Family Satisfaction Survey

Melanie Gager, Sara Evans and Helen Vollmer
Intensive Care Unit, Royal Berkshire Hospital
Special thanks to...

* Sheila Hill, Sandra Barrow and Heather Winder, the bereavement team.
Family Satisfaction with Care in the Intensive Care Unit

FS-ICU (24)
How are we doing?
Your opinions about your family member’s recent admission to the Intensive Care Unit (ICU)

Your family member was a patient in this ICU. You have been recorded as being the “next-of-kin”. The questions that follow ask YOU about your family member’s most recent ICU admission. We understand that there were probably many doctors and nurses and other staff involved in caring for your family member. We know that there may be exceptions but we are interested in your overall assessment of the quality of care we delivered. We understand that this was probably a very difficult time for you and your family members. We would appreciate you taking the time to provide us with your opinion. Please take a moment to tell us what we did well and what we can do to make our ICU better. Please be assured that all responses are confidential. The Doctors and Nurses who looked after your family member will not be able to identify your responses.
Background: Patient experience

* ‘How can we use the experiences of patients and families to improve intensive care?’
* DOH has indicated that patient views are essential to achieving high quality of care

In 2010, NHS In London commissioned King’s College London and The King’s Fund to undertake research into: What Matters To Patients? Developing the Evidence Base for Measuring and Improving Patient Experience.
In critical care, there is a high mortality rate and patients often have little recollection of their experience.

Originally a questionnaire with 34 items developed in Canada in 2001. Least satisfaction with waiting room and frequency of communication with doctors across 6 ICUs.

Shortened to FS-ICU (24) in 2007.

2 main domains: satisfaction with care and satisfaction with decision making.

Good validity against other markers of ICU quality.
Background: UK perspective

- FREE study run by ICNARC.
- Aimed to establish internal consistency and construct validity and reliability of the FS-ICU and describe family satisfaction using the questionnaire
- 7173 family members from 4615 patients (58% response rate) from 20 ICUs
- Overall satisfaction was high and comparable to results from other ICUs internationally
- Significant variation in scores across the ICUs
- Satisfaction higher for family members of ICU non-survivors
The RBH FS-ICU (24) Survey

* 215 consecutive patients admitted between 01/10/15 and 01/01/16
* 2 patients had 2 admissions within the 3 month period
* 210 questionnaires sent out
* 96 questionnaires returned (45.7% response rate)
DEMOGRAPHICS:

Please complete the following to help us know a little about you and your relationship to the patient.

1. I am: □ Male □ Female

2. I am ________ years old

3. I am the patient's:
   □ Wife □ Husband □ Partner
   □ Mother □ Father □ Sister □ Brother
   □ Daughter □ Son □ Other (Please specify): _________________

4. Before this most recent event, have you been involved as a family member of a patient in an ICU (Intensive Care Unit)?
   □ Yes □ No

5. Do you live with the patient? □ Yes □ No

   If no, then on average how often do you see the patient?
   □ More than weekly □ Weekly □ Monthly □ Yearly □ Less than once a year

6. Where do you live? □ In the city where the hospital is located □ Out of town
Female 60 (62.5%), Male 36 (37.5%)
Age 60.4 +/- 15.7 yrs (mean +/- SD)
25.2% had previously experienced an ICU
71.6% lived with the patient at time of illness

How often do you see the patient?

- >Weekly: 67%
- Weekly: 15%
- Monthly: 7%
- Yearly: 11%
Relationship to patient

- Wife: 38%
- Husband: 19%
- Daughter: 14%
- Partner: 9%
- Son: 8%
- Mother: 7%
- Friend: 3%
- Cousin: 1%
- Brother: 1%
Part 1: Satisfaction with care

Symptom management: Agitation

- Excellent
- Very good
- Good
- Fair
- Poor
- N/A
- Not answered
Concern and caring by the ICU staff

5. Consideration of your needs
   How well did the ICU team show interest in your needs?

6. Emotional support
   How well did the ICU team support your emotional well-being?

7. Co-ordination of care
   The team who took care of you worked well together.

8. Concern and caring by the ICU staff
   The courtesy, respect and compassion you were given

Royal Berkshire NHS Foundation Trust
Skill and competence of ICU doctors

9. Skill and competence of ICU nurses
How we communicate with you about your condition and family member.

10. Frequency of communication with ICU nurses
How often was your family member included in these discussions?

11. Skill and competence of ICU doctors
How well we communicated with you about your condition and family member.
14. Some people were left out of the research while others were included. How satisfied are you with the level of healthcare your relative received in the study?
### INFORMATION NEEDS

1. **Frequency of Communication With ICU Doctors:**
   - How often doctors communicated to you about your family member’s condition
   - Possible responses: Excellent, Very Good, Good, Fair, Poor, N/A

2. **Ease of getting information:**
   - Willingness of ICU staff to answer your questions
   - Possible responses: Excellent, Very Good, Good, Fair, Poor, N/A

3. **Understanding of Information:**
   - How well ICU staff provided you with explanations that you understood
   - Possible responses: Excellent, Very Good, Good, Fair, Poor, N/A

4. **Honesty of Information:**
   - The honesty of information provided to you about your family member’s condition
   - Possible responses: Excellent, Very Good, Good, Fair, Poor, N/A

5. **Completeness of Information:**
   - How well ICU staff informed you what was happening to your family member and why things were being done.
   - Possible responses: Excellent, Very Good, Good, Fair, Poor, N/A

6. **Consistency of Information:**
   - The consistency of information provided to you about your family member’s condition (Did you get a similar story from the doctor, nurse, etc.)
   - Possible responses: Excellent, Very Good, Good, Fair, Poor, N/A
Did you feel supported during the decision making process?

- Totally overwhelmed: 35%
- Slightly overwhelmed: 13%
- Neither: 1%
- Supported: 4%
- Very supported: 42%
- N/A: 2%
- No Answer: 4%
Did you feel you had control over the care of your family member?

- Really out of control: 2%
- Somewhat out of control: 4%
- Neither: 4%
- Some control: 4%
- Good control: 24%
- N/A: 41%
- No Answer: 21%
Did you feel you had control over the care of your family member?

* ‘Leaving it to the experts.’
  (1 - Really out of control)

* ‘Which is what I want. I’ve no idea how to do ICU work.’
  (2 - Somewhat out of control)

* ‘The doctors needed to make decisions as was medical, but I was very happy with their decisions.’
  (3 - Neither)
When making decisions, did you have adequate time to have your concerns addressed and questions answered?

- Could have used more time: 80%
- Had adequate time: 11%
- N/A: 3%
- N/A: 6%
- No Answer: 3%

Royal Berkshire NHS Foundation Trust
47 out of 214 patients did not survive their ICU stay (21.9%)

18 out of 47 bereaved relatives completed the survey (38.3%)

[78 out of 167 relatives of survivors (46.7%)]

Bereaved relatives
If your family member died during the ICU stay, please answer the following questions (11-13). If your family member did not die please skip to question 14.

During the final hours, I felt

- Very abandoned
- Abandoned
- Neither
- Supported
- Very supported
- No answer

4. I felt supported by the health care team
5. I felt very supported by the health care team
Qualitative Feedback

* 99 responses -- 79 wrote comments
* Set questions – provided scope to add depth
* 3 questions that focussed on:
  * How to make care provided in ICU better?
  * Comments on things we did well
  * Comments/suggestions may be helpful to staff in the hospital
Suggestions to make care provided in the ICU better

* 44/79 responded
* 30 stated ‘nothing’ or ‘no’ on the continuum
* ‘Everything was perfect, superb’
* ‘I think the team does a FANTASTIC job! The area could definitely benefit from an upgrade though...’
* ‘No, Very efficiently run and supportive during difficult times.’
* ‘Absolutely none all staff were amazing had all our interests at heart. Just wish they had a magic potion so dad didn’t die.’
Suggestions to make care provided in the ICU better

- It would have been very helpful if it was explained to us the events that led up to my wife being transferred to the ICU.
- Maybe pre-warn family member how patient is doing before they see them. I was totally not prepared to see my mum in the state she was.
- ‘I appreciate the restrictions, but more frequent visits from doctors would have helped.’
Suggestions to make care provided in the ICU better

* 'My wife was reluctant to ask for the bed pan because its design was poor and she was soiled in the process of using it. Having said that, the staff were excellent in cleaning up with no fuss and little embarrassment’

* ‘The only thing I think that could make it better is for all staff to be aware that the stress and agitation a patient is feeling does not necessarily reflect how they are in their normal life, and being scared can have an impact on their condition.’
Comments on things we did well

* 67/79
* Staff – focus on all staff ‘even the cleaner’

* ‘Great respect’ ‘commitment’ ‘dedication’ ‘caring’
* ‘Efficient’ ‘compassionate’ ‘skilled’ ‘safe hands’
* ‘Professionalism’ ‘100% focused’ ‘supportive’
* ‘Everything was done to help our friend. We were so pleased that we donated what our friend had left in the bank to the ICU on his behalf.’
* ‘Not only did they look after my partner, they showed care and concern for me during one of the most stressful times of my life.’
Comments on things we did well

* Unit itself – culture and atmosphere

* ‘A very calm and helpful atmosphere made things easier for me and my family’

* ‘Above all everyone in the unit was calm and gave us confidence in what was going on. It was great to be in a place where information was freely given whether we asked or not.’

* ‘At all times on the unit, I was made to feel welcome and people recognised me and remembered my name. Please do not underestimate how much better that makes anxious relatives feel!!’
Comments on things we did well

* ‘On days when my partner was very agitated, I received a great deal of emotional support from staff and was encouraged to help in his care where it was appropriate. That gave me a great feeling of being able to do something rather than just observing and feeling helpless.’

* ‘Everything - you saved my mother's life - happy to be a tax payer with such a dedicated, quality service available!’

* ‘Access at all times. Made to feel welcome.’

* ‘Absolutely no complaints when husband in beds 1-9. Felt that (Bed 12) communication not quite so good but staff always ready to stop and speak to us’
Comments or suggestions that you feel may be helpful to the staff in the hospital

* 46/79
* 19 reinforcing great teamwork and thanks

* Trust wide issues: Parking, other wards, discharge into the community, hospital sign posting

* Unit issues: Buzzer entry, waiting room experience, transition anxiety, understanding the role of ICU, involvement in general care
Comments or suggestions that you feel may be helpful to the staff in the hospital

∗ ‘Entry system. I know that staff are involved in care of patients which should be the priority but sometimes the wait to get buzzed in was too long as anxious to see the patient. The wait increased the anxiety.’

∗ ‘I found the relative's waiting room to be a really good source of support at the RBH and JR. Talking about your experiences with others in the same position is very helpful. The only drawback I felt with the RBH waiting room is that there is no visitor toilet. It was sometimes quite difficult to get back on the unit through the security doors, especially if the nurses were busy. Providing toilet facilities in the unit might be something to consider although the constraints of the building might make this difficult.’
‘Might have been useful if someone had explained the role of ICU (for people who are unfamiliar and don’t follow medical soaps). E.g. the objectives of a stay in ICU and criteria for releasing to the ward’

‘We went home the first night because we thought he was going to recover. I would have stayed if I had known there was any chance he would not. Perhaps the staff also thought he would recover, that was the impression we got, but if they did not it would have been better to know the truth. I would have liked to speak to him again before he was sedated as we never spoke again,’
‘Go on doing what you do and in my and my family's opinion, you - the dept- cannot be better.’

I appreciate everything the staff in ICU did for me. They were all very professional and helpful. Fantastic people doing a great job. Thank you.’

‘If every team worked as hard as the ICU team the RBH would be one of the best hospitals in England. Please keep up your great work.’

‘ICU Reading is a great example of top notch care. When all hope is lost, they find a way. You guys are great, next best thing to God.’
Strengths and limitations of this survey

- Well validated survey that has been used across developed countries, particularly in North America and has been recently validated in the UK (ICNARC Free study).
- Family members are more likely to have clearer memories of the ICU than the patients in many cases.
- Subject to response bias.
- Low response rate.
- Need to avoid sending questionnaire twice to re-admissions.
- Not appropriate for bereaved relatives.

“I find the present tense distressing. My husband is dead. I am no longer his wife but his widow. I no longer live with him. Perhaps the questionnaire should be reframed for the bereaved.”
Conclusions

* Something to be proud of!

* BUT....
Room for improvement?

ALWAYS!

* Communication:
  * Dissemination of a summary of relative’s comments to all unit staff
  * Poster in relatives waiting room explaining what to expect when patients are admitted
  * Family ward rounds
  * Identify those who may need more time/support/communication
  * Awareness of relatives in waiting room

* Logistics:
  * Facilities for relatives – larger waiting room with new build!
  * Entry system
Measuring family satisfaction with care in the intensive care unit: the development of a questionnaire and preliminary results.
Heyland DK1, Tranmer JE; Kingston General Hospital ICU Research Working Group.

Family satisfaction with care in the intensive care unit: results of a multiple center study.
Heyland DK1, Rocker GM, Dodek PM, Kutsogiannis DJ, Konopad E, Cook DJ, Peters S, Tranmer JE, O'Callaghan CJ.

Refinement, scoring, and validation of the Family Satisfaction in the Intensive Care Unit (FS-ICU) survey.
Wall RJ1, Engelberg RA, Downey L, Heyland DK, Curtis JR.