Implementing a Family Presence Program at Ministry Health Care

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"Witnessing a [resuscitation attempt] is an experience that is non-therapeutic, regretful and traumatic enough to haunt the surviving family member as long as he or she lives."

"*Keep the Family Out," NEJM, 1991*

"Parents or family members seldom ask if they can be present unless they have been encouraged to do so. Health care providers should offer the opportunity to family members whenever possible."

American Heart Association Guidelines 2000

Our Promise….
"We earn trust by working together as One Ministry to keep patients first in everything we do."

Ministry Health Care

Ministry Health Care adopted Our Promise in 2009. It complements our Mission and Values by asking us to make a personal commitment to collaboration and collegiality with one another, while always maintaining our focus on our patients, putting them first.

Later in 2009, I learned about a formalized program for allowing "Family Presence" (FP) during resuscitation attempts and other critical or rescue procedures. The research was overwhelmingly in favor of the practice and showed that families, even those brought to grief by the death of their loved ones, benefited greatly from the experience of being present during the last moments of life. Instituting such a program seemed a way to make Our Promise visible.

This article will outline the steps taken and the procedures that we have adopted to institute FP and describe our training program for Family Facilitators (FF). Our system policy and some suggestions for further reading are also included for reference. See Bibliography in *Resources* on page 33.

Laying the Groundwork

The first step in developing a FP program was to take the concept and the literature to our system Clinical Ethics Team (CET). There we learned that some of Ministry Health Care's smaller hospitals had been providing a FP option for years, while other system hospitals had a long-standing tradition of keeping the family out of the room in rescue situations. CET members, who represent all the hospital ethics committees in Ministry Health Care, were asked to take the research back to their individual committees along with a request that I come and discuss the option with them and others who might be interested, such as emergency department and intensive care staff. We anticipated that there would be reservations among some physicians about allowing FP and, in fact, there were. Pediatricians, however, were more favorably inclined as were nurses, spiritual services staff, patient advocates, and social workers. During the course of the several months during which I was providing this education, local "champions" emerged and soon we formed a system-wide team to develop a FP plan, policy and computer-based training program.

Some Ethical Issues

There are at least four ethical issues at play when considering the FP option: (1) the responsibility to provide the best care possible to the patient and consideration of how the presence of spectators might affect care; (2) our responsibility to the family/loved ones of the patient to help them process grief; (3) our responsibility to the patient to allow him/her to be surrounded by loved ones during what may be their final moments of life; and (4) the obligation to respect each patient's privacy and dignity. There are also values that can come into conflict in these situations: quality and efficacy of patient care vs. compassion towards family members by using presence to help them through the process, vs. effects on the staff, vs. what is best for the patient. All of these need to be carefully thought through and weighed.

Possible Advantages and Disadvantages of Family Presence

While discussing the development of an FP program, some possible advantages of allowing a family presence option were identified:

- Actually *witnessing* a code is probably better than *imagining* what it is like;
- Waiting rooms, often fraught with the drama of other patients and their families as family members wait for some word, can be a terrible place to be;
- The family may gain a better understanding of the procedures being used and are able to see that the medical team is working hard to do everything possible for their loved one;
- Being in the room can foster staff-family communication, in particular about death;

- With family in the room, staff may be even more aware that the patient is a member of a family;
- FP facilitates family involvement in decisions if appropriate;
- The family can be together with their loved one at the end-of-life.

To date we have been unable to find any evidence of increased complaints or litigation. Though not an ethical consideration, it is interesting to consider the possibility, presented anecdotally by several physicians, that even if a code goes imperfectly, the family is willing to forgive because they can see the level of effort being put forth by everyone present.

We also considered possible disadvantages of instituting a family presence program:

- It might prove to be too stressful for the family;
- The dramatic nature of a code (or other rescue procedures), the sight of blood, and what might appear to be chaos during a code could leave a devastating last impression on families;
- There could be infringement of the patient's need for privacy and dignity;
- Instead of being a calming influence, family members could exacerbate an already stressful experience if the patient is even minimally conscious;
- The family could interfere with treatment or distract the medical team from their work, hampering the team's performance and/or causing risk to the sterile environment.

Developing our Family Presence Program

There is a richness of literature on the FP option. After reviewing a number of studies conducted over the past decade, we were reassured that our concerns could be addressed and were persuaded to move forward. We formed a system-wide team which crossed all relevant disciplines and began working on a policy for the Ministry Health Care system. An essential part of our program, we believed, would be identifying and training staff to serve as Family Facilitators (FF). This led to the development of a computer-based training program and considerations in selecting appropriate FF that were embodied in our policy. While shown to be advantageous to families and consistent with Our Promise, the FP option could not be mandated. There would be situations where it would not be appropriate. In addition, there were some physicians who, at least initially, would not allow it.

The Family Facilitators are key to the success of a FP program. It is their responsibility to assess the family for their level of coping, their cooperative or uncooperative behaviors, their emotional readiness and their grasp of the situation. They can also identify any safety or security concerns. The assessment is done in a very few minutes and calls for a degree of intuition and common sense. Obvious exclusion criteria include

combativeness, agitation, extreme emotional instability, altered mental status and intoxication. The FF must stay with the family (generally only two people) at all times and may not be drawn into the code situation. Of course, if the patient is alert and oriented, they are asked if they would like family members present, but usually the situation is such that the patient is not fully conscious. After the FF has assessed the family, the clinician directing the code is informed that the family is present in the hospital. If the clinician agrees, the family may then be offered the option of being present.

After determining that the family wishes to be present, the FF explains the circumstances and ground rules, including that patient care is the top priority. The FF gives the family an idea of what they may see and hear within the treatment room, explains that they may be asked to leave at any time and must comply, and also that they may choose to leave the room at any time and that the FF will accompany them. The family is told that the medical team will update them when they are able, but that in the meantime, the family's role is to be a quiet supportive presence, maintaining their composure, and finally, that there must be absolutely no cell phone use or photography. At the conclusion of the code, the FF stays with the family to offer whatever additional support or resources the situation calls for.

It is clear that well-prepared Family Facilitators are essential. Based on the work of the Emergency Nurses Association, we have developed a training program (with permission) for our Family Facilitators. The program includes details of the policy and offers implementation guidance. We decided that rather than limiting the role to specific disciplines (for example, chaplains or social workers) that FF volunteers could come from any discipline, but that they would need to be selected with care.

Clear champions of the FP option have emerged. The majority of the 15 hospitals in our system are moving forward with the FP option. Indeed, for some, it merely formalizes their long-standing practice. Our hope is that early success will cause the program to expand and that FP will become routine throughout the system.

A final thought: "…the paternalistic desire to protect relatives misunderstands the human response to possible death. Death is a personal, private or family event. We may feel strongly that we should be there to support, hold, or talk to someone we love – that the dying person, even if unconscious, needs companionship. Professionals, however kind, are strangers" (Adams S, Whitlock M, Higgs R, Bloomfield P, Baskett PJ. "Should Relatives Be Allowed to Watch Resuscitation?" *BMJ*. 308 [June 25, 1994]: 1687-9).

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