Patient and Family-Centered Care at Emory, Who Cares?
Current Perceptions and Beliefs

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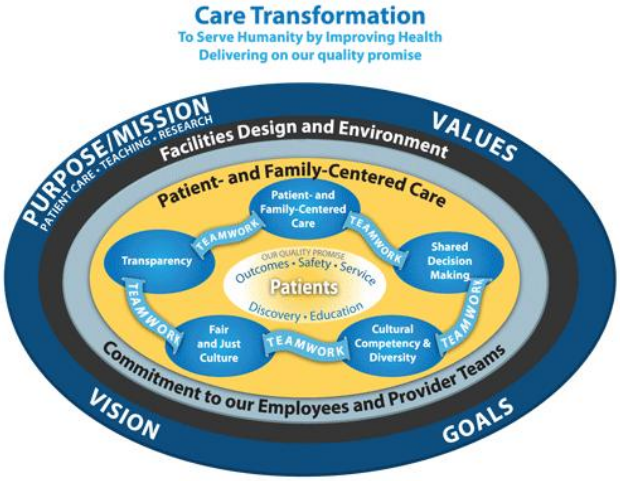
Summary:

- Patients/ families and providers differ in the perceived importance of Patient- and Family-Centered Care (PFCC).
- Patients/ families viewed Emory's delivery of PFCC more favorably than did providers for all indicators except for awareness of a written policy on error disclosure.
- Patients/families and providers agree that Emory performs poorly in the actual practice of disclosure of medical error.
- Family-witnessed resuscitation is not perceived by patients/families or providers as an important practice.
- The obstacles to implementation of PFCC at Emory include:
  - Lack of "buy in" from more seasoned Emory providers
  - Lack of "buy in" from physicians
  - Providers' discomfort with error disclosure

Introduction

The Woodruff Health Sciences Center is currently engaged in several major initiatives designed to inprove performance across our clinical, research, and educational missions. One of the major performance improvement initiatives embraced by top leadership is the **Care Transformation** model: improving the quality of our health care, and strengthening alignment of care delivery with research and educational activities. The Care Transformation initiative includes five attributes, as pictured in Figure 1: Patient and Family-Centered Care, Transparency, Shared Decision Making, Fair and Just Culture, and Cultural Competency and Diversity. Our team,



Team ESTEEM, chose a project sponsored by Susan Grant, CNO, entitled "Engaging Patients and Families more Actively in their Care." Specific questions were "How do we do this now?"; and "Where should we focus our efforts next and how can we measure success?"

The make-up of our team is fortuitous and significant to how we have approached our project, as we represent the major constituencies involved. The five team members include three clinicians (two physicians and one nurse) and two non-clinicians (a social psychologist and an Information Technology (IT) executive) We chose our team name, Team ESTEEM, from an acronym of the leadership qualities we selected as those most important to emulate while collaborating on this project:

- **E**xcellence / Expertise
- **S**trategic Thinking / Visionary
- **T**eam building / Inclusive
- **E**thics / Integrity
- **E**motional Intelligence
- **M**otivator / Empowering
- Communications (didn't fit into acronym, but no less important)

Patient- and family-centered care (PFCC) is an approach to the planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients and families. Redefining the relationships in health care, PFCC's core concepts are dignity and respect, information sharing, participation and collaboration. In January 2008, Emory underwent a site visit and consultation by the Institute for Family-Centered Care; their report revealed institutional strengths in advancing the practice of PFCC at Emory as well as multiple opportunities for improvement.

What struck our team immediately was a huge 'disconnect' in the understanding of what was involved in enacting the principles of patient- and family-centered care among the physicians, nurse and non-clinicians on our team. We had differences in knowledge of what PFCC means, current efforts at Emory, leadership's vision and plans for implementation of this concept. It was clear that we were not all engaged in the same conversation.

We felt strongly that the institution would need to bridge the differing perceptions of patients and families, nursing, and the physicians in order to implement a culture of PFCC. We broke the project into three levels: 1) defining the various barriers to PFCC as viewed by these three constituencies, 2) trying to suggest areas of focus to advance PFCC, and 3) identifying elements of PFCC that are areas of strength for the WHSC that might help create a unified vision of PFCC for all parties.

Methodology

To address these objectives, we conducted a survey of Emory patients and their families, Emory Healthcare nurses, and The Emory Clinic (TEC) physicians. The survey instrument was adapted from a hospital self-assessment created by the Institute of Family-Centered Care (http://www.familycenteredcare.org/resources/other/hospital_self_assessment.pdf) and is available here as Appendix 1. In order to condense the survey, we selected two key subscales from the hospital self-assessment for use in our survey: Definition of PFCC and Patterns of Care. Paper surveys were

distributed to patients and families in a cross section of inpatient and outpatient waiting rooms at EUH, EUHM and The Emory Clinic. Patients and families were incentivized to complete and return the survey with the offer of a parking voucher. This helped to ensure that those who completed the survey were not just those with the greatest interest in the topic. Surveys were distributed and collected by nurses on the career Lattice. The Lattice acknowledges professionalism and clinical expertise by nurses in the delivery of patient and family-centered care, and no personal identifying information was recorded. A web-based survey with the same questions was sent via an email message with an embedded link to all Emory Healthcare nurses and TEC physicians. The provider email offered a chance to win an iPod nano for participating in the survey. The survey to nurses was sent from Susan Grant, Chief Nursing Officer's office and was sent one time. The physicians' survey was sent from Dr. Wright Caughman's office twice and then a final third time with a personal request by Dr. Caughman embedded in the email.

Both the paper and online surveys asked questions in three areas: 1) Definition of Patient- and Family-Centered Care; 2) Patterns of care at Emory; and 3) Demographic data. The survey asked respondents to rank how well Emory performs in specific PFCC areas and for each item to rank how important those areas are to the respondent. The survey was designed to take 10 to 15 minutes to complete and included one additional item of free text comments.

Provider on-line survey data were downloaded into a Microsoft Excel spreadsheet for analysis. Patient and family surveys were manually entered directly into SPSS data files and the provider data were imported in SPSS. Statistical analysis was performed using SPSS. Level of significance was set at $p \leq 0.05$. Mean scores were compared by t-tests. Descriptive analysis of free text comments were performed through graphical representation using word mapping software (Wordle.net).

Our analysis provides a map of where the concept of PFCC stands today in the minds of our internal and external community. We also include recommendations on how the institution should allocate resources to continue advancing the practice of PFCC.

RESULTS

SURVEY PARTICIPANTS

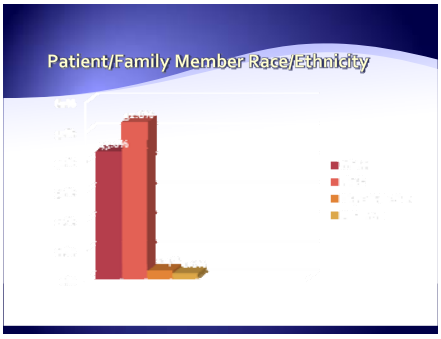
We had an incredibly robust response from the Emory nurses to a single email survey request. Emory physician response was minimal even after three emails, and our team members made requests to individual colleagues for participation.

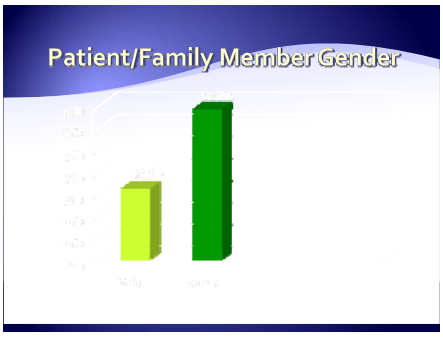
One thousand-one hundred and fourteen (n=1114) participants responded to the survey. This includes 987 providers and 127 patients/family members (PFM). Of the 987 service providers, 29 were physicians, 779 were nurses, and 179 did not identify their profession. Of the 127 EHC PFM, 47 reported to be patients, 74 to be family members of a patient, and 6 individuals did not indicate their status.

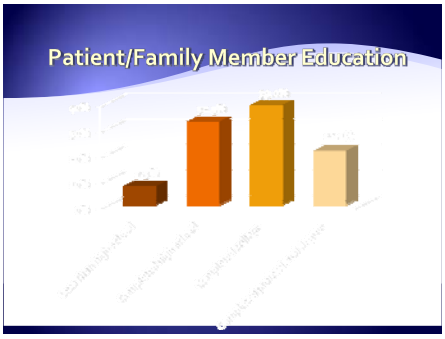
The providers reported that they had worked at Emory from 5 months to 40 years (M=12 years; SD=10 years); 752 of them (91%) were women. Among PFMs, 63 (53%) self-identified as Black/African American, and 50 (42%) as White. Seventy-nine PFMs were female (68%). Regarding their highest

level of education, 39 (33%) had graduated high school, 46 (39%) college, and 25 (21%) graduate or professional school.

Due to the low number of physician responses, reliable differentiation of physician and nursing responses cannot be made. Therefore results are described for 'providers' and 'patients/families.'







Analysis of Open-ended responses

Qualitative review of the data reveals striking differences in the perceptions of the patients and providers regarding the status of PFCC at Emory. These differences are represented graphically in the word maps in Appendix 2. Patient and family comments are largely positive and embracing with recognition of strong loyalty. Patient comments also reflect a connection to Emory personnel. Provider comments are more focused on barriers and processes and limitations to PFCC. Comparisons suggest that Emory patients feel that Emory Healthcare is doing a good job with projecting PFCC while Emory providers feel a strong need but identify barriers.

Quantitative Analysis:

Scale Reliability

The 25 item survey scale was comprised of four subscales. For items 1-5, respondents were asked to report how well they feel Emory is performing on five key inter-related definitions of PFCC (creating a Definition-Status subscale). For the same five items, participants were also asked to report how important this key indicator is to them (creating a Definition-Importance subscale). For items 6-25, respondents were asked to report how well they feel Emory is performing on each of 20 key specific indicators of PFCC care delivery (creating a Care Delivery-Status subscale) and how important this key indicator of care delivery is to them (creating a Care Delivery-Importance subscale).

Thus, participants were given a total score for each of the four subscales, which were demonstrated to be internally consistent: Definition-Status (α=.92), Definition-Importance (α =.86), Care Delivery-Status (α =.96), Care Delivery-Importance (α =.94). Results are presented for (a) both dimensions of how well Emory is doing, then (b) both dimensions of how important these key indicators are to the respondent. Higher scores indicate that Emory is doing better and that the indicator is of more importance to the respondent.

Status at Emory

Do patients/families and service providers significantly differ in their perceptions of how Emory is doing in terms of (a) each of the key indicators of PFCC or on (b) each of the key indicators of PFCC care delivery? In what specific areas do differences exist?

Our results indicate that patients/families and service providers did not significantly differ in their overall perceptions of how Emory is doing in terms of the key indicators of PFCC and the key indicators of care delivery. Nevertheless, because subscale totals can mask group differences that exist among the individual items and because of the exploratory nature of this assessment, we explored mean differences between patients/families and providers on each individual item.

On the five key definitions of PFCC, patients/families and providers only differed on one item: "*the extent to which Emory partners with patients and families at all levels of care*." Patients/families (mean score *M*=4.03) thought Emory was performing significantly better than service providers (mean score *M*=3.73), *p*=.004.

For the key indicators of care delivery there were seven items in which patients/family responses significantly differed from provider responses. On six of the seven items patients/families thought Emory was performing better than providers (see Table 1). There was one item (#16) on which patients thought Emory was performing worse than providers perceived: "the extent to which there is open disclosure with the patient and family regarding errors in written policy."

Table 1: Differences in perceptions of how well Emory is doing in terms of PFCC care delivery among patients/families vs. service providers

At Emory…	Respondent Type	Mean (*SD*)	*p*-value
6. Family members are not viewed as visitors, but are always welcome to be with the patient, in accordance with patient preferences.	Patient/family member	4.18 (1.38)	.002
	Service provider	3.79 (1.30)	
Families and patient choices about whether or not families may remain with the patient are respected and supported by staff during:			
10. Clinic visits/examinations.	Patient/family member	3.78 (1.79)	.027
	Service provider	3.40 (1.76)	
11. Painful/invasive procedures.	Patient/family member	3.54 (1.84)	.000
	Service provider	2.88 (1.63)	
16. There is open disclosure with the patient and family regarding all errors in written policy.	Patient/family member	2.78 (2.17)	.037
	Service provider	3.22 (1.74)	
18. Patients and families are asked about their observations, goals, and priorities for the patient in outpatient settings.	Patient/family member	3.26 (1.93)	.000
	Service provider	2.61 (1.79)	

21. Each patient has a single, identified coordinator of care.	Patient/family member	3.60 (1.82)	.000
	Service provider	2.78 (1.56)	
22. Patients and families have help with transitions in care (e.g., unit to unit, hospital to other facility, hospital to home, and between outpatient and inpatient).	Patient/family member	3.56 (1.84)	.008
	Service provider	3.09 (1.54)	

Note: The 13 items for which no differences exist are not included in this table.

Do patients/families and Emory providers agree on whether any key indicators of PFCC or indicators of specific PFCC care delivery are performed above or below the average for Emory Healthcare? In what areas do they agree?

Our results indicate that patients/families and service providers did not significantly differ in their overall perceptions of how Emory is doing in terms of the key indicators of PFCC and the key indicators of care delivery. The PFCC key indicators total mean for patients was 20.08 (SD=6.55); for providers 19.44 (SD=4.13). The patterns of care indicators total mean for patients was =70.50 (SD=27.15); for providers, the total means score was=66.00 (SD=23.51).

Three specific indicators stood out as all respondents (providers and PFMs) being in agreement that Emory performed significantly better or worse than the average. Most items were scored in the range of 3.5 on a Likert scale of 1-5. One item scored over a "4" for all respondents, and 2 items scored beneath a "3."

On item 8 "*During doctor's visits if the patient wishes, families can remain with the patient*" all respondents agreed that this was an Emory strength, with a patient/family mean of 4.02 and a provider mean of 4.12. On two items there was agreement that Emory performed significantly lower than the mean. Item 12 "*Families' and patient choices about whether or not families may remain with the patient are respected and supported by staff during: Resuscitations (cardiac arrest)"* the patient/family mean was 2.97 and provider mean score was 2.59. For item 17 "*There is open disclosure with the patient and family regarding all errors (whether or not there is a bad outcome) <u>in actual practice</u>"* the patient/family mean score was 2.82 and the provider score was 2.84. Note that the related item 16: "*There is open disclosure with the patient and family regarding all errors (whether or not there is a bad outcome) <u>in written policy</u>*" was an instance above where patients/families significantly and negatively disagreed with providers on Emory's performance.

TABLE 2: Agreement in best/worst practices of PFCC between patients/families and providers

At Emory…	Respondent Type	Mean (*SD*)
8. During doctor's visits if the patient wishes, families can remain with the patient.	Patient/family member	4.02 (1.72)
	Service provider	4.12 (1.32)
12. Families' and patient choices about whether or not families may remain with the patient are	Patient/family member	2.97 (2.15)

respected and supported by staff during: Resuscitations (cardiac arrest)	Service provider	2.57 (1.68)
17. There is open disclosure with the patient and family regarding all errors (whether or not there is a bad outcome) in actual practice	Patient/family member	2.82 (2.15)
	Service provider	2.84 (1.65)

Note: The 17 items for which no differences exist are not included in this table.

IMPORTANCE TO THE RESPONDENT

Do patients/families and service providers significantly differ in their perceptions of the importance of (a) each of the key indicators of PFCC or on (b) each of the key indicators of PFCC care delivery? In what specific areas do differences exist?

Results indicate that patients/families and service providers did not significantly differ in their perceptions of how important the key indicators of PFCC are ($p > .05$). However, they did significantly differ in their perceptions of the importance of the key indicators of PFCC care delivery. Patients/families (means score M=68.40) reported that the key indicators of care delivery were significantly more important to them than the service providers (mean score M=55.37), p=.000.

Examination of the individual items also revealed no significant differences in the means for each of the five key indicators of PFCC for patients/families and service providers. However, as would be expected for the PFCC care delivery items, almost every item yielded group differences (as evidenced by the group differences in the overall mean scores). Table 3 presents the 17 items for which group differences exist. For all 17 items, the same pattern emerged in that patients/family members held greater importance to the indicator than providers (see Table 2).

Table 3: Differences in importance of PFCC care delivery among patients/families vs. service providers

Priority for Improvement along each key indicator. At Emory…	Respondent Type	Mean (*SD*)	*p*-value
6. Family members are not viewed as visitors, but are always welcome to be with the patient, in accordance with patient preference	Patient/family member	3.90 (1.71)	.000
	Service provider	2.92 (2.30)	
7. Families can remain with the patient during nurse change of shift, in accordance with patient preference.	Patient/family member	3.61 (1.86)	.001
	Service provider	2.97 (2.28)	
During doctor's visits if the patient wishes, families can:			
8. Remain with the patient	Patient/family member	3.78 (1.81)	.007
	Service provider	3.29 (2.24)	

9. Participate in doctor's discussions	Patient/family member	3.70 (1.89)	.039
	Service provider	3.31 (2.24)	
Families' and patient choices about whether or not families may remain with the patient are respected and supported by staff during:	Patient/family member	3.71 (1.84)	.000
10. Clinic visits/examinations	Service provider	2.69 (2.32)	
11. Painful/invasive procedures	Patient/family member	3.42 (2.01)	.000
	Service provider	2.08 (2.23)	
12. Resuscitations (cardiac arrest)	Patient/family member	2.81 (2.21)	.000
	Service provider	2.06 (2.17)	
15. You feel that there is encouragement for communication among patients, families, and staff.	Patient/family member	3.54 (1.82)	.000
	Service provider	2.67 (2.33)	
There is open disclosure with the patient and family regarding all errors	Patient/family member	3.09 (2.10)	.001
16. In written policy.	Service provider	2.41 (2.30)	
17. In actual practice.	Patient/family member	3.01 (2.13)	.009
	Service provider	2.46 (2.32)	
Patients and families are asked about their observations, goals, and priorities for the patient in:	Patient/family member	3.29 (1.94)	.000
18. Outpatient settings.	Service provider	2.35 (1.32)	
19. Inpatient settings.	Patient/family member	2.94 (2.08)	.019
	Service provider	2.46 (2.34)	
20. Staff collaborate with the patient and family to manage pain.	Patient/family member	3.44 (1.96)	.001
	Service provider	2.76 (2.36)	
21. Each patient has a single, identified coordinator of care.	Patient/family member	3.56 (1.82)	.000
	Service provider	2.83 (2.34)	

22. Patients and families have help with transitions in care (e.g., unit to unit, hospital to other facility, hospital to home, and between outpatient and inpatient).	Patient/family member Service provider	3.38 (1.85) 2.82 (2.35)	.003
24. Patients and families are asked about learning needs and priorities regarding care after discharge.	Patient/family member Service provider	3.40 (1.94) 3.02 (2.34)	.003
25. Opportunities to learn and practice caregiving are provided to patients and families prior to discharge.	Patient/family member Service provider	3.37 (1.99) 2.98 (2.35)	.046

Note: The 3 items for which no differences exist are not included in this table.

LENGTH OF TIME AT EMORY

Among service providers, is *length of time at Emory* associated with perceptions of how Emory is doing (both in terms of the key indicators of PFCC and the key indicators of PFCC care delivery) or how important the key indicators are to them (both in terms of the definition of PFCC and PFCC care delivery)?

Because length of time working at Emory is not normally distributed, we dichotomized the variable by conducting a median split. Thus, respondents were categorized as working at Emory for less than 9 years or for 9 or more years. The results indicate no significant group differences in terms of three of the subscales: Definition-Importance, Care Delivery-Status, and Care Delivery-Importance. However, those who worked at Emory for less than 9 years (mean =19.80) reported that Emory is doing significantly better at the key indicators of PFCC than those who have worked at Emory for 9 or more years (M=19.18), p=.03.

DISCUSSION:

Patient- and family-centered care (PFCC) is an integral part of the Care Transformation initiative implemented by the top Woodruff Health Science Center leadership. At the start of the project, we were struck by the lack of awareness of the Care Transformation concept by the two physicians in our team in contrast to the familiarity and engagement in the initiative by our nurse teammate. Discussions with providers within WLA and within our clinical settings confirmed a deep cultural divide in terms of awareness, understanding and commitment to PFCC.

We speculated that there was not a good common understanding of how Emory patients, families, nurses and physicians viewed the practice and importance of PFCC at Emory. We surveyed both providers and patients/families with the same instrument and compared and contrasted their responses to gain better insight and to make recommendations to the WHSC leadership for allocation of resources in promoting Care Transformation and particularly PFCC.

Our first finding was that the Emory physicians are not currently aware, interested and or engaged in the Care Transformation initiative. The WHSC leadership may need a different strategy for physician

engagement. We hope that by addressing some of the specific responses to our survey characterized below that we might provide this opportunity. The good news is that overall, from both perspectives, but mainly the families and patients; Emory is doing a great job.

Patients, families and providers did not differ in defining the attributes of PFCC. However, patients/ families consistently evaluated the current delivery of PFCC as both better and more important than did providers. It was reassuring to note that patients/ families considered Emory to be accepting of family members during procedures, clinic visits and painful procedures. In addition, patients/ families viewed Emory as being considerate of their goals and priorities for the patients in the outpatient settings, and in their transition from one facility of care to another.

There was one aspect of care delivery that patients/families evaluated Emory's performance as significantly poorer than did providers: open disclosure of medical errors in written policy. Additionally, patients/families and providers agreed that open disclosure of medical errors in actual practice was not done well. Clearly this area of disclosure of medical area- an important indicator of PFCC-- is a focal point of concern for providers and patients and represents a clear opportunity for improvement. A deeper understanding of this issue is essential to improving this aspect of PFCC delivery.

We pose several explanations for this concern. Clearly patients and families are not as aware of written policies regarding disclosing medical error as providers believe they are. Nor do they know who is responsible for the discussion and when. Additionally, providers may not have clear expectations or training in how to handle and disclose errors. This can lead to both uncertainty and discomfort with the issue. It is also possible that due to lack of training or insight of providers in how to disclose errors it is done in a way that is dismissive or inconsiderate of the level of understanding of the situation by the patient/family. It may be that patients/ families do not feel that they get clear or appropriate answers when asking questions about the error. Or the problem may be that providers do not handle error disclosure in a consistent manner. Patients/families may feel that the providers are evading the question or providers may be unaware that the patients or families are concerned or suspicious of an error since it never occurred. Another reason may be providers' perception of medico-legal liability if they admit to error, and thus reluctance to say more than the minimum. And when pressed by patients/families to explain further, the providers may retreat. All of these possible reasons revolve around the general issues of patients' expectations or trust, and of the providers' discomfort and lack of knowledge about the art of disclosure. Training and open discussion of the uncomfortable task of disclosure ought to help narrow this credibility gap.

As mentioned, the results show that patients/ families and providers did not differ on the important key attributes of PFCC, but that patients/families regard it as much more important. This finding is not surprising since the object of PFCC is the patient and family. However, this finding also sheds light on potential barriers to implementation. If providers, who are already mandated to do an increasing number of tasks, are not "buying in" to the notion of PFCC delivery, then it is expected that executing PFCC will be more challenging. There were no PFCC delivery areas in which the provider ranked as more important than patients/ families did.

Interestingly, both groups did not view families' presence during resuscitations (cardiac arrests) as a priority for improvement. Perhaps, less emphasis should be made on this aspect of health care delivery as we move forward. Families/patients evaluated the importance of family presence during nurse change of shift more important than providers did. Providers were also much less likely to view family members as an integral part of the patient/family/provider relationship. This suggests that further emphasis on provider engagement during shift change and during floor care is needed. Exploring why providers do not view this practice as important may offer targets for behavior change and modification.

Our results also indicated that providers who were employed at Emory longer had a lower regard for how Emory is doing in PFCC. This suggests that some of our most experienced providers may be suffering from burn out. It is disturbing to see that our most seasoned providers are the least likely to view Emory's delivery of PFCC as favorable. They may have higher expectations than newer Emory providers or they may have become more "jaded" or skeptical of Emory. Again, engaging this important subset of providers would be essential to a successful implementation of PFCC.

Only 3% of Emory physicians completed the online survey. This is a dismal response rate. This lack of response may be construed as apathy, failure of reaching physicians by email surveys, lack of interest in the subject of PFCC, or simply that they are overworked and too busy to check email and respond to surveys. Whatever the reason is for the abysmal response rate of physicians, the reality is clear: there are major obstacles to engaging the physicians in PFCC.

There were several limitations to our study. First, the survey was liberally adapted from a previous created survey from the Institute of Family Centered Care and may not have the same validity and reliability of the original survey. Time pressures did not allow for the piloting, revision and validation that careful scientific study would demand. Our goal was to provide practical information for the WHSC leadership, not to hold up to scientific scrutiny. The response rate of physicians (3%) is too low to conclude any meaningful information regarding physician's knowledge and perceptions of PFCC. We did our best to sample patients from different Emory Healthcare settings (EUHM, EUH, TEC), inpatients and outpatients, and from medical and surgical areas. Nevertheless, patients were queried in a convenience sample and thus, these results may not be generalizable to Emory patients as a whole. For many of the patients, the questions were hypothetical and their view might be radically different if, for instance, faced with a resuscitation, painful procedure or instance of medical error. Finally, because of the sample size, we were neither able to split the data and evaluate different Emory Healthcare settings, evaluate by physicians vs. nurses, nor compare medical vs. surgical settings.

Conclusions:

Despite these limitations, our study does allow for several practical observations:

- Patients/families and providers differ in the perceived importance of PFCC.
- Patients/families viewed Emory's delivery of PFCC more favorably than did providers for all indicators except for awareness of a written policy on error disclosure.
- Patients/families and providers agree that Emory performs poorly in the actual practice of disclosure of medical error.

- Family-witnessed resuscitation is not perceived by patients/families or providers as an important practice.
- The obstacles to implementation of PFCC at Emory include:
    - Lack of "buy in" from more seasoned Emory providers
    - Lack of "buy in" from physicians
    - Providers' discomfort with error disclosure

We recommend that new strategies for dissemination of the Care Transformation Model are needed. Our results suggest that the idea is not penetrating the providers, especially the physicians, sufficiently to engage "buy-in." Concrete strategies are needed to reach the provider community and clear expectations for leaders at all levels will be required in order to activate those strategies. Specific training related to areas such as error disclosure is needed to ensure successful implementation of PFCC.

In conclusion, PFCC is well received by patients/ families and by most providers. Differences arise in the perception of how well Emory is doing and how important various aspects of the definition of PFCC and its delivery. Pursuing excellence in this initiative of PFCC is well worth our while as we serve our patients; however, this survey also serves to warning us that the current efforts in dissemination the information to providers, training the providers in PFCC delivery, and engaging them are insufficient.

Appendix 1 – PFCC Assessment Instrument.

Patient- and Family-Centered Care at Emory Healthcare

Woodruff Health Sciences Center

Emory University

Spring 2010

Thank you for agreeing to complete this survey! It is designed to help us gather general information about how well you think the health care provided by our physicians, nurses and staff demonstrates that Emory Healthcare values patient and family participation in care and decision-making.

This questionnaire may take 10-15 minutes to complete. There are 3 sections. The first two sections ask you to rate how well we are doing with the concepts of patient- and family-centered care AND how important these concepts are to you. The third section asks basic questions about you.

We want your honest opinions. You are free to skip any questions that you do not want to answer. All of your answers will be kept confidential. If you have further questions about the survey please contact Dr. Kimberly Jacob Arriola at 404-727-2600.

As a small token of appreciation for completing the survey we would like to offer you a parking voucher that can be used when exiting this Emory facility. Once you turn in your completed survey, please request your voucher from the staff person who accepts your survey.

Thank you for your help!

I. Definition of Patient- and Family-Centered Care

KEY INDICATORS	CURRENT STATUS					HOW IMPORTANT IS THIS TO YOU?				
Does Emory…	**Not at all**		**OK**		**Very Well**	**Low**				**High**
1. Convey respect and preserve the dignity of each patient and family?	1	2	3	4	5	1	2	3	4	5
2. Acknowledge the individuality, culture, capacity, and abilities of each patient and family?	1	2	3	4	5	1	2	3	4	5
3. Support a broad definition of family?	1	2	3	4	5	1	2	3	4	5
4. Show the importance of families to the care and comfort of patients?	1	2	3	4	5	1	2	3	4	5
5. Partner with patients and families at all levels of care?	1	2	3	4	5	1	2	3	4	5

II. Patterns of Care

KEY INDICATORS	STATUS					PERCEIVED PRIORITY FOR CHANGE/ IMPROVEMENT				
At Emory…	**Not at all**		**OK**		**Very Well**	**Low**				**High**
6. Family members are not viewed as visitors, but are always welcome to be with the patient, in	1	2	3	4	5	1	2	3	4	5

KEY INDICATORS	STATUS					PERCEIVED PRIORITY FOR CHANGE/ IMPROVEMENT				
At Emory…	Not at all		OK		Very Well	Low				High
accordance with patient preference.										
7. Families can remain with the patient during nurse change of shift, in accordance with patient preference.	1	2	3	4	5	1	2	3	4	5
During doctor's visits if the patient wishes, families can:										
8. Remain with the patient.	1	2	3	4	5	1	2	3	4	5
9. Participate in doctor's discussions.	1	2	3	4	5	1	2	3	4	5
Families' and patient choices about whether or not families may remain with the patient are respected and supported by staff during:										
10. Clinic visits/examinations.	1	2	3	4	5	1	2	3	4	5
11. Painful/invasive procedures.	1	2	3	4	5	1	2	3	4	5
12. Resuscitations (cardiac arrest).	1	2	3	4	5	1	2	3	4	5
13. Patients and families are viewed as members of the health care team.	1	2	3	4	5	1	2	3	4	5
14. Patients and families have the opportunity to participate in interdisciplinary meetings to plan	1	2	3	4	5	1	2	3	4	5

KEY INDICATORS	STATUS					PERCEIVED PRIORITY FOR CHANGE/ IMPROVEMENT				
At Emory…	Not at all		OK		Very Well	Low				High
care.										
15. You feel that there is encouragement for communication among patients, families, and staff (e.g. chart, email, bulletin boards in patient's room, pagers, telephone contact).	1	2	3	4	5	1	2	3	4	5
There is open disclosure with the patient and family regarding all errors (whether or not there is a bad outcome).										
16. In written policy.	1	2	3	4	5	1	2	3	4	5
17. In actual practice.	1	2	3	4	5	1	2	3	4	5
Patients and families are asked about their observations, goals, and priorities for the patient in:										
18. Outpatient settings.	1	2	3	4	5	1	2	3	4	5
19. Inpatient settings.	1	2	3	4	5	1	2	3	4	5
20. Staff collaborate with the patient and family to manage pain.	1	2	3	4	5	1	2	3	4	5
21. Each patient has a single, identified coordinator of care.	1	2	3	4	5	1	2	3	4	5

KEY INDICATORS	STATUS					PERCEIVED PRIORITY FOR CHANGE/ IMPROVEMENT				
At Emory…	Not at all		OK		Very Well	Low				High
22. Patients and families have help with transitions in care (e.g. unit to unit, hospital to other facility, hospital to home, and between outpatient and inpatient).	1	2	3	4	5	1	2	3	4	5
23. Patients and families are encouraged to participate in discharge planning.	1	2	3	4	5	1	2	3	4	5
24. Patients and families are asked about learning needs and priorities regarding care after discharge.	1	2	3	4	5	1	2	3	4	5
25. Opportunities to learn and practice caregiving are provided to patients and families prior to discharge.	1	2	3	4	5	1	2	3	4	5

III. OPTIONAL DEMOGRAPHIC QUESTIONS

26. What is your date of birth? _____/_____/ 19____ month/ day/ year	**29. What is your current marital status?** ☐ Never married/single ☐ Married ☐ Divorced/separated ☐ Widowed
27. What is your gender? ☐ Female ☐ Male	**30. How many years have you been with Emory?**
28. What racial/ethnic group do you consider yourself? ☐ Black/African American ☐ White/Caucasian ☐ Latino/Latina ☐ Asian/Pacific Islander ☐ American Indian/Alaska Native ☐ Other _____	**31. What is the highest degree that you have completed?** ☐ MA ☐ MS ☐ MD / DO ☐ PhD ☐ Other : _____
	32. Is there any additional information you would like to add?

Appendix 2 - Provider Free Text Word Map

Appendix 2 - Patient/Family Member Free Text Word Map