Being Present During the Resuscitation of a Loved One: Family Members’ Perspectives

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Dedication: To Family Members

Funding Acknowledgement

- Manitoba Medical Services Foundation (MMSF)
- American Association of Critical Care Nurses (AACCN)
- Canadian Intensive Care Foundation (CICF)

Statement of the Problem

- Historically, family presence not allowed during CPR in hospital
- Staff concerns re:
  - psychological impact on family members and
  - disruption of resuscitation efforts

Health Care Personnel Perspectives

- Mixed opinions and variety of concerns expressed by health care personnel despite positive consequences identified by FMs

- Attitudes and opinions of doctors and nurses appear to be primary obstacles of family being present in Resuscitation Room (Artley 2003)

Health Care Personnel Perspectives

- Fear is a primary reason: (Belanger & Reed, 1997)
  - Fear that family may interrupt staff performance
  - Fear that staff emotions may be evoked
  - Fear of legal ramifications
  - Fear of giving up control

- May be too traumatic for relatives (Robinson et al., 1998)
Health Care Personnel Perspectives

- These concerns have not been borne out in the literature
  - No legal ramifications reported by Foote Hospital (MI) since 1992
  - Contrary to belief re traumatic event, FP has shown to have psychological benefits for FM (Clark et al., 2001; Martin 1991; Robinson et al., 1998)
  - In one RCT in ER, study stopped early b/c randomization process was threatened as staff became convinced of benefits of allowing FM to witness resuscitation (Robinson et al., 1998)

Exclusion of family members now being questioned

Statement of the Problem

- Impetus for change
  - Consistent with principles of family centered-care
  - In home resuscitations
  - Survival to discharge after in-hospital cardiac arrest <15% (AHA, 2000)
  - Historical pattern – deliveries/c-sections (Shu, 1973)
  - Consumer driven

Family Perspective

- Empirical evidence suggests “being present” or attending a “witnessed resuscitation” (Ackerly 2003) may afford positive benefits for family members
  - Hanson & Strawser (1992)
    - 9-year study at Foote Hospital (MI)
    - Retrospective survey of 47 bereaved families
    - 76% felt their adjustment to death of loved one made easier by their presence in the resusc room

Chicago Tribune

July 24, 2006
By Judith Graham (Chicago Tribune Staff Reporter)

Emergency rooms find place for family: Hospitals see value in having loved ones present during life-and-death moments of trauma care
Family Perspective

Myers et al., (1998)
- Survey of 25 FMs
- 80% would have wanted to be present during resuscitation
- 96% believed that individuals have the right to be present if they desire

Clark et al., 2001
- Witnessing resuscitation helps remove doubts of FMs of what is happening to patient and reinforces that everything possible was done.

Downey (2005) reported on high stress levels and anxiety families experience when left in the waiting room
- Encouraged health care professionals to not let the everyday routines and technical skills interfere with the human side of the job.

Why Are We Studying FPDR?
- Methodological limitations of previous works (retrospective designs: survey data)
- Lacking is:
  - Prospective studies to assess likelihood of interference by FMs (McLennan et al., 2002)
  - Canadian data
  - Perspective of Family Facilitators
- Limited information on personal experiences of family members/health care providers bearing witness to resuscitation in hospital absent.
- Information from key informants needed to:
  - Better understand experience and
  - Provide foundation/direction for clinical practice

Purpose of the Study
- To examine & describe the experiences & perspectives of family members involved in hospital resuscitation of an adult in ICU/ER where family presence is practiced.
Methodology

- Descriptive-exploratory design
- Qualitative paradigm
- Appropriate given paucity of emic (insiders) perspective in the literature

Sample

- Purposive, convenience sampling of adult family members
- Goal - thick rich description to the point of saturation
- 28 family members witnessed resuscitations
- N=14 adult family members agreed to participate in interviews

Procedures

- Up-front work done to gauge receptiveness of health care provides & secure administrative support
- Ethical approval University of Manitoba REB
- Access approval from facility
- Multi-disciplinary working groups involved in development & implementation of study

FPDR Committee Subgroups

- Education Subgroup
- Implementation Subgroup
- Evaluation Subgroup

Protocol

- Process flowchart showing steps and decision points for the study.
Ethical Considerations

- “Bookmark” given to family member after resuscitation with brief explanation regarding contact at later date
- Family approached at 3 months (sensitive to grieving period) to determine willingness to participate in study
- Sympathy card

RESULTS

- Interviews transcribed verbatim
- Content analysis & constant comparative approach by 2 researchers (SM & WF)
- Demographic data → descriptive statistics
Sample Characteristics (N=14)

- Gender:
  - Male = 3 (21%)
  - Female = 11 (79%)

- Age
  - <20 = 1 (7%)
  - 20-29 = 0
  - 30-39 = 0
  - 40-49 = 3 (21%)
  - 50-59 = 4 (29%)
  - 60-69 = 2 (14%)
  - 70-79 = 2 (14%)
  - >80 = 2 (14%)

Sample Characteristics

- Witnessed patient being resuscitated outside hospital
  - No = 9 (64%)
  - Yes = 4 (29%)

- First time witnessing resuscitation
  - Yes = 10 (71%)
  - No = 4 (29%)

Sample Characteristics

- Relationship to Patient
  - Child = 7 (50%)
  - Spouse = 3 (21%)
  - Parent = 2 (14%)
  - Sibling = 2 (14%)

- Living with Patient
  - Yes = 5 (36%)
  - No = 9 (64%)

Benefits of Being Present During Resuscitation

- Family Member
- Patient
- Health Care Team

Benefits of Being Present

- Not abandoned left to wonder & worry
- Makes the situation “real”
- Assurance the team “did all they could”
- Understanding re decision to stop resuscitation

Findings

- Benefits & Burdens of being present
- Factors influencing the choice to be present
- Factors facilitating a positive experience
- Factors contributing to a negative experience
- Implications for practice
Benefits of Being Present

- Provide information to team and serve as proxy decision-makers
- Opportunity to talk to/touch patient
- Present during last moments of life - patient doesn’t die alone

Data Exemplar

- It would really not have been very good if I’d been sitting outside in the waiting room, waiting for someone to tell me what had happened. It would have been more difficult if I’d been on the other side of a door, and not able to see him take his last breath.

Data Exemplar

- I was thinking that it was the last time I was going to see her, and I wanted to be able to really talk and say my last word to her. I was able to hold her hand and whisper to her…

Data Exemplar

- I was just thinking about him and how he would be feeling wondering if he was conscious enough to know what was going on. He would have been very embarrassed…, I felt embarrassed for him……

Burdens of Being Present

- Concerns patient is experiencing pain from interventions
- Concern patient would be embarrassed if aware what was being done to him/her
- Residual bad memories of resuscitation scene

Factors Influencing Family Decision to Present/Not Present

- Past experience witnessing/participating in codes
- Past experience being with/caring for dying people
- Portrayal of resuscitation procedures in the media
FACTORS CONTRIBUTING TO POSITIVE & NEGATIVE EXPERIENCES

Nobody was unkind. They were all very kind, and the doctor and the people working around him. You could tell that they were doing their utmost for him. They were a team.

STAFF CARE TENOR

POSITIVE                           NEGATIVE
- kindness & compassion            - being asked about
- professionalism                  organ donation right
- maintaining patient dignity      after having witnessed
- working as a team

Data Exemplar

It was a way for me to see that all effort was put into helping her and knowing that it was all done and it was done professionally. That was very important.

INFORMATION & SUPPORT NEEDS

POSITIVE                           NEGATIVE
- explanations about what is happening
- emotional support provided
- clergy contacted if requested
- lack of clear communication re:
  a) status of patient when family brought to bedside
  b) ability “opt-out” of being present

Data Exemplar

She just stood beside me and just gave that touching, she touched me and just explained everything. She put her arm around me and well, let’s face it, she let me cry....
Data Exemplar

When they came and got us, like I thought they were done. And, she’s like, do you want to go and see him and I was like well, yeah. But I didn’t really know that they were doing stuff, still working on him and that, I did not want to see.

After-death Care of Family

**POSITIVE**
- body prepared to look as “normal & peaceful as possible”
- being allowed to spend time with loved one in private
- receiving a sympathy card from resuscitation team

**NEGATIVE**
- presence of ET tube following discontinuation of resus
- barrier to saying goodbye

Data Exemplar

A few weeks after he passed away, I got the most marvelous card from everybody signed that was in that room that day and help to try and resuscitate him. Which is so touching you know.

Study Limitations

- Findings not generalizable beyond sample
- Perspectives of those declining participation unknown
- Sample lacks cultural diversity
- Data not longitudinal

Implications for Practice

- Have dedicated staff member available to provide info and support to family members
- Ensure family knows that patient is still being resuscitated & that they can opt-out of being present at any time
Implications for Practice

- Time requests for organ donation as sensitively as possible
- Remove blood, debris, ET-tube? from body prior to having family view
- Facilitate family time with patient after death
- Consider a team sympathy card

Significance of Findings

- Empirical basis from which to:
  1) understand & respond to needs of family members
  2) understand how to prepare and support health care team re FPDR
  3) evaluate FPDR practice in a Canadian context

FPDR Education Binder and Video

- Available for other facilities from VGH

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