

## EVMS EM JC CRITICAL REVIEW FORM:

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**Background:** There is a limited amount of literature available that discusses parent-physician dynamic in delivering bad news. Available studies in the pediatric setting focus on inpatient and outpatient oncology. Therefore, it is difficult to apply these studies to the ED because there are often longitudinal relationships at play.

**Study Objectives:** Explore parental experiences when receiving life changing news (Type 1 Diabetes Mellitus or a malignancy) about their child in the ED.

**Study Methodology:** Direct messages were sent to administrators of 52 existing Facebook groups requesting to share recruitment message with their members. 19 administrators agreed to post. 13 groups were for parents of children with malignancy. 6 groups were dedicated to children with diabetes. Potential participants were screened via telephone and were asked 4 questions. To be considered for the study, the participants must answer "yes" to all 4 questions. A total of 28 participants were included in 4 focus groups. 15 children had type 1 diabetes and 13 children had malignancy. Participants lived in various regions of US and Canada and are fluent in English though not all were native speakers. Private Facebook groups were created. Caregivers for children with type 1 diabetes joined group separately from groups for children with malignancy. Each group consisted of 6-8 parents with 1 research team member. Each group was open for 5 days. The moderator posted questions from the questionnaire to the discussion board with an average of 3 questions posted per day. Participants could respond to the original questions, replies or reactions to other participant's posts or they could share their own questions and comments. The groups were closed after the 5-day period. Three members of the research team individually analyzed the data. The team then reviewed texts and discussed discrepancies until a consensus was reached. Broader patterns in the codes were discussed to identify emergent themes.

### Questions Posed to Parents:

- Please share some of your experiences receiving your child's diagnosis in the ED, both good and bad
- How did you feel about the information you received (i.e. were you given too much information or too little? Did you feel like you were too early or too late about the diagnosis?)?
- Did you have an opportunity to ask questions?
  - o If so, when?
  - o What types of questions did you have and were you satisfied with the answers provided?
- Regarding the person who told you about your child's diagnosis, how would you characterize their communication skills/bedside manner? Do you think this impacted your experience? If so, how?
- Was your child included in your initial discussion?
  - o How old were they?
  - o Were you given a choice?
  - o Do you wish it was done differently?
- Was there anything about the physical environment that helped or hindered the experience?
- Who was in the room with you specifically in that moment when you received the diagnosis? In hindsight, do you wish that this had been different?
- Please discuss the role that hope played in your experience. How was hope addressed by

- the medical team?
- What advice would you give physicians in training about how to best deliver difficult life-altering news in the ED?
- Please describe any past experiences that you feel influenced how you received the news
- Can you try and describe how you felt when you received the diagnosis?

#### **Four major themes were identified**

1. **Lens:** describes their perspectives based upon prior experiences and personal context in healthcare settings.
2. **ED Encounter:** factors that helped or harmed their ED experience.
3. **Response:** physical and emotional responses and how to managing “control” information.
4. **Impact:** relationships with self, child, medical team, family

#### **Additional insights from the major themes:**

##### **Lens:**

- Medical experiences
  - o Can either provide comfort or increase fear for those with a loved one previously diagnosed with similar condition to their child
- Medical knowledge
  - o Background knowledge can provide reassurance but most feel that it is a stressor. Often times, medical knowledge was incomplete/incorrect
- Outside stressors
  - o Outside circumstances such as family responsibilities can increase negative emotions
- Patient factors
  - o Patient age and acuity were controversial. For a young child, some felt that cautious language should be used while others thought less censored communication could be utilized secondary to the child’s limited understanding. Parents of higher acuity patients would like to stay at bedside and have a quick and direct discussion.
- Outpatient encounters.
  - o Some were grateful for their pediatricians for priming them for possible diagnosis and taking the concerns seriously. Those with missed and delayed diagnosis before the ED encounter were often upset and feel dismissed.

##### **ED encounter:**

- Communication style
  - o Empathy and honesty are the most important traits. Parents would like an introduction to the medical team that would help them. Participants accepted uncertainty if the physician was upfront about it.
- Timing
  - o Parents expressed frustration for perceived delays in wait time and some felt like information was being with-held
- Setting
  - o The news should be delivered in a private setting.
- Participants
  - o There was some divide on whether to include the child in the discussion up front. Some felt that it was important in helping with acceptance. Others felt that a private conversation allowed them to process the information and develop a way to deliver the news to their child on their own terms.
- Information shared
  - o Many feel that the diagnosis is overwhelming and recommend providing information in chunks and following the parent’s lead.

##### **Response:**

- Emotional response
  - o Parents felt shocked and overwhelmed in relation to the amount and newness if the information. Some felt guilty when believing that they could have done

something to cause the disease or that they should have recognized the symptoms earlier.

- Physical response
  - o A few required medical attention secondary to severe hypertension or near syncope.
- Control
  - o Some valued the chance to react to the news in private to hide their emotions from their child. They also appreciated being able to control the information given to the child.
- Information desired
  - o Most participants would like for the physician to return after delivering the news to answer follow up questions or give further information

#### **Impact:**

- Parent and medical team
  - o Some parents report reliving trauma for years and have a negative perception of the medical establishment
- Parent and self
  - o After hearing the news, many immediately became an advocate for their child. Some changed jobs and adjusted familial responsibilities.
- Parent and community
  - o Many seek support outside of the treatment team and were happy to find communities of people with similar stories.
- Parent and family
  - o Other family members had to adapt and take on new responsibilities.

#### **Strengths:**

- Provides a unique parental perspective that has not been explored in previous studies.
- Gives some guidance and aspects to consider when delivering bad news in the pediatric setting even though each encounter should be tailored to the patient and situation.
- I think it is valuable that a chronic illness was included. Many times we think of malignancies when we hear of someone getting bad news however, a chronic illness also greatly impacts families.

#### **Weaknesses/Bias:**

- No demographic information was collected. Participants were also recruited virtually and were already members of support groups and may differ from those recently receiving bad news.
- I am unsure if this is representative of our patient population as many families are underserved and may not be aware of these resources.
- 27 mothers 1 father likely creates some bias
- It is unclear if participants were required to answer all questions. The study does not quantify what “many parents” or “some parents” means. Also, some of the questions may be leading and prompted participants to consider certain aspects of their experience.
- Open access to all participants responses could create bias as opposed to individual interviews which are more common in qualitative studies
- The time since bad news was delivered was weeks to 15 years which is pretty broad and perceptions may change over time.

#### **Bottom Line/ Discussion Points**

- Prior to delivering bad news, it may be beneficial to explore the parent’s lens which can help guide your discussion.
- Participants in the study valued empathy and honesty. It is also very important that the news is delivered privately. It is acceptable to have other people present but, they should have well defined roles.
- Overall, there is not one way to deliver life changing news to parents in the ED. Differing

situations call for differing strategies.

- Discussion: strategies utilized that have been successful/unsuccessful