

A Family's Perspective on Family-Centered Rounds: Progress and Frustrations

Morgan Gleason, a patient, and Amy Gleason, the patient's mother

As a mom and a teenage patient with a rare autoimmune disease that requires monthly hospitalizations, we are big believers in making communication in the hospital more cohesive and inclusive. Family-centered rounds make a lot of sense from a patient and family point of view. When we first heard that our hospital was an advocate of rounds including the family, we were interested and happy that we would be included. It seems that so much of health care happens without the patient being in the center and with different people talking to the patient about the same thing at different times throughout the day. This study on family-centered rounds is interesting because the perception and definitions seem to vary greatly depending on whom you ask.

The study in this issue by Pickel et al highlighted both things that we appreciate and things that frustrate us. For example, the study highlighted that the attending physicians talk outside the room as much as or more than they do inside the room. It is frustrating to hear the team speaking about you in the hallway before they come in and wondering what they are saying. Then, after they leave the room, they continue to have discussions in the hallway, where we can hear pieces and parts but not all of the discussion. We would prefer that all discussion happen in the room with the nurses and the family present. The nurses are the ones who have spent the most time with us, and they have a lot of information to offer. However, as the study highlighted, we often notice that the nurse does not have much of an opportunity to speak during the rounds. From our experiences, we really related to the examples given. Sometimes, the entire rounds process is effectively over by the time the medical team comes into the room, and rounds are more of a procedural event than a discussion.

One of the frustrations we have that we would like to see studied more is the rounding schedule in general. It would be nice if all physicians involved in the care could participate in the family-centered rounds experience, even if some need to be on the phone. Many times, the rounding process happens but then we are left with a statement that they will wait until the other doctors come by to make a decision. This not only prolongs the decisions but also splinters the care that the concept of family-centered rounds is trying to improve. Also, we appreciate when the medical teams sit down in the room with us. It makes us feel as if we are having a discussion where everyone is invited to participate instead of a group of people standing over us. This style of communication seems to engage the patient and family in honest, open conversation, and it seems to cause the team to slow down enough to listen to our story. Additionally, it would be nice to have some idea of when they are coming to the room because it seems that no matter what we do, the team comes in when one of us has run to the cafeteria to get breakfast or to take a phone call in the lobby.

Health care in general seems to be trying to figure out how to get patients engaged in their care and how to drive to personalized medicine where treatments are tailored to an individual's preferences, values, and goals.

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Address correspondence to

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Family-centered rounds is a great step in that direction when the teams work to put the patient and family in the center by having an open visit and discussion. We are strong believers that patients and health care providers need to be partners in care, and we are pursuing how to better tackle this challenge in several ways. Morgan maintains a blog (<http://morgangleason.com>) on patient experience and has made videos on YouTube (<https://www.youtube.com/channel/UCq3XY0hPVxzKp2qBxydUCoQ>) to highlight positives and negatives of the patient experience. We hear from patients around the world who identify with similar frustrations, and studies like this, which highlight the mismatch between physician perception and reality, can drive change that makes the experience better for the patient. We belong to the Society of Participatory Medicine (<http://participatorymedicine.org>), and we are excited about the increasing networks and opportunities for patients

and families to tell their stories and express their goals for the improvement of health care.

Every patient and family comes from a different background and experience level in health care. For example, Morgan has been dealing with dermatomyositis for 5 and a half years and is a very experienced, opinionated, and engaged patient. She knows exactly what she wants from her providers and experience, and she is confident enough to speak up and ask for it. However, when she was first diagnosed, she was scared, intimidated, frustrated, embarrassed, and overwhelmed. Health care is so fast paced, stressful, and resource limited that sometimes doctors and nurses forget to ask simple questions about how the patient wants to be treated and what the family needs at that time. We applaud this study because it attempts to evaluate and understand new delivery

methods such as family-centered rounds. We would love to see additional studies in this area. One example that would be great is having a truly patient-centered rounding system to evaluate whether it is possible to include all providers and family in rounds at 1 time and then assess whether it makes a significant difference in patient experience or outcomes. We would also like to see a study examining whether waking patients up early for rounds affects their participation and outcomes compared with letting them wake up naturally. Another valuable study would be to evaluate the perceptions of the patient on the rounding process compared with the perceptions of the providers and nurses on discharge. This study provides a great model for additional understanding, and we hope to see more like it in the future.

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