EXECUTIVE SUMMARY

Current “visiting” policies in many of our nation’s hospitals, even for traditionally defined “families,” are inappropriately restrictive, costly, put patients at risk, and contribute to emotional suffering for both the patient and family…even if administered without a trace of discrimination (Lee, et al., 2007; Spuhler, 2007). Not only is it vital to enact change as President Obama has outlined, including how families are defined, it is also imperative to transform the restrictive policies and practices of many of our nation’s hospitals (Berwick & Kotagal, 2004).

Fundamental change is necessary to move away from the current prevailing view that families are visitors. To achieve this, the family must be “respected as part of the care team—never visitors—in every area of the hospital, including the emergency department and the intensive care unit” (Leape et al., 2009, p. 426).

As well as changing the language typically used in “visiting” policies, it is equally important to revise many of the rules and practices that limit the times and places families and other “partners in care” are able to provide support. For a number of years, The Joint Commission has recommended that patients bring a family member or trusted friend with them to the hospital as a safety strategy (McGreevey, 2006).

Recently, the Institute for Patient- and Family-Centered Care formed a working group composed of health care leaders, staff, and patient/family advisors, all with expertise in patient- and family-centered care, to develop a set of guidelines with respect to changing hospital “visiting” policies and practices. Their recommendations are found in the accompanying document, in addition to specific comments regarding restrictions on visitation rights, and the format, style, and language used in policies and procedures.

Also included are Appendix A: Members of the Working Group for Changing Hospital “Visiting” Policies And Practices: Supporting Family Presence and Participation; Appendix B: Guidelines for the Presence and Participation of Families and Other Partners in Care — A Template; and a list of References.
President Barack Obama addressed the issue of visiting in hospitals in an April 2010 memo to the Secretary of Health and Human Services (Obama, 2010). The memo clarifies that hospitalized patients have the right to determine who can visit them, participate in their care plan, and make decisions for them in medical emergencies.

The President’s memo is written to protect patients and their significant relations (as defined by the patient) from discrimination when hospitalized. The President’s clear statement of a patient’s right to self-determination as to who can be present in his or her hospital room and who shall be responsible for medical decision-making during medical emergencies, as well as the promotion of non-discrimination, is to be applauded.

While the President’s memo raises the issue of hospital “visiting” policies, it appears that he is endorsing any existing policy that is implemented in a nondiscriminatory manner. The proposed rule from the Department of Health and Human Services, Centers for Medicare & Medicaid Services, promulgated in response to the President’s memo, refers to requiring “hospitals to ensure that all visitors designated by the patient (or representative, when appropriate) enjoy “visitation privileges that are no more restrictive than those that immediate family members would enjoy.”

THE NEED FOR CHANGING CURRENT POLICY AND PRACTICE

Current “visiting” policies in many of our nation’s hospitals, even for traditionally defined “families,” are inappropriately restrictive, costly, put patients at risk, and contribute to emotional suffering for both the patient and family…even if administered without a trace of discrimination (Lee, et al., 2007; Spuhler, 2007). Not only is it vital to enact change as President Obama has outlined, including how families are defined, it is also imperative to transform the restrictive policies and practices of many of our nation’s hospitals (Berwick & Kotagal, 2004).

In his May, 2010 Yale Medical School graduation address, Don Berwick, MD, Director of the Centers for Medicare & Medicaid Services, described a recent incident when a patient (who was also a physician) could only be “visited” by his wife four times a day for 30 minutes, even though he protested, “She is not a visitor; she is my wife.” Berwick went on to comment about the restrictive visiting policy and practice, “This is the voice of power; and power does not always think the whole thing through. Even when it has no name and no locus, power can be…‘cruel’” (Berwick, 2010).
Research has demonstrated that the presence and participation of family members and friends—as partners in care—provides cost savings, enhances the patient and family experience of care, improves management of chronic and acute illnesses, enhances continuity of care, and prevents hospital readmissions (Boudreaux, Francis, & Loyacono, 2002; Brumbaugh & Sodomka, 2009; Chow, 1999; Davidson, et al., 2007; Edgman-Levitan, 2003; Fumagalli, et al., 2006; Garrouste-Orgeas, 2008; Halm, 2005; Lewandowski, 1994; Sodomka, 2006; Titler, 1997).

The research is also clear that isolating patients at their most vulnerable times from the people who know them best places them at risk for medical error, emotional harm, inconsistencies in care, and costly unnecessary care (Cacioppo & Hawkley, 2003; Clark, 2003). In addition, research indicates that for many older patients, hospitalization for acute or critical illness is associated with reduced cognitive function (Ehlenbach, 2010). Families and other “partners in care” are much more keenly aware of any change in cognitive function than hospital staff and therefore are a valuable resource during hospitalization.

As the President’s memo indicates, situations arise when some people come to the emergency room or are admitted to the hospital and are denied the presence of their chosen loved one at their side. Sometimes this means that the patient, in the President’s words, “is made to suffer or even to pass away alone, denied the comfort of companionship in their final moments while a loved one is left worrying and pacing down the hall.” It should be noted that American patients who die in the hospital are nearly five times more likely to spend some of their last days in the intensive care unit (Wunsch, 2009). Therefore, restricting family presence in intensive care units carries a great risk of separating patients from their loved ones at a most critical time. No one would want a loved one to die alone.

Fundamental change is necessary to move away from the current prevailing view that families are visitors. To achieve this, the family must be “respected as part of the care team—never visitors—in every area of the hospital, including the emergency department and the intensive care unit” (Leape et al., 2009, p. 426).

As well as changing the language typically used in “visiting” policies, it is equally important to revise many of the rules and practices that limit the times and places families and other “partners in care” are able to provide support. For a number of years, The Joint Commission has recommended that patients bring a family member or trusted friend with them to the hospital as a safety strategy (McGreevey, 2006).

Our nation’s hospitals need to adopt the view that “families” as defined by the patient are allies for quality and safety—they are not “visitors.”
THE IMPORTANCE OF LANGUAGE

Much of the language used in hospital “visiting” policies is exclusionary and suggests that the determination of “family” is dictated not by patients but by hospital staff, policies, and traditional practices. New guidelines would invite patients to decide which family members and important friends would be identified and encouraged to play a role in the recovery of the patient. At certain times in a hospitalization, it may only be a “friend” who is readily available. At times of medical illness and uncertainty, patients should not be deprived of the emotional support such individuals can provide.

A first and critical step is developing policies that support a patient’s right to identify individuals whom they view as “family” and choose to be “partners in their care.” These individuals should be seen as integral to healing, essential to the delivery of health care services, supporting transitions in care, decision-making, and stewards of patient safety. As President Obama has noted, these individuals need to be determined by the patient and not by hospital policies. This broad concept of family is recognized by the American Academy of Family Physicians, which defines “family” as “a group of individuals with a continuing legal, genetic and/or emotional relationship” (American Academy of Family Physicians, 2009).

In implementing this approach, hospital staff should ask the patient, at the time of admission or at the beginning of an emergency room visit, to define their family and other “partners in care” and determine how they will be involved in care and decision-making. Such a conversation, based on mutual respect, provides the opportunity for the patient to indicate preferences and for hospital staff to indicate what needs they may have related to family presence to ensure the patient’s safety and the quality of care. Paper or electronic charting should document these preferences and they should be honored throughout the patient’s care experiences.

RECOMMENDATIONS FOR CHANGE

In April 2009, the Institute for Patient- and Family-Centered Care formed a working group (Appendix A) composed of health care leaders, staff, and patient/family advisors, all with expertise in patient- and family-centered care, to develop a set of guidelines with respect to changing hospital “visiting” policies and practices. The goal of the working group is to broaden the understanding of who should define family and determine who can be a “partner in care” and how they can participate in providing care and support. The core concepts of patient- and family-centered care—respect and dignity, information sharing, participation, and collaboration—form the foundation of these guidelines (Johnson, et al., 2008). For further information, see www.ipfcc.org.
The working group recommends that hospitals:

▼ Ensure that senior executives provide leadership and support to change restrictive “visiting” policies and practices, including any signage and informational materials that communicate policies to patients, families, and communities.

▼ Begin a process to change “visiting” policies to guidelines which support the presence and participation of family and other “partners in care” according to patient preference and which support front-line staff in providing care safely and efficiently with families present.

▼ Develop the organizational infrastructure to support this change in policy and practice and ensure that executive leaders, mid-level managers, front-line staff, and patient and family members who are prepared to serve as advisors, are part of this process of change and improvement.

▼ Involve patient and family advisors in revising “visiting” policies and practices as well as in orienting, training, and supporting hospital staff for change in practice.

▼ Build on the experiences and advice from other hospitals that have broadened their view and practice with respect to family presence and the documented evidence that improved care, enhanced staff satisfaction, and reduction of errors are associated outcomes.

▼ Acknowledge the important role of families and other “partners in care” in the care process and use language of partnership, support, and mutual respect. Avoid using terms like “visit,” “visitors,” “visitation,” when referring to family members and friends recognized by the patient as “partners in care.” Words such as “welcome,” “encourage,” or “invite” are preferable to “allow,” “permit,” or “authorize.”

▼ Develop systems and processes to:
  • Determine which family and friends the patient designates as “partners in care,” and how they will be involved in care and decision-making as part of the admission process;
  • Determine if the patient has a designated representative, such as a power of attorney for health care or a health proxy; and
  • Ensure this information is documented in paper charting or electronic health records, and communicated consistently and comprehensively to all who are involved in the patient’s care across all settings.

▼ Develop a system to clearly identify family members and other “partners in care” who are present overnight to ensure a safe environment for all patients, families, and staff.

▼ Identify the concerns and learning needs of staff for this change in practice and provide education and support for the entire staff to:
  • Fundamentally change their perspectives from “families are visitors” to a view that families and other “partners in care” are allies for quality, safety, and comfort; and
  • Develop the communication skills to work collaboratively with patients and families and learn to perform care and procedures with families present (Griffin, 2003; Titler, 1997).
Share stories from patients and their families and other “partners in care” who have been denied access to their loved ones as a powerful way to change and improve organizational culture. Stories from patients and families, along with those of staff and clinicians, can encourage people to begin conversations about what works well and what does not in healthcare settings (Crocker & Johnson, 2006).

Provide guidance for patients and their families and other “partners in care” that will help them be respectful of other patients and families who share the same patient room.

Ensure that information is shared with families and other “partners in care” on how to support the patient during the hospital stay and during the transition to home and community care.

In situations where the patient cannot speak for him or herself, is otherwise incapacitated and cannot identify who should be present, or when there is no obvious significant other, such as a spouse or life partner, or parent or adult child, hospital staff make the most appropriate decisions possible under the circumstances. Taking a broad definition of family and other “partners in care” into account, staff welcome whoever has arrived with the patient. Decisions about the presence of family and other “partners in care” made under emergency situations may need to be revised.

If an outbreak of infection requires some restrictions to access, consider ways selected family members and other “partners in care” can still have access and assure safety (for guidance on this topic, see Pandemic Planning and Patient- and Family-Centered Care available from the Institute for Patient- and Family-Centered Care).

Work with individual departments (such as security, housekeeping, dietary) to develop policies and systems that support the presence of families and other “partners in care.” (Refer to Spencer, 2008).

Clarify for all—patients, families, other “partners in care,” and front-line staff—what are considered disruptive behaviors and unsafe practices and communicate that such situations are unacceptable and, if they occur, will be addressed directly and promptly.

Appendix B includes a template that hospitals can use to develop guidelines for family presence and participation to replace existing restrictive visiting policies.

RESPONSE TO REQUEST FOR COMMENTS

Proposed rule §482.13(h) would require a hospital to have written policies and procedures regarding the “visitation” rights of patients, including any clinically necessary or reasonable restriction or limitation that the hospital may need to place on such rights and the reasons for the clinical restriction or limitation. In addition the proposed rule would require that patients or their representatives be “informed of his or her visitation rights.”

The notice of proposed rulemaking “specifically” requests comments on “the style and form that patient notices or disclosures would need to follow so that patients would be best informed of these rights” (75 Fed. Reg. 36612, 2010). In addition to the recommendations listed above, below are specific comments regarding restrictions on visitation rights, and the format, style, and language used in policies and procedures.
COMMENTS REGARDING RESTRICTIONS

Except when the patient chooses to restrict family and other “partners in care,” limitations on the presence of these individuals may be appropriate in exceptional circumstances, such as when:

▼ There is a legal reason that is documented in the chart, (e.g., a restraining order or the patient is in legal custody with a court order prohibiting visitors).

▼ Their behavior creates a direct risk or threat to patients, families, staff, or others in the immediate environment or is disruptive of the functioning of the patient care unit.

▼ They have a contagious illnesses or have had known exposure to a communicable disease that would jeopardize the patient’s health.

▼ An infectious disease outbreak in the community requires severe access restrictions. Hospitals can develop a process for selected family members to have access to the patient and ensure that families understand any risks they may be subject to by choosing to stay with their family member in the hospital. The hospital may choose to limit family movement or access to specific areas within the hospital (e.g., public areas such as cafeterias, family lounges).

▼ A patient in a shared room requires immediate lifesaving measures (e.g. resuscitation) or a sensitive/private discussion needs to occur. In these instances those present with the other patient may be asked to temporarily step out of the room.

Decisions to restrict or limit presence must be discussed with the patient and documented in the medical record.

Nurses and others on the health team can provide guidance to patients, families and other “partners in care” about honoring privacy and being respectful of other patients and families in close proximity or who share the same patient room. Families and other “partners in care” whose loved ones are sharing rooms with other patients are expected to be respectful and honor their privacy. Families are also asked to work together with the staff so that their presence does not limit staff access to the patient at any time.

COMMENTS REGARDING FORMATS

Hospitals have a variety of formats to share this information with patients, their families, and the general public. These include the hospital website, patient handbook and/or admission packet, inpatient television or informational video, posters placed in public areas throughout the hospital and in patient rooms. It is important that these notices are translated into the primary languages spoken by the communities the hospital serves.

COMMENTS REGARDING STYLE AND LANGUAGE

The following is an example of style and language to consider when developing a statement to share family presence policies with patients, families, and the general public.
Patients and families are welcomed as essential members of the health care team, helping to ensure quality and safety. Families provide support, comfort, and important information throughout a hospital stay from admission through the transition to home and community care.

During admission, patients will be asked to define their “family” and other “partners in care” and how they will be involved in care and decision-making. The hospital will honor patients’ choices.

During a hospital stay or an emergency room visit, families and other “partners in care” are encouraged and supported to be present and participate in care, care planning, and decision-making according to patient-identified preferences.

The hospital asks that families and other “partners in care” whose loved ones are sharing rooms with other patients be respectful and honor patient privacy. Although rare, there may be times when families and other “partners in care” are asked to temporarily step out of the room to honor the privacy of the other patient during certain procedures or discussions.

Families and other “partners in care” are asked to work together with staff so that their presence does not limit safe access to any patient at any time.

Rarely, the hospital may need to limit family presence (in response to public health and hospital safety and security concerns). The hospital will keep patients and families informed and assure that these limitations are kept to a minimum.

CONCLUSION

In the midst of significant health care reform dealing with payment structures and issues of accessibility to care, there are some simple and profound changes that can be made, with minimal cost, to improve both outcomes and the quality of the experience of care for all concerned. Revising hospitals' current language, policies, and practices related to “visiting” to encourage and support family presence is an important step in advancing the practice of patient- and family-centered care and enhancing the safety and quality of care.

When patients and their designated “partners in care” are welcomed and cared for in a spirit of mutual respect and collaboration, the positive effects are profound. Not only are outcomes improved, medical errors reduced, and safety enhanced, evidence demonstrates an increase in staff and patient satisfaction.

Changes which welcome families and others as “partners in care” do not require major financial investments, but rather investments in mutual respect, collaboration, common sense, and kindness. Are these not the hallmarks that we would want to define our health care system?

These are changes we can begin to make today. It only takes leadership and the will to begin.
APPENDIX A

Working Group Members
Changing Hospital “Visiting” Policies and Practices:
Supporting Family Presence and Participation

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APPENDIX B

Guidelines for the Presence and Participation of Families and Other Partners in Care — A Template

The purpose of this document is to provide guidelines regarding the presence and participation of families and other partners in care. This document replaces the hospital’s previously existing visiting policies.

[Note: insert name of hospital] promotes and supports a patient- and family-centered approach to care.

DEFINITION OF FAMILY

The hospital uses a broad definition of “family” as defined by each patient. This concept is recognized by the American Academy of Family Physicians, which defines “family” as “a group of individuals with a continuing legal, genetic and/or emotional relationship” (American Academy of Family Physicians, 2009).

Patients, their families, and other partners in care are respected as essential members of the health care team, helping to ensure quality and safety. Patients define their “family” and how they will be involved in care, care planning, and decision-making. Family members, as identified by the patient, provide support, comfort, and important information during ambulatory care experiences, a hospital stay in critical care, medical/surgical, and specialty units, in an emergency room visit, and in the transition to home and community care.

GUIDELINES

The following guidelines are intended to be flexible in order to respond to the diverse and individual needs and preferences of each patient and unanticipated and unique circumstances, as well as to assure the safety of patients, families, and staff.

1. Families and other partners in care are welcome 24 hours a day according to patient preference.

2. At the beginning of an ambulatory care experience, inpatient stay, or emergency room visit, patients are asked to define their “family” and other “partners in care” and how they will be involved in care and decision-making. Also identify whether a patient has a designated representative, such as a power of attorney for health care or a health care proxy. Clarify patient preferences regarding who may be present during rounds, change of shift report, exams, and procedures, and who may have access to written or electronic clinical information.
a. Document these preferences documented in paper or electronic charting and communicated consistently and comprehensively to all who are involved in the patient’s care across settings.
b. Patients may modify their preferences during their hospital experience.

3. In situations where the patient cannot speak for him or herself, is otherwise incapacitated and cannot identify who should be present, or when there is no obvious significant other, such as a spouse or life partner, or parent or adult child, hospital staff make the most appropriate decisions possible under the circumstances. Taking a broad definition of family and other “partners in care” into account, staff welcome whoever has arrived with the patient. Decisions about the presence of family and other “partners in care” made under emergency situations may need to be revised.

4. All hospital staff and clinicians encourage families and other partners in care to be involved and supportive of the patient according to patient preference. They recognize and reinforce that families are integral to patient safety, comfort, medical and psychological well-being, and the healing process.

5. Nurses and others on the health team provide guidance to patients, families and other partners in care in a variety of ways over time about:
   a. How to partner to ensure safety and quality of care;
   b. How to be involved in care, care planning, and decision-making, and how to support the patient during the hospital stay and during the transition to home and community care; and
   c. How to honor privacy and be respectful of other patients and families in close proximity or who share the same patient room.

6. [NOTE: Insert name of hospital] has developed the following system for families and other partners in care to be clearly identified: [NOTE: Insert the identification system].

7. Patients, families, nurses, and other members of the health care team can ask to reevaluate or modify the presence and participation of families. All such collaborative decisions will be documented in the patient record.

8. The number of people welcomed at the bedside at any one time will be determined in collaboration with the patient and family. In situations where there are shared rooms, this negotiation will include the other patient, his or her family, and other partners in care.
9. In respect to the presence of children:

   a. Children supervised by an adult are welcomed. Children are not restricted by age. Although younger children may be developmentally unable to remain with the patient for lengthy periods of time, contact with these children can be of significant importance to the patient.

   b. Children are prepared for the hospital environment and the family member’s illness as appropriate.

   c. Children are expected to remain with the adult who is supervising them unless there is a supervised playroom for siblings and other children.

   d. Children’s behavior is monitored by the responsible adult and the nurse to ensure a safe and restful environment for the patient(s) and a positive and developmentally appropriate experience for children.

10. Families are encouraged to designate a family spokesperson to facilitate effective communication among extended family members and hospital staff.

11. Disruptive behavior and unsafe practices are not acceptable; these situations, while usually rare, will be addressed directly and promptly.

12. All partners in care, and any guest of a patient, must be free of communicable diseases and must respect the hospital’s infection control policies.

13. If an outbreak of infection requires some restrictions for public health, the staff must collaborate with the patient and family to ensure that selected family members are still welcomed to assure safety and offer emotional support to the patient (for further guidance, see Pandemic Planning And Patient-And Family-Centered Care Retrieved from http://www.ipfcc.org/tools/Pandemic_Planning_and_PFCC.pdf or available at http://www.ipfcc.org/tools/downloads.html).

14. The hospital has an interdisciplinary committee, involving patient and family advisors and representatives from clinical areas, patient relations, security, housekeeping, dietary, risk management, and other relevant departments to implement, monitor, and evaluate these guidelines.
REFERENCES


