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Title page

Title:

Experiences of long-distance visitors to intensive care units at a regional major trauma centre in the United Kingdom: a cross-sectional survey

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Conflict of Interest: The authors declare no conflicts.

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TITLE

Experiences of long-distance visitors to intensive care units at a regional major trauma centre in the United Kingdom: a cross-sectional survey

ABSTRACT

Objectives: This study aimed to investigate the experiences of long-distance visitors of major trauma patients admitted to intensive care units at a regional major trauma centre (MTC).

Research Methodology/Design: Postal survey

Setting: Survey participants (n=103) at a regional MTC in England, United Kingdom, were identified from hospital records. Included were adult visitors (next of kin) of major trauma patients admitted to intensive care at the study site between January 2016 and July 2018, with ordinary residence located more than one hour's drive from the MTC.

Findings: Response rate was 45.6%. Median (range) driving distance between respondents' residence and the MTC was 57.8 km (28.8-331.5). Median (range) number of days respondents visited at the MTC was 18 (1-200). The quality of care at the MTC was rated highly. Visitors described their often-challenging circumstances, negotiating the emotional, psychological, physical and financial impact of the situation. Suggested areas for improvement included car parking, signposting on and around the MTC site, information provision, waiting areas, and accommodation at or nearby the MTC.

Conclusions: This study has described experiences of long-distance visitors at one regional MTC in England and identified opportunities to ameliorate visitors' stress points locally. Replication at other regional MTCs may be warranted.

Keywords:

Adult intensive and critical care

Experience

Major trauma

Patient visitors

Regional/tertiary centre

Survey

IMPLICATIONS FOR CLINICAL PRACTICE

- This has been the first study addressing the issue of long-distance visiting in major trauma care in the United Kingdom, providing important data on an under-researched aspect of regionalised major trauma care.
- Long-distance visiting can put relatives under considerable strain, and there is a need to consider implications of service regionalisation on families who travel from far.
- Care providers and policymakers may incorporate recommendations for periodic service evaluation and improvement cycles with a focus on long-distance visitors into major trauma care guidelines and standards.

INTRODUCTION

Major trauma describes serious and often multiple injuries where there is a strong possibility of death or disability. The most common cause for major trauma in England is road traffic accident. In 2010, the National Audit Office (2010) estimated that there are at least 20,000 cases of major trauma in England each year, out of which 5,400 result in death. Non-fatal cases of major trauma often lead to life-changing disability and long-term care needs.

Over the past decade, the provision of major trauma care in England has undergone restructuring, from care provided at the geographically nearest hospital to specialised care provision at select regional major trauma centres (MTCs) (McCullough et al., 2014). MTCs have the necessary infrastructure to provide rapid and organised care, delivered by specially trained multidisciplinary teams. The first MTCs became operational in London in April 2010, and further regional centres and networks across England followed in April 2011 (Sleat and Willett, 2011).

Performance of MTCs is monitored by the Trauma Audit and Research Network (TARN, 2015). Since the inception of MTCs, there has been an improvement in the probability of survival after trauma in England, and a reduction in variation between centres through standardised care (McCullough et al., 2014; Davenport et al., 2010). As the major trauma infrastructure matures, further improvements in hospital care and patient outcomes can be expected (Sleat and Willett, 2011; Metcalfe et al., 2014). However, while service organisation and patient outcomes of the new major trauma pathway are undergoing continuous audit and evaluation, little attention has been paid to the experiences of visitors at MTCs.

A large body of literature is available to elucidate the needs and experiences of visitors to intensive care units (ICUs) in general (Kynoch et al., 2016; Ciuffo et al., 2011; Latour and Haines, 2007; Linnarson et al., 2010; Thalanany et al., 2006; Verhaeghe et al., 2005). Much of this

evidence has evolved around the concept of Patient- and Family-Centred Care (PFCC), a model of collaboration between and among patients, families and healthcare providers (Ciuffo et al., 2011; Latour and Haines, 2007). Qualitative and quantitative studies have shown how the emotional experience of visiting is often characterised by feeling overwhelmed, while wanting to guard and protect one's loved one by being near (*e.g.* by being observant and watchful of the care provided) (Vandall-Walker and Clark, 2011); and how communication between staff and visitors is crucial in meeting the need for accurate information that still leaves room for hope (Minton et al., 2019; Linnarson et al., 2010; McKiernan and McCarthy 2010; Thalanany et al., 2006; Verhaeghe et al., 2005). Furthermore, it is acknowledged that family members and friends play an important supporting role for seriously injured patients – during the patient's hospital stay, during the transition from hospital to discharge destination, and in the longer term through ongoing informal caring activities (Gibson and Houser, 2007; Thalanany et al., 2006; Kalassian and Angus, 2003; Swoboda and Lipsett, 2002; Johnson et al., 2001).

However, little attention has been paid specifically to the experiences of patient visitors at MTCs, and in particular visitors who may have to travel far from the peripheries of catchment regions. Visiting a family member or friend who requires intensive care presents a challenging situation in itself. This may be compounded by specific issues relating to major trauma care (*e.g.* the sudden change in circumstances, serious and uncertain clinical developments, and legal implications) and the practicalities of visiting at a tertiary centre that, owing to newly established regional catchment areas, may be located far away. There is therefore a need to explore whether the new major trauma care structure presents new challenges for visitors or shifts perspectives on already known issues. In particular, the practical and financial implications of travelling far (Thalanany et al., 2006) may become increasingly problematic for visitors who live in the more distant areas, or indeed outside the MTC catchment area.

This study therefore aimed to investigate the experiences of long-distance visitors of major trauma patients admitted to the ICUs at one regional MTC in England, in order to identify needs and opportunities for service improvement. Study objectives were (a) to explore and describe experiences of long-distance visitors; (b) to identify areas of good practice at the study site; and (c) to identify areas for service improvement.

METHOD

This was an anonymous postal survey of former long-distance visitors of major trauma patients admitted to the ICUs at the study site. Research ethics and governance approvals were obtained from the United Kingdom (UK) National Research Ethics Service (reference 17/EE/0381) and Health Research Authority.

Theoretical framework

This study was conducted on the principle of collaboration between users and providers of healthcare services, in the context of both service delivery and research. The underlying assumption is that such collaboration will contribute to improved quality and safety of healthcare delivery. Collaboration in healthcare has been conceptualised from different viewpoints and under different labels, for example as co-creation or co-design (Richards et al., 2016; Robert et al., 2015). Suited to the context and setting of this study, the research team drew on the collaborative concept of PFCC (Ciufo et al., 2011; Institute for Patient- and Family-Centered Care, 2017), which is a commonly utilised framework in intensive care research; complemented with the concept of Patient and Public Involvement (PPI) in research (INVOLVE,

2015, 2012), which provides a framework for operationalising collaboration in a research context (figure 1).

Touch points and opportunities for collaboration between service users, MTC staff and researchers were created throughout the course of the project. In spring 2016, PPI conversations were held with 7 long-distance visitors of major trauma patients admitted to the ICUs at the study site, to gain service user feedback on the relevance of this proposed research and to inform the grant application. From summer 2017, a service user advisory group of long-distance visitors was established. Study advisors were subsequently involved in several aspects of the study design and conduct (reviewing study materials, piloting the survey questionnaire, and participating in study steering group meetings and in the final dissemination event; figure 1).



Chronology of survey and strategies for collaboration

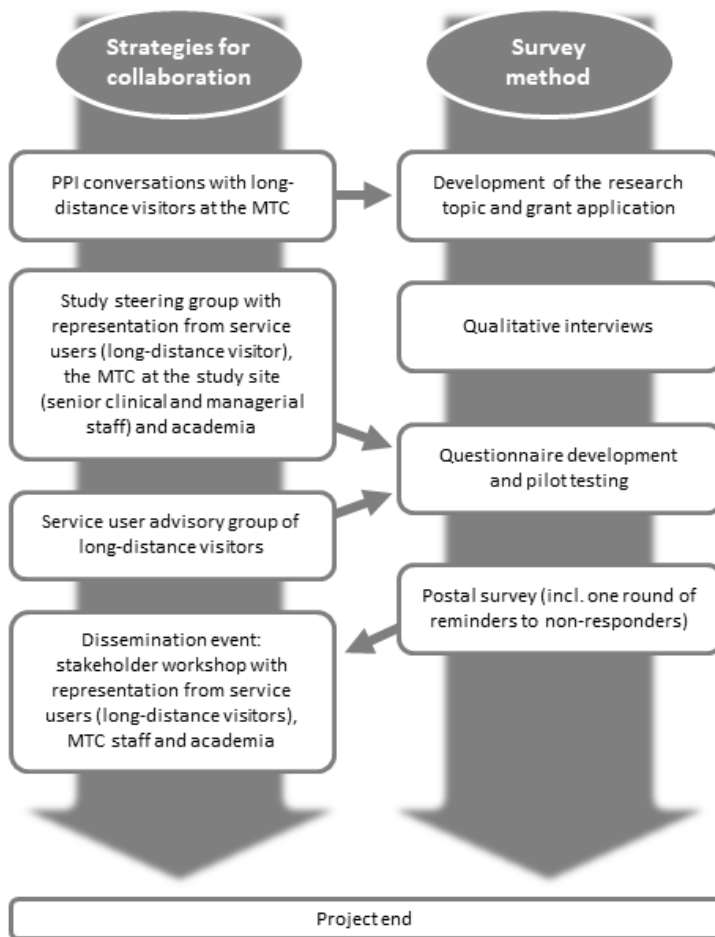


Figure 1. Theoretical framework, chronology of survey and strategies for collaboration (MTC, Major Trauma Centre).

Questionnaire development

No existing survey instrument was available to address the study aim, and a new questionnaire was developed following a thorough process (Brace, 2013). Questionnaire content and structure were based on semi-structured qualitative interviews with 10 long-distance visitors of major trauma patients who were at the time admitted to the ICU at the study site. All interviewees gave written informed consent. Interviews were audio-recorded, transcribed verbatim and analysed through thematic analysis (Braun and Clarke, 2006) using NVivo11 software (QRS International, 2017). Initial pilot testing of the draft questionnaire was conducted by all members of the study steering group (including a service user representative) in a group setting. Steering group members reviewed the draft questionnaire and articulated their understanding, thought processes and suggestions for improvements as they went through the questionnaire in a 'think out loud' method (Brace, 2013). For further pilot testing, the questionnaire pack was posted to 4 service user advisors, who individually completed the draft questionnaire at home and amended content, wording and layout. Service user advisors returned annotated questionnaires using the pre-paid response service that had been set up for the survey, thereby also testing the logistics of receiving responses at the research office. The finalised questionnaire comprised 63 items with multiple-choice, Likert-scale and free-text response options, covering the following domains:

- Relationship to patient, time period and home location when visiting
- The journey to and from the MTC
- Spending time at the MTC
- Visiting the dying patient
- Work and home life
- Own physical, psychological and mental wellbeing

- Staff values and standards of behaviour
- NHS England Friends and Family Test (NHS England, no date)
- Respondent socio-demographic information

Participants

Eligible were visitors (*i.e.* the designated next of kin and/or other family member or friend with a close relationship and significant involvement in the patient's circumstances and care) of patients admitted to ICUs at the study site under the major trauma care pathway, who were adults (18 years and over); and whose ordinary residence was further than one hour's drive away from the MTC (estimated driving time in mid-week mid-morning traffic according to Google Maps, 2018). This driving distance corresponded to the distance between the MTC and the furthest peripheries of its official catchment area. Visitors were excluded, if the patient had been admitted for less than 2 days.

Data collection

A survey sampling frame was compiled from hospital patient records, for all major trauma admissions from January 2016 to July 2018. Survey packs were posted to the documented next of kin. Where the next of kin's address was not given in the patient record, the survey pack was posted to the patient's residence and addressed for the attention of the next of kin. The survey pack included a cover letter, participant information sheet, researchers' contact details, the paper questionnaire, the link to an online version of the questionnaire, and a pre-paid return envelope.

Survey participation was anonymous. Informed consent was implied by respondents completing and returning the questionnaire. Participation was incentivised through a small donation for each completed and returned questionnaire, which was made to the hospital charity to benefit major trauma care. Survey packs were posted in May 2018. As a prompt to non-responders, a second survey mail out was conducted in August 2018.

Data analysis

Data analysis was conducted using Microsoft Excel (2016). Only completed questionnaires were included in analysis. Descriptive statistical analysis was conducted to summarise categorical and numerical data, using frequencies, percentages, mean, standard deviation median, upper and lower quartiles and range as appropriate. The driving distance between respondents' location of residence and the MTC was calculated using Google Maps (2018), entering the first part of respondents' home postcode and selecting the shortest suggested driving route. Qualitative data were analysed thematically.

RESULTS

Response rate and respondent characteristics

Out of 103 posted questionnaires, 47 completed questionnaires were returned, giving a response rate of 45.6%. Mean (range) item completion was 99.1% (88.9-100). Respondents' socio-demographic characteristics are given in table 1.

Table 1. Socio-demographic characteristics of the sample (n=47) and, where available, of the sampling frame (n=103)

Characteristic		Frequency (%) in the sample (n=47)	Frequency (%) in the sampling frame (n=103)
Sex	Female	40 (85.1%)	76 (73.8%)
	Male	6 (12.8%)	27 (26.2%)
	Prefer not to say	1 (2.1%)	-
Age group	under 20 years	-	-
	20-29 years	1 (2.1%)	
	30-39 years	4 (8.5%)	
	40-49 years	8 (17.0%)	
	50-59 years	16 (34.0%)	
	60-69 years	6 (12.8%)	
	70-79 years	10 (21.3%)	
	80 years and over	1 (2.1%)	
	Prefer not to say	1 (2.1%)	
Respondent's relationship to the patient	Parent (mother, father)	18 (38.3%)	28 (27.2%)
	Child (daughter, son)	3 (6.4%)	3 (2.9%)
	Other family member	1 (2.1%)	9 (8.7%)
	Spouse (wife, husband, civil partner)	23 (48.9%)	38 (36.9%)

	Neighbour	-	-
	Friend	1 (2.1%)	-
	Partner	1 (2.1%)	14 (13.6%)
	Other (e.g. former spouse)	-	4 (3.9%)
	Not given	-	7 (6.8%)
Day-to-day activities limited by a health problem or disability	Yes, limited a lot	6 (12.8%)	-
	Yes, limited a little	7 (14.9%)	
	No	32 (68.1%)	
	Prefer not to say	2 (4.2%)	
Marital status	Single / unmarried	4 (8.5%)	-
	Married / civil partnership	34 (72.3%)	
	Separated	2 (4.2%)	
	Divorced	2 (4.2%)	
	Widow / widower	5 (10.6%)	
Ethnic group	Asian / Asian British	-	6 (5.8%)*
	Black / African / Caribbean / Black British	-	1 (1.0%)*
	White / White British	43 (91.5%)	71 (68.9%)*
	Mixed / multiple ethnic groups	1 (2.1%)	1 (1.0%)*
	Other	1 (2.1%)	5 (4.8%)*

	Prefer not to say	2 (4.2%)	-
	Not given	-	19 (18.4%)*
First language	English	45 (95.7%)	-
	Other	3 (6.4%)	
Highest completed level of education	Primary school or less	1 (2.1%)	-
	Secondary school	13 (27.7%)	
	Tertiary / further education	29 (61.7%)	
	Other general education	1 (2.1%)	
	Prefer not to say	3 (6.4%)	
Accommodation	Owner occupied flat or house	32 (68.1%)	-
	Privately rented flat or house	2 (4.2%)	
	Rented from local authority / council or housing association	10 (21.3%)	
	Prefer not to say	3 (6.4%)	
Employment	Paid employment	20 (42.6%)	-
	Self employed	4 (8.5%)	
	Student	-	

	Homemaker (housewife / husband)	3 (6.4%)	
	Retired	17 (36.2%)	
	Unemployed	1 (2.1%)	
	Other	1 (2.1%)	
	Prefer not to say	1 (2.1%)	
Main income source	Salary / wage	21 (44.7%)	-
	State benefits	4 (8.5%)	
	Pension	15 (31.9%)	
	Family support (e.g. from spouse)	2 (4.2%)	
	Prefer not to say	5 (10.6%)	
Annual total personal income after tax	up to £2,599	-	-
	£2,600 - £5,199	1 (2.1%)	
	£5,200 - £10,399	2 (4.2%)	
	£10,400 - £15,599	7 (14.9%)	
	£15,600 - £20,799	7 (14.9%)	
	£20,800 - £25,999	6 (12.8%)	
	£26,000 - £31,199	1 (2.1%)	
	£31,200 - £36,399	2 (4.2%)	
	£36,400 - £41,599	-	
	£41,600 - £46,799	1 (2.1)	
	£46,800 - £51,999	5 (10.6%)	

	£52,000 or more	4 (8.5%)	
	Prefer not to say	11 (23.4%)	
*ethnicity of the patient, which may differ from ethnicity of next of kin			

Time period and duration of visiting

During the survey reference period (January 2016 to July 2018), the median (range) number of participating visitors per month was 3 (0-10); patients' length of admission at the MTC was 25 days (4-212); and number of days respondents visited at the MTC was 18 (1-200). Relative to patients' length of stay, respondents visited on 16.7% to 100% of days (median 97.4% and lower quartile 70.7% of days).

Visitors' location of residence

The location of survey addressees' ordinary residence is shown in figure 2. The median (range) driving distance between respondents' residence and the MTC was 57.8 km (28.8-331.5), with a lower and upper quartile of 43.8 and 81.0 km, respectively. For 40 respondents (85.1%), this location was also where they travelled from most of the time. Three visitors (6.4%) stayed nearby the MTC for the majority of the time, and 4 (8.5%) stayed at a relative's or friend's residence for most of the time, but not nearby the MTC.

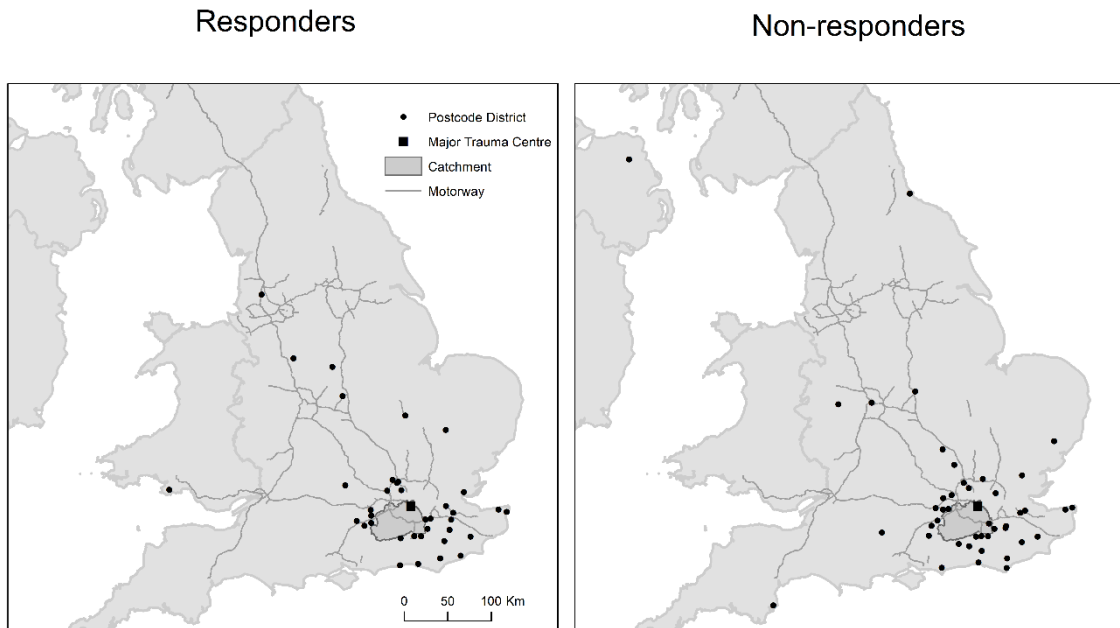


Figure 2. Survey addressees' location of residence. Indicated are United Kingdom postcode districts of responders (n=47) and non-responders (n=56). Some postcode districts include multiple addressees (data not shown).

Travel to and from the Major Trauma Centre

Thirty-five respondents (74.5%) travelled to and from the MTC mostly by car, and 12 (25.5%) mostly by public transport. Respondents' estimates of the average duration of a one-way journey from their home to the MTC ranged from 45 minutes to 4 hours (mean (SD) 103 (45) minutes, median 90 minutes, interquartile range 75-120).

Out of 47 respondents, 15 (31.9%) found car parking at the MTC to be good or very good; 19 (40.4%) found it requires improvement or urgent improvement; 5 (10.6%) found it neither good nor requiring improvement; and 8 (17.0%) never needed car parking.

Forty-four respondents (93.6%) provided estimates for the average cost of one return journey (round trip) from their home to the MTC. Estimates were based on public and/or personal

transportation (mileage, petrol, parking charges), and ranged from £5 to £80 (mean (SD) £22.4 (16.2), median £18.9, interquartile range 10.75-25).

Staying overnight at or near the Major Trauma Centre

Nineteen respondents (40.4%) had stayed overnight at or near the MTC, and 28 respondents (59.6%) had not. The number of overnight stays ranged from 1 to 30 (median 5, interquartile range 2-10). Relative to patients' length of stay, the majority of visitors (n=11) spent up to 20% of the patient's admission duration staying at or near the MTC, and a minority of visitors (n=3) spent over 80% of the patient's admission duration staying at or near the MTC.

Out of 19 respondents who had stayed overnight at or near the MTC, 11 had used paid accommodation, and 8 had not. The mean (SD, range) cost of paid accommodation per night was £71.4 (11.9, 60-100). Those who had not paid for overnight accommodation reported staying in the hospital waiting room, sleeping in their car, or staying with friends.

Spending time at the Major Trauma Centre

At the MTC, most respondents spent the majority of their time visiting at the neurological ICU (n=26, 55.3%), followed by different wards (n=12, 25.5%), the general ICU (n=7, 14.9%), and the cardiothoracic ICU (n=2, 4.2%). Respondents' ratings of their experience of different aspects of visiting are given in table 2. Table 3 gives an overview of suggestions for improvement from respondents' free-text survey responses.

Table 2. Experience of different aspects of visiting

Experience	Response (Frequency, %)						Total number of responses
	Very good	Good	Neither / nor	Needs improvement	Urgently needs improvement	Don't know	
Being introduced to the unit / ward and hospital when you first came	11 (23.4%)	17 (36.2%)	7 (14.9%)	8 (17.0%)	-	4 (8.5%)	47
Being able to access the unit / ward	15 (31.9%)	26 (55.3%)	3 (6.4%)	1 (2.1%)	-	2 (4.2%)	47
Getting information about the care of your family member or friend:							

	from nurses	15 (31.9%))	22 (46.8%))	3 (6.4%)	4 (8.5%)	2 (4.2%)	1 (2.1%))	47
	from doctors	13 (27.7%))	17 (36.2%))	4 (8.5%)	9 (19.1%)	2 (4.2%)	2 (4.2%))	47
	from therapists	6 (13.6%))	17 (38.6%))	10 (22.7%))	6 (13.6%)	1 (2.1%)	4 (8.5%))	44
	Getting information about amenities and facilities on site (cafés, shops, cash points, etc.)	5 (11.4%))	13 (29.5%))	11 (25.0%))	9 (20.4%)	3 (6.8%)	3 (6.8%))	44
	Spending time:							
	at the bedside	18 (39.1%))	20 (43.4%))	4 (8.7%)	3 (6.5%)	-	1 (2.2%))	46

in the visitor waiting room/are a	6 (13.3%))	18 (40.0%))	7 (15.6%))	12 (26.7%)	-	2 (4.4%))	45
Visiting hours	13 (27.7%))	25 (53.2%))	2 (4.2%)	6 (12.8%)	-	1 (2.1%))	47
Signposting inside the hospital and hospital grounds	10 (21.3%))	24 (51.1%))	7 (14.9%))	4 (8.5%)	-	2 (4.2%))	47

Table 3. Suggestions for improvement from free-text survey responses (number of respondents and example quotes)

Suggestions for improvement	Number of respondents	Example quotes
Car parking	11	<i>No allocated parking for anyone in ICU or A+E. Sometimes busy and wouldn't always get a space unless I arrived early. (R36)</i>
Accommodation nearby	8	<i>Hotels are very expensive in area, would be good if the first few days hospital could provide a bed maybe. (R2)</i>

Signposting on the hospital site	8	<i>The staff were amazing and friendly, but at times it was difficult to get directions easily by asking staff or signposts, also it is not easy for people who may be disabled and visiting. (R34)</i>
Experience on ICUs better than on the wards	7	<i>We could not have had better treatment than at ICU. At/on the wards things/circumstances can be improved. (R42)</i>
Signposting to the hospital site	6	<i>Better signposting on the streets leading to the hospital would have been much better as we were new to the area. (R41)</i>
Waiting area	6	<i>The time we spent at the hospital, the waiting room was full and so there was no time to sit and reflect on your situation. Also, it was always very noisy. (R18)</i>
Personal support and advice	2	<i>Regular scheduled support drop-ins by staff who can sign-post relatives & visitors. (R42)</i>
Chairs at the bedside	1	<i>CHAIRS for visitors – I appreciate this is difficult in an ICU/trauma ward. Two per bedside would be good. (R23)</i>
A+E, Accident and Emergency; ICU, Intensive Care Unit		

Visiting the dying patient

Five respondents (12.8%) commented on their experiences of terminal care at the MTC. These free-text responses described general appreciation for the kindness and efforts of staff to

accommodate visitors during this time; and some difficult experiences unrelated to the issue of long-distance visiting.

Work and home life

Twenty-three respondents (48.9%) said the situation had affected their ability to work. Ten respondents (21.3%) had not been affected in their ability to work, and 14 respondents (29.8%) had not been working at the time. Out of those whose ability to work had been affected, 16 (69.6%) did not have any loss of income by using annual leave, compassionate leave, sick leave, unpaid leave or flexible work arrangements. Seven respondents (30.4%) reported mean (range) loss of income of £1,114 (150-2,700) for the entire time period of visiting at the MTC.

Sixteen respondents (34.0%) needed to make arrangements for dependants to be looked after, and 31 (66.0%) did not. Arrangements were made for children (n=6, 37.5%), dependent adults (n=2, 12.5%) and pets (n=8, 50.0%). Four respondents (25.0%) reported additional costs due to these arrangements. Additional costs were estimated at £30, £200 and £1000 by 3 respondents, and one respondent was unable to provide an estimate. Twelve respondents (75.0%) who did not have additional costs received assistance from family members, neighbours and friends.

Twenty-nine respondents (61.7%) said they had spent more than usual on food and drink for themselves while visiting at the MTC, with a mean (range) cost of £12 per day (5-30).

Being a long-distance visitor of a major trauma patient

Out of a given list of words and phrases in the questionnaire describing the experience of visiting, the most frequently selected were: *stress* (85.1%), *worried* (83.0%), *emotional* (80.9%), *shock* (76.6%), *unexpected* (68.1%), *comfort in knowing they are getting the best care* (68.1%), *take it one day at a time* (66.0%), *tiring* (63.8%), *not sleeping well* (57.4%), *appreciative* (57.4%), and *very distressed* (51.1%). Additionally, survey respondents expanded on their experience in free-text comments, which signified three aspects (themes): (a) shock, anxiety and worry about the patient, their survival and recovery; (b) efforts in planning and organising the practicalities of visiting, including financial implications of the situation; and (c) the emotional and physical drain of visiting. The following quotes illustrate the profound impact of circumstances on visitors:

[It was] like being in a bubble watching the world go by, life shattering, anxious, ironic (R1)

While my husband was in the hospital, I had no home life. My life was visiting the hospital. (R3)

I had no capacity left for my own wellbeing. My sole focus during the day was my daughter's welfare. (R12)

[It was] Like an 'earthquake' with my son being the epicentre and us reverberating with aftershocks! "Suspended animation"! (R15)

Home life did not exist, it was: up – hospital – lunch – hospital – home – feed cats – eat – bed. The same again for those weeks [...] totally exhausting & financially draining. [...] Our health & wellbeing went out the window!! (R27)

Staff values and standards of behaviour

Asked to rate their experience against the values and standards of behaviour expected from staff at the study site, the majority of respondents agreed or strongly agreed that staff at the MTC were excellent (n=42, 89.4%), kind (n=43, 91.5%), responsible (n=39, 84.8%) and respectful (41, 89.1%).

NHS Friends and Families Test

Forty-six respondents completed the first question of the NHS Friends and Family Test ('How likely are you to recommend the major trauma centre to friends and family if they needed similar care or treatment?'). Forty-two visitors (91.3%) responded 'extremely likely' or 'likely', 2 (4.4%) responded 'neither likely nor unlikely', 1 (2.2%) responded 'unlikely', none responded 'extremely unlikely', and 1 visitor (2.2%) responded 'don't know'. Forty-one respondents expanded on their rating in free-text answers, which were largely complimentary and highly appreciative of the care received:

My husband is still here! I genuinely believe that if he had suffered his trauma locally and been taken to a local hospital – he may not be here with me now. (R8)

There is no other hospital I know with the facilities to treat my husband's injuries. I am eternally grateful for the care and attention given to my husband in the ICU that led to him being alive today. (R33)

DISCUSSION

This has been the first study to address the issue of long-distance visiting in major trauma care in the UK, describing experiences of long-distance visitors at one MTC in England using a survey design. Of 47 survey respondents, the majority were female (85.1%), ≥40 years old (87.2%), and either the patient's spouse (48.9%) or parent (38.3%). Long-distance patients' length of stay varied widely and averaged 25 days. Visitors attended on average 18 days. Relative to individual patients' length of stay, three quarters of visitors came to see the patient for at least 70% of the patient's admission, and half visited almost daily. The average driving distance from visitors' home to the MTC was 58 km. On average, visitors' daily round trip to and from the MTC took 3 hours and 26 minutes and costed £22.40 per day, or £403.20 for the entire period. Visitors rated the staff and the quality of clinical care at the MTC highly and expressed their gratitude and appreciation for the major trauma service. Visitors also described often challenging circumstances, having to negotiate the emotional, psychological, physical and financial impact of the situation. Several areas for improvement were highlighted, which present opportunities to ameliorate (at least to some extent) visitors' experience during this difficult time: car parking, signposting and information provision about amenities and facilities on site, receiving information about the patient's care from doctors, waiting areas, accommodation at/nearby the MTC, discrepancies between ICUs and wards, and signposting on local roads to the MTC.

With respect to visitors' experiences, findings from this study align with other research. A recent qualitative study from a trauma unit in the United States described the experiences of 12 trauma caregivers as 'life interrupted', highlighting the impact of sudden change in circumstances and exposure to tragedy, and the importance of access to the patient, information provision, and communication between service provider and caregivers (Newcomb and Hymes, 2017). Similarly, a recent literature review of needs of families of ICU trauma patients echoes findings from the present study, for example the importance of 'being

there' for the patient, information provision, and support regarding different aspects such as financial, emotional, practical, spiritual and general guidance in relation to the ICU and hospital environment (Wetzig and Mitchell, 2017). While these authors acknowledge that trauma patients form a unique population within the ICU, and their families have specialised needs, the issue of long-distance visiting at a tertiary trauma centre features little in the literature. The present study therefore provides data on an important under-researched aspect. The Care Quality Commission in the UK carries out regular inspections of NHS hospitals, which also capture some of the points covered in the present survey; however, these inspections take a more general view and focus on standardised questions of service performance (are services safe, effective, caring, responsive to people's needs, and well-led). In contrast, the survey method employed in the present study allowed the collection of targeted data from a select, yet relatively representative sample. For the purpose of identifying concrete priorities for improvement in this context, this may be regarded a preferable method over small qualitative studies or generic quality assurance procedures. The inclusion in the questionnaire of a number of open-ended survey questions gave respondents the option to provide in-depth qualitative answers and highlight concerns that otherwise might have been missed.

In accordance with the concept of PFCC, the present study was based on the premise that ICU healthcare providers should facilitate family members' involvement and participation in the patient's care, and that relatives should be supported to be near and spend time with the patient. This premise is based on the principle of humanistic healthcare and 'doing the right thing'. But there is also an emerging evidence base that PFCC can lead to improved quality and safety of healthcare, decreased costs, and increased provider and patient/family satisfaction (Institute for Patient- and Family-Centered Care, 2017). A recent systematic review investigated PFCC interventions that focussed on information/communication, and respect for patient/family values, preferences and needs in ICU. Positive effects were identified for

patient/family satisfaction and mental health, achievement of medical treatment goals, and ICU costs and length of stay (Goldfarb et al., 2017). Another recent systematic review found that communication interventions could promote family involvement and decision-making in the patient's care and improve clinician and family interaction; and that comfortable physical environments could increase family satisfaction, although the evidence was limited by a lack of high-quality intervention studies (Kynoch et al., 2016). Addressing areas for improvement that have been highlighted in the present study may result in similar positive effects locally.

The issue of long-distance visiting at tertiary/regional centres, and in particular the financial implications for visitors, has been explored to some extent in contexts other than major trauma, for example in tertiary ICUs serving rural and remote areas in Australia (Mackie et al., 2014), but mostly in paediatrics, where the premise that parents should be near their minor child is perhaps most intuitive (Callery, 1997). The present study has provided some data to quantify the potential financial burden to long-distance visitors of major trauma patients at one MTC in England. It has also demonstrated that, although visitors rated the clinical service and standard of care at the MTC highly, long-distance visiting puts relatives under considerable strain. This research therefore links with one of the top-ten intensive care research priorities identified by the James Lind Alliance (Reay et al., 2014): *How can we use the experiences of patients and families to improve intensive care?* While the many clinical and operational benefits of regionalised major trauma care are acknowledged (Kahn et al., 2008; Willett, 2009), this study has highlighted the need to consider implications of service regionalisation on families who travel from far. Accordingly, MTC providers and policymakers may include recommendations for periodic service evaluation and improvement cycles with a focus on long-distance visitors in major trauma service guidelines and standards. At the study site, this research has provided evidence from which improvement projects can now be developed, leading to locally relevant service improvement. Future work could replicate this research at

other MTCs, which is likely to identify common issues across the major trauma network, in addition to site-specific issues.

Study limitations

The study is limited by the fair – rather than high – response rate of 45.6%; however, the high completion rate (99.1%) reflects good content validity and acceptability of the questionnaire. High completion, together with the fact that respondents who visited 2 years prior were motivated to respond, also demonstrates that the topic resonates with service users. Non-response may to some extent be due to change of address, of which the tertiary centre was not informed, or other change in circumstances. In compiling the list of survey addressees, some long-distance visitors may have been missed due to our method of identifying visitors via the patient's postcode in the first instance. Therefore, if patients resided near the MTC but their next of kin lived far away, these visitors would have been missed. Also, we sought the views of relatives of patients who were admitted to the ICU (as opposed to the wards) because the impact of the trauma and its consequences were likely to be particularly severe for these families. Response bias presents a possible limitation and was assessed by comparing gender, relationship to patient and ethnicity between responders and non-responders. Female visitors, parents or spouses of patients, and respondents from a white ethnic background were somewhat more likely to respond. Visitors of patients admitted for less than 2 days were excluded from the survey, thereby screening out patients who had died soon after admission. This accounts for the small number of respondents commenting on terminal care and may also have contributed to possible 'survivor' bias, whereby favourable patient outcomes led to more positive ratings of the service. While the postal survey method ensured anonymity and standardised administration of the questionnaire, it is acknowledged that self-report and recall

bias present limitations inherent to this study design. In our PPI, we acknowledge that we had no representation from major trauma patients themselves, for example in our study advisory group or at the final dissemination event, but that this would be desirable. Although our approach was principally inclusive and patients were invited to contribute, a more focused effort may be required to include this patient group in PPI activities.

CONCLUSION

In summary, this has been the first study addressing the issue of long-distance visiting in major trauma care in the UK. The study has provided data to demonstrate that long-distance visiting can put relatives under considerable strain, thus supporting the need to consider implications of service regionalisation on families who travel from far. Care providers may address the issue by conducting service evaluation and improvement projects, to identify problems and implement solutions locally. At the level of healthcare policy and clinical governance, this may be supported by incorporating recommendations for periodic service evaluation and improvement cycles with an emphasis on long-distance visitors into clinical guidelines and standards for major trauma care. External agencies, *e.g.* policymakers and local planning authorities, may also learn from these findings, for example by including a focus on long-distance visiting in stakeholder consultations for the planning and configuration of healthcare services.

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