHT. Several underlying assumptions, influenced by the world

views of Heidegger¹⁰ and Gadamer¹¹, informed the theoretical framework that guided the research process. In Heideggerian terms, family members are human beings with a capacity to reflect upon the nature of their existence in such a way that meaning is revealed.¹² The essence of how families are involved and engaged in the practical activities and relationships experienced during IHT are shaped by their background culture and illuminate significance for them. Family members as temporal beings are capable of attributing meaning to such involvement, as influenced by the past, and their ability to anticipate their future.¹³

Setting

The setting was the ICU of a large adult metropolitan hospital in Queensland, Australia. The ICU admitted 2,345 patients during 2011-2012.¹⁴ During the screening period (March until November 2012), 130 patients were admitted to the ICU via IHT of which 56 were from rural or remote Queensland.¹⁴ The ICU had an open visiting policy for families, operated 25 beds and admitted adult patients for specialist cardiothoracic, spinal, trauma, neurological, medical or general surgical care. The hospital and ICU provide families with information on local accommodation, counselling and financial support.

Participants and Participant Recruitment

A purposeful sample of RRFMs were invited to participate in two interviews. Sampling was considered adequate following recruitment of seven family members as no new descriptions were heard and a redundancy in themes was evident.¹⁵ Inclusion criteria comprised: (1) the participant's relative was admitted to the site ICU via IHT from a rural or remote area as per the Australian Standard Geographical Classification-Remote Area system (ASGC-RA);¹⁶ (2) they were 18 years of age or older; (3) they visited the patient whilst in the tertiary ICU; (4) they had a close and

continuing relationship or formed part of the patient's pre-existing support system; (5) their primary place of residence was in rural or remote Queensland. RRFMs were excluded from the study if another family member was already participating, and likewise on compassionate grounds for those whose critically ill relative died within 12 hours of being admitted to the ICU.

All patients that were admitted to the ICU via IHT were screened daily by an ICU nurse trained in clinical research procedures. If families met inclusion criteria, this ICU nurse provided them with a brief summary of the study's aims, participant information and consent form. Families gave approval to be contacted by the researcher to clarify any questions and gain written consent.

Data Collection

Demographic data were collected from each participant. Initial interviews were audio-taped conversations in a private ICU conference room. These interviews typically occurred within the first two weeks of the RRFM's relative being admitted to the ICU and lasted between 45 to 90 minutes. In line with Drapers' view,¹⁷ the interviews commenced with stem questions, such as: "What circumstances lead up to your relative's accident and the need for transfer to the metropolitan ICU?"; "Can you recall one moment during the IHT period that stood out for you?"; "How did hospital staff involve you during the IHT process?" Informed by Heideggerian philosophy¹⁸ the interviewer (BM), employed probing questions relating to significant incidents, barriers, concerns, and anticipated future possibilities.

Follow-up interviews occurred within 2-10 weeks, lasted approximately 20 to 60 minutes, and took place in a private room in the hospital (n=6) or via telephone (n=1). Participants reviewed a written summary of their initial interview which enabled validation of key aspects of their experience and clarification and probing of

significant issues. The interviewer was a registered nurse with over 10 years of critical care nursing experience.

The interviewer used a diary to reflect on his own experiences of living in rural Australia, being a family member, a registered nurse and caring for families within an ICU and how this could influence the interpretive process. Immediately following an interview, field notes were written to capture descriptive data (gestures, facial expressions, or vocal intonations) that afforded an appreciation of the interview content and context.

Data analysis

All interviews were tape recorded and transcribed verbatim. The verbatim transcripts from 14 in-depth narrative interviews, field notes and diary entries all formed the text for analysis. Crist and Tanner's¹⁹ five overlapping phases of hermeneutic textual analysis were followed.

Firstly, transcripts, diary notes and field notes were read and re-read. Secondly informed by Heideggerian assumptions each text was reviewed to elicit background information. A questioning method was adopted that enquired: *'Who are the members of this family?'*, *'How are family values and traditions discussed?'*, *'What can I glean about social relations within this family?'*, and *'How have the family evolved over time?'*. Initial interpretations were then written.

In the third phase, re-reading of transcripts occurred to identify aspects of the IHT experience that were significant across participants. Recognition of both differences and similarities in shared IHT experiences which transcended the particular situation were identified. Fourthly, the four authors met to clarify the emerging interpretations. The fifth and final phase was guided by Heidegger's notion of Dasein, the ontological nature of the IHT experience¹⁰. By looking within the shared

meanings, an appreciation of the background of meaning for each family and the focused experience of the transfer event, uncovers the modes of Being a RRFM in the IHT context.

Ethics

Ethical approval to conduct this study was granted from both the hospital and university Human Research and Ethics Committees. The research team (BM, MM, UK and AT) had no relationship with the participants or their critically ill relative, were not involved in the direct care of patients in the hospital nor involved in the IHT of patients to the ICU. Pseudonyms were used in data collection, analysis and findings.

Findings

Demographic Profile

The majority of participants were female, a spouse, parent or adult offspring. The participants in this study ranged in age from 26 to 75 years. RRFM characteristics are presented in Table 1. All the participants of this study had a family member who suffered some form of traumatic head or spinal cord injury.

*insert Table 1 here

Lived Experience of RRFM

Four embedded modes of Being in the world as a RRFM and 14 shared meanings were generated from an interpretation of the lived experience of participants following an IHT event (see Table 2). Detailed parts of RRFMs' stories, those parts defined as significant by the narrators, were fused with the researcher's interpretation of the meanings embedded in the stories shared.²⁰

*insert Table 2 here

Being Confused

From the onset participants described their experience when involved in an IHT to a tertiary ICU as being one of confusion. This confusion was represented by three shared meanings which emerged through RRFM's stories: (i) feeling unsupported; (ii) need for information; and (iii) sense of panic. From the onset, the journey for relatives was disorientating as the need to travel away from home forced many into unfamiliar surrounds without support. Patricia's son was involved in a serious car accident which resulted in him sustaining a permanent spinal cord injury. Patricia said:

"I was just thinking he'd be in our regional hospital. I didn't know the extent of the damage by then. I just took some clothes with me and that's all I've got because I didn't go back home again. So we came down here and then we had to find somewhere to stay. Nobody suggested any accommodation whatsoever. They paid my fare down and that was all...we were left to our own devices."

The timing and manner in which information was provided by ICU staff did not always alleviate family members' anxiety when searching for certainty. Sue's youngest son who suffered a permanent spinal cord injury following a motorbike accident said:

“I thought he could die...and you don't really take in everything they're saying and then they use really big words. I've been sitting downstairs all frigging day and no one's told me nothing...and I didn't even know he was in here yet (in the ICU), that he was out of surgery... I hadn't been kept up to date with my son's progress, or that he was being transferred to ICU, or that he would be on a respirator with every bell, bob and whistle hanging out of him...that he'd broken his neck and his back, and it was like well, why can't he feel his legs? It still wasn't explained to me that he'd actually had severe damage to his spinal cord.”

Relatives talked about how their feelings of anxiety and lack of information resulted in escalating confusion and a sense of panic. As Sue said:

“Because when you're in a state of emotional panic and just - everything goes through your head is bad... I got so confused. And when you get confused, you start to panic... I was so busy trying to find my way (to the hospital)...I didn't know where I was going, I just went straight through a red light and a truck almost cleaned me up.”

Being Engaged

The experience of engagement and involvement for RRFM's during the IHT event was revealed through three shared meanings which emerged through RRFM's stories: (i) saying goodbye; (ii) focus on the patient; and (iii) seeking information. Families talked about the importance of having access to their loved one prior to transfer and being able to say goodbye. Diana's partner of over 10 years suffered a high level permanent spinal cord injury following a fall from the roof of their family home. Diana said:

“They all came in and they were putting him on the bed and I met the doctor that was going to be flying with him. I knew everything, I wanted to meet everybody... they just let me say goodbye to him. I mean his family were there and everything as well.... His mum’s like, “Okay, let’s go now,”... no, not until he goes out that door and I know he’s on his way because I just didn’t know – he was so fragile and I didn’t know what was going to happen to him.”

Families spent a great deal of their time at the bedside because they believed it was important to their loved one’s recovery. Amanda’s mother suffered an out-of-hospital cardiac arrest and prolonged cardiopulmonary resuscitation prior to her transfer to ICU. Amanda said:

*“Just holding her hand and talking to her and reading stories to her from *That’s Life*, and yeah, just talking to her loads and holding her hand. I was so confident that she was going to wake up, so I was really shocked when they (nurses) said that to me that she would not wake up... so I had a bit of a cry...then I was like, no, she’ll wake up...so then I started talking to her more and she started responding and so, we thought, oh, well, she’s responding, she’s going to wake up.”*

Some families found that they could maintain a sense of hope by actively requesting information from medical and nursing staff. Diana said:

“When I spoke with the spinal recovery team, I did ask like what the percentage rate of recovery was for people and they said it’s 5%, which he (partner) is going to be in that 5% for sure. But he’s got feeling all over, he can feel us touching him; some bits

are a bit patchy so the guy said that it goes up to 10% if he can feel things. We're just hoping, that's all we can do."

Being Vulnerable

RRFM's experienced vulnerability during the IHT event and this was revealed through five shared meanings which emerged through RRFM's stories: (i) sense of shock; (ii) feeling the pressure; (iii) old wounds; (iv) financial burden; and (v) threatened breakdown of family. Families described how they initially felt they coped and understood information they were receiving, however, this changed once the transfer was completed and their loved one was admitted to the ICU. After feeling unwell for several days, Dave's wife deteriorated rapidly and she required urgent neurosurgical intervention. Dave said:

"It was a shock when the doctor came in...My head just wasn't there. My brain wasn't there... No, I sucked in a fair bit in our local rural hospital. But I think then the reality of what happened to my wife set in with me."

Relocating to a new environment and uncertainty in relation to the outcome of the transfer caused family members significant concern and stress. Over time the build-up of pressure led to a decline in the family member's own health. Amanda said:

"Sleep, what's that strange thing... not a lot of sleep. I actually collapsed here (in the ICU) twice from lack of sleep. Just from the stress and being tired, 'cause it's hard to sleep when you're so worried."

Seeing their loved one close to death in the ICU caused some families to relive past traumatic events. Stella's husband of over 40 years suffered a severe head injury as a result of falling from the roof of their home. Stella said:

"This is very similar to when he died (son). You sort of, you go through the motions but you have no idea what you did from one day to the next sort of thing, you know, and it is you sort of go into a limbo state. You're functioning but you're not really, you know. It's hard to describe."

For families, the need to be present and accommodated in close proximity to their loved one created a new and unexpected situation. The interviews revealed relatives' growing concern regarding the financial burden of an IHT. Kate's son was involved in a serious motor vehicle accident which resulted in him suffering a significant spinal cord injury and multiple minor injuries. Kate said:

"Coming down here with Brian's (son) accident has pretty much drained all our savings...and I've tried Centrelink. You can't get anything out of them. 'Cause Brian (son) is still in hospital, I can't get any money. So we just keep draining our bank account because we still have to pay rent up home. We still have bills coming in... that don't stop."

This event caused families significant turmoil which led to internal conflict and threatened to breakdown the family unit. Amanda said:

“Just living in each other pockets and having to feed and just having to pay for so many people, just puts a strain on you. And everything’s just caused lots of tension, and then there’s tension over mum...the family’s fallen apart now.”

Being Resilient

RRFM’s displayed resilience during their experiences and this was evident in the three shared meanings which emerged through RRFM’s stories: (i) holding it together; (ii) sense of support; and (iii) life goes on. Despite the uncertainty, families talked about their need to maintain hope and to be constructive in their thinking when thinking about the future. Kate said:

“But we’ve had to stay positive. I didn’t want him (son) to start thinking that just because he couldn’t use his legs ever again that life was over. It’s not over; it’s just a different way of life.”

The IHT journey gave many family members the opportunity to reflect and recognise the value of the support they themselves were receiving from extended family and friends. Dave said:

“I think the family thing is the big thing...without them I don’t think I’d be sitting here talking to you today, I’d be a mess somewhere, probably over there on the sidewalk...I lay there in bed and think about it and – while they’re all, yak, yak, yakking, but if you didn’t have like have them there, I’d be a basket case and my wife wouldn’t know where I was.”

The need to continue on with important life events was revealed in the interviews with family members as being significant. Dave said:

“My son and daughter in law only got married the week after my wife got crook... that night here (in the ICU), with my sister-in-law and our son and his future wife, we had a talk and we knew my wife would want to go ahead with it, so everything went ahead.”

Discussion

Rural and remote families experience significant disruption to family life when a critically ill relative is required to undergo an IHT. Being confused, Being engaged, Being vulnerable and Being resilient emerged as significant aspects of the family's experience. Limited research has been undertaken to inform ICU staff how to assist families who are involved in an IHT.

Initially, being confused emerged as a significant aspect within each family's journey and was expressed through feelings of uncertainty and disorientating thoughts. The need for regular and clear information and support in relocating to a new environment was a salient issue for families in this study. This finding is consistent with other literature²⁰ in which common needs of family members of all patients in an ICU were: (1) to know about their condition, progress and prognosis; (2) to feel hope; (3) to receive daily information in an understandable form; (4) to be contacted at home for any change in condition; and (5) to be reassured that staff care for the patient and are providing the best possible care. Other researchers concur that practical needs, such as finding accommodation and transport, increase with the number of dependent children and the distance between their home and the hospital.

²¹⁻²³ Studies also report that hospitals give low priority to meeting the practical needs of family members.²¹⁻²³

Being engaged was a central experience for all families in this study. Being by the bedside in ICU is the preferred place of relatives.^{24,25} In this study, family members talked about the importance of being with their relative at all times, sharing personal knowledge with staff, watching over them, and ensuring that everything was done in the best possible way. Similar findings have been described in other studies^{20,26,27} stressing the significance of an open visiting policy in ICU as it ensures the integrity of the family unit and allows families to contribute in meaningful ways as they attempt to regain control over an unpredictable experience.

Being vulnerable was a significant aspect of the families' experience in this study. However, the cause was not always a direct result of the IHT. Previous exposure to trauma, added financial burden and conflict within the family were factors that contributed to relatives' personal feelings of helplessness and isolation and have been reported elsewhere.^{21,22} Other ICU studies have also revealed that intense conflict can emerge among family members during a critical illness experience.^{31,32} Financial burden has been identified in other studies.³⁰ Public funds exist within Queensland to subsidise accommodation for an approved RRFM. At the time of this study, the accommodation subsidy was \$30/day. The average cost of local accommodation near the ICU was \$770/week and is an amount most families would not budget for.

This notion of Being resilient and adapting has been reported earlier.³³ In this study, relatives employed a strategy of enduring in order to constantly watch over and support the patient. Enduring has been described as the way individuals 'get through' extraordinary physiological or psychological assaults or stressful conditions, and

remain intact.³⁴ The need for family members to have friends or other family members close by visiting the patient is unclear in the literature²⁰ This study however, indicates that families felt more supported with extended family present as they experienced social connections, were able to reconstruct a positive sense of self and regain equilibrium. Furthermore, RRFM's viewed the future in a constructive way when situated in a familiar and supportive network. It is unclear if this positive future perspective is shared by the RRFM's relative.

Implications and Recommendations

The findings of this study have important implications for the care provided to RRFMs involved in an IHT. A model of care to support families during this uncertain and chaotic period should: emphasise that staff provide regular, clear and timely updates; adapt accommodation information to each family, thus reducing feelings of helplessness and powerlessness³⁵; and formalise the practice of family involvement within IHT practice guidelines. Future research should attempt to understand if the findings of this study are representative of the Australian context. Furthermore, studies examining how to meet the information needs of RRFMs and develop resilience within these families is recommended.

Limitations of the Study

The limitations of this study include that it was conducted in a single tertiary ICU and the participants' relatives were admitted to the ICU suffering severe spinal or head injuries. Instead the findings can be transferred to similar situations and be modified to comply with the context.³⁶ One of the reported limitations of family interviews is the issue of the location of interviews which may affect participants'

responses.¹⁵ Within this study interviews were conducted with family members in a private room, beside the ICU waiting room. Families may have been more open about their experiences, especially any negative experiences, if the interviews were conducted outside the hospital environment. In these instances, however, the family members expressed their desire to stay in close proximity to their relative and share their IHT experiences.

Conclusion

Being confused, being engaged, being vulnerable and being resilient emerged as significant aspects of the family members' experience during an IHT. Understanding the personal concerns and barriers for families revealed aspects of care that were meaningful to them. This study supports findings from numerous other studies, that families of critically ill patients need information, assurance, proximity, support and comfort. ICU nurses have the ability to significantly influence the experience of rural and remote families during their IHT journey. This study emphasises the uniqueness of human situations and how rural and remote differences influence the family's experience. This study highlights the specific experiences of rural and remote families during an inter-hospital transfer journey to a tertiary ICU in Queensland, Australia. It also informs nurses of the meaningful ways in which they can support these families with the uncertainty and chaos experienced as part of this journey.

Table 1 RRFM characteristics

Age (years)	18-25	0
	26-35	2
	36-45	0
	46-60	1
	61-65	2
	66-75	2
Gender	Male	1
	Female	6
RRFM's residential location as per the ASGC-RA system	RA2- Inner Regional Australia	3
	RA3- Outer Regional Australia	4
Where you approved as an 'escort' under the PTSS?	Yes	5
	No	2
RRFM that lived with the patient?	Yes	5
	No	2
RRFM who identified themselves with a cultural group? (e.g. A&TSI)	Yes	-
	No	7
RRFM finances or ability to earn an income had been affected due to their relatives IHT?	Yes	6
	No	1
RRFM's highest level of education?	Less than high school	1
	High school certificate	2
	Some college/trade apprenticeship	1
	Certificate/Diploma	1
	Bachelor's degree	1
	Post graduate certificate degree or higher (Master, doctorate)	1

Abbreviations: RRFM = rural remote family member; ASGC-RA = Australian standard geographical classification – remote area; RA = remote area; A&TSI = Aboriginal and/or Torres Strait Islander; IHT = inter-hospital transfer.

Competing Interests

None

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