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“I want to know everything”

Patient perspectives on access to information during hospitalization

Presentation Overview

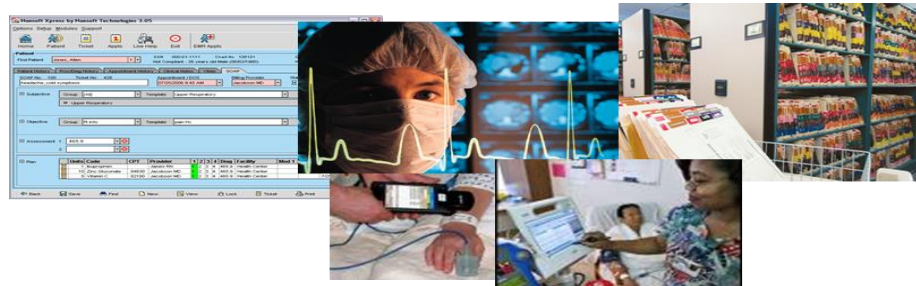
- Provider focused communication and information exchange
 - The Influence of a Hybrid Information System on Patient Care Coordination
 - Measuring Network Stability and Fit
- Including the patient
 - Exploring Patient Centered Handoffs in Surgical Oncology
 - Bridging the Gap: Chronic Disease Self Management
- COVID-19
 - New patient communication challenges



The Influence of a Hybrid Information System on Patient Care Coordination

What communication patterns are exhibited by healthcare providers from multiple professions during patient handoff between units?

Patient Information Documentation System Network Analysis Results from one handoff



*IRB Approval: University of Arizona (BSC:B07.323)
Partial Funding was received from Sigma Theta Tau
– Delta Theta Chapter*



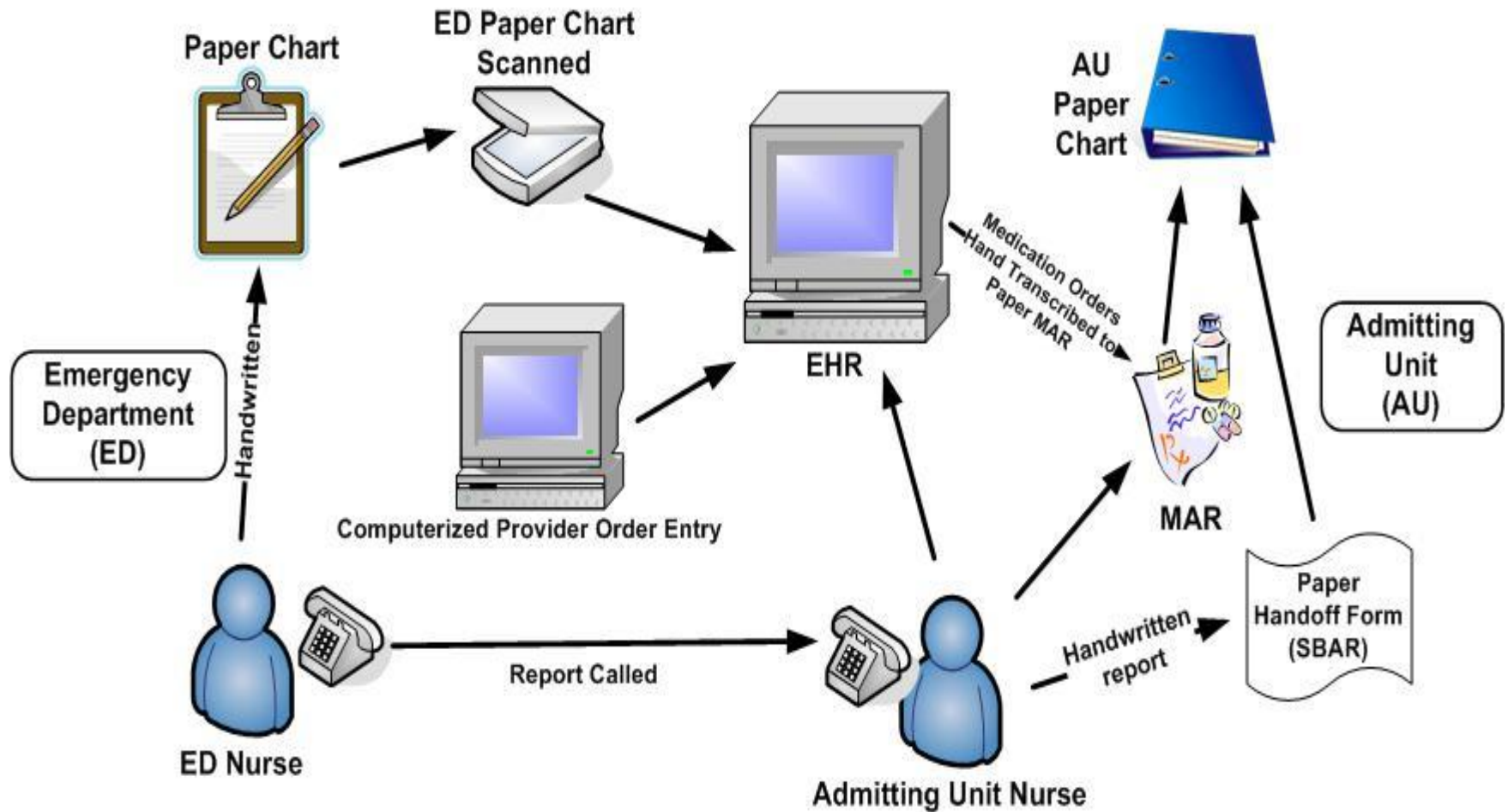
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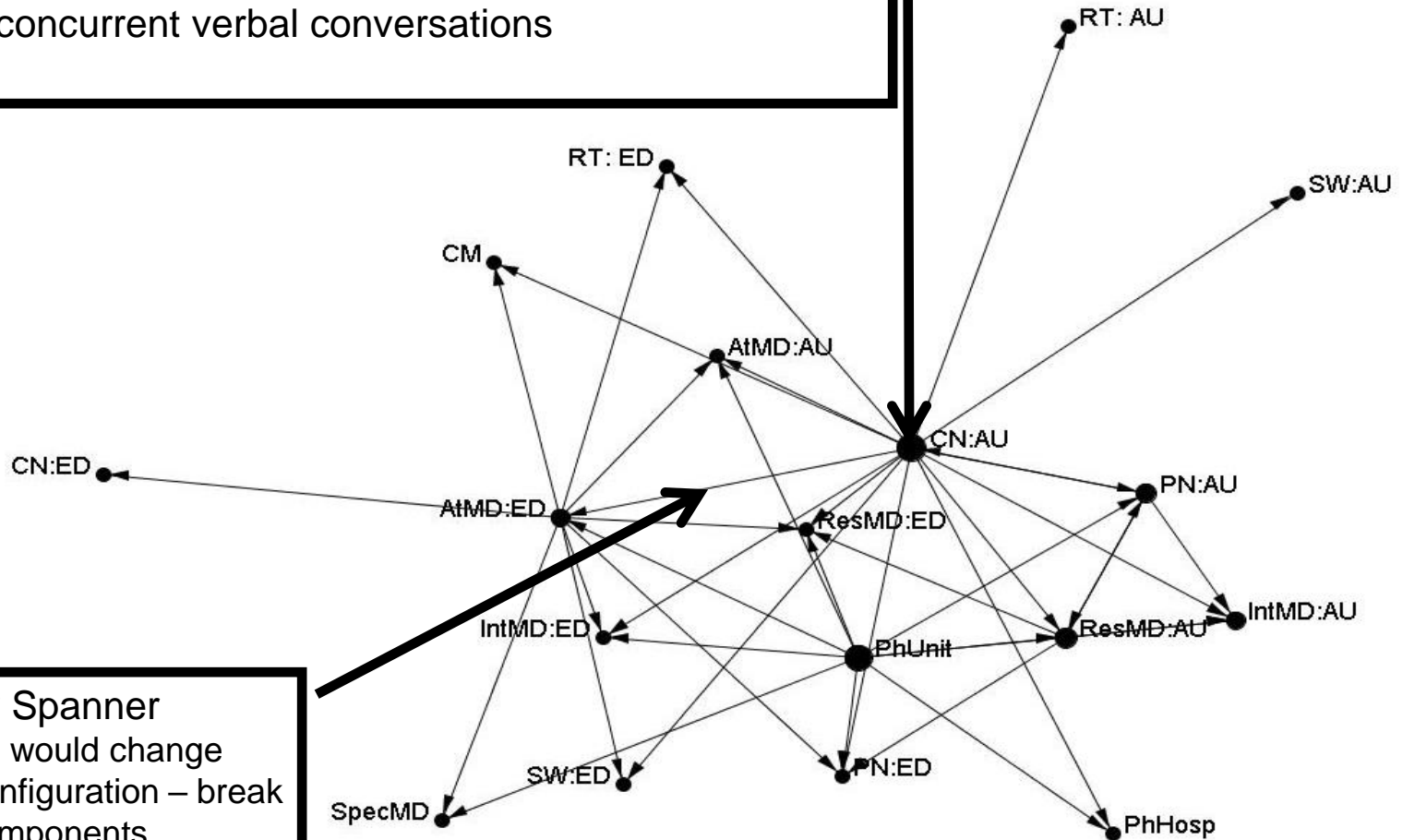
Patient Information Documentation Process

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- Admitting Unit Charge Nurse
 - Highest total degree centrality (Measure of providers direct ties)
- Multiple documentation processes and concurrent verbal conversations

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Boundary Spanner
Elimination would change
network configuration – break
into two components.

Conclusion

- Snapshot view of one patient handoff revealed:
 - Nonlinear and unpredictable communication dynamics
 - Shaped by:
 - Physical Infrastructure
 - Staffing
 - Information needs of providers
 - Information infrastructure (Design)

Benham-Hutchins, M., & Effken, J. (2010). Multi-professional patterns and methods of communication during patient handoffs. *International Journal of Medical Informatics*, 79(4), 252-267. doi: 10.1016/j.ijmedinf.2009.12/005

Benham-Hutchins, M., & Clancy, T. R. (2010). Social networks as embedded complex adaptive systems. *Journal of Nursing Administration*, 40(9), 352-356. doi: 10.1097/NNA.0b013e3181ee42bc

But what was missing?

- Realization that my role as a researcher - following the patient - resulted in me having more information than many members of the patient care team (and the patient).
- Most common question from ER providers was “has xx been to see the patient” and from inpatient providers “who was the admitting doctor”
- Realization that the patient is “out of the communication loop” and depended on me, as a researcher, to “bridge the gap”



Exploring Patient Centered Handoffs in Surgical Oncology

Research Team: Staggers, N., Benham-Hutchins, M., & Langford-Heerman, L.

Purpose: Examine nursing bedside handoffs from the patients' perspective

Setting: Large cancer center, western US, 25 bed surgical oncology unit

Sample: 20 patients **Age:** 28-85 (average 58) **Gender:** 10/10

Education: 50% some college, 2 had not graduated from high school

Data Collection: Observations, Interviews (recorded and transcribed), artifact tool capture

Data Analysis: Qualitative content analysis

Acknowledgement: Partial funding was received from Texas Woman's University (TWU) small grant award program. **IRB Approval** was obtained from the participating hospital, the University of Utah and TWU Institutional Review Boards.



Table 1. Themes and categories with code frequencies.

Themes and Categories	Code Frequencies
Depends Upon How Sick I am	122
Level of Participation by Patients	48
Frequency of Patient Participation	15
Location of Nurses' Handoff	17
Negotiation With Patients After Handoff	4
Patient Barriers to Participating	27
Patient Facilitators to Participating	11
I Want To Know Everything	153
Information Needs of Patients	49
Preferences of Patients	26
Patients' Discharge Information Needs	24
Patient Tools	35
Shared EHR Information	19
My Life Is in Their Hands	81
Take Care of Me	29
Being a Good Patient	24
Perceptions of the Nurses' Role	15
Perceptions of Care	13
Total	356



User experience (UX) considerations: No patients used electronic tools Notes (patients and family); Whiteboards

Today's Date: Thurs. July 26 Room: [redacted]
Nurse: Cam. Room: [redacted]
HCA: Matt Telephone: [redacted]
Attending Doctor/Service: [redacted]
APP: [redacted]
Physical Therapy: [redacted]
Social Worker: [redacted]
Case Manager: [redacted]
Respiratory Therapist: [redacted]
Housekeeping: [redacted]
Family Contact: [redacted]
Your DIET is: [redacted] Your ACTIVITY is: [redacted]
Today's Goals: [redacted] Questions/Concerns: [redacted]
Walks:
Up to the Chair:
Bath: [redacted]
Linen Changed: [redacted]
Pain Management is OUR Goal! El Control del Dolor Es Nuestra Meta!
1 2 3 4 5 6 7 8 9 10
Charge RN: [redacted] Telephone #: [redacted]
Nurse Manager: Jennifer Kelley Telephone: 587-4569

Today's Date: Thurs. 26, 2012 Room: [redacted]
Nurse: Shaari Telephone: [redacted]
HCA: Matthew
Physical Therapy: [redacted]
Attending Doctor/Service: [redacted]
APP: ENT
Social Worker: [redacted]
Case Manager: [redacted]
Respiratory Therapist: [redacted]
Housekeeping: [redacted]
Family Contact: [redacted] morphine IV Q2
next @ 8:30 pm tramadol q8 - @ 0830pm
ibuprofen q6 - @ 0630pm
Your DIET is: Regular Your ACTIVITY is: next @ 9:30 AM
Today's Goals: [redacted] Questions/Concerns: [redacted]
Walks:
Up to the Chair:
Bath: [redacted]
Linen Changed: [redacted]
Pain Management is OUR Goal! El Control del Dolor Es Nuestra Meta!
1 2 3 4 5 6 7 8 9 10
Charge RN: [redacted] Telephone #: [redacted]
Nurse Manager: Jennifer Kelley Telephone: 587-4569

Staggers, N., Benham-Hutchins, M., Goncalves, L., & Langford-Heerman, L. (2013). Exploring Patient Centered Handoffs in Surgical Oncology. *Journal of Participatory Medicine*, 5. <http://www.jopm.org/evidence/research/2013/07/10/exploring-patient-centered-handoffs-in-surgical-oncology/>

Staggers, N., Benham-Hutchins, M., & Heermann-Langford, L. (2014). User Experience Considerations for Patient-Centered Handoffs in Surgical Oncology. In C. Stephanidis & M. Antona (Eds.), *UAHCI/HCI 2014, Part III, Lecture Notes in Computer Science* (pp. 378--386). Switzerland: Springer International. Presented at the 16th International Conference on Human-Computer Interaction; Crete, Greece. June 22-27, 2014.

Bridging the Gap Pilot #1

Chronic Disease Self-Management Transitions

Research team: Benham-Hutchins, M., Stagers, N., Mackert, M., Johnson, A., & deBronkart, D.

Purpose: Elicit patients' perspectives about barriers and facilitators to information access and participation in provider-patient information exchange during hospitalization.

Data collection: Researcher designed questionnaire, social media snowball sampling (online support groups, listservs, blogs, social media)

Sample: 34 participants, 88% female, Age: 20-76 (48, 16.87), highly educated

Table 2 Hospital setting and region

		United States Regions				
		Northeast	Midwest	South	West	Total
Setting	Urban	4	5	10	3	22
	Rural	0	0	1	0	1
	Suburban	1	1	6	2	10
	Total	5	6	17	5	33

Acknowledgement: Funding - NIH/NINR Center for Transdisciplinary Collaborative Research in Self-Management Science (P30NR015335).

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

IRB approval was obtained from the University of Texas at Austin



Bridging the Gap Pilot #1

Findings: Most participants identified provider behaviors that inhibited patient participation in medical rounds and bedside shift change handoff. The majority also expressed a desire to “know everything” and frustration with access and sharing of information while hospitalized.

Table 3 Themes and categories with code frequencies

Themes and categories	Frequencies	
	Theme	Code
Caring for myself	148	
Care coordination		38
Discharge information		22
Provider contact post discharge		29
Self-Care		59
I want to know everything	97	
Communication - inpatient		25
Here is the information I want		72
Include me during handoffs and rounds	49	
Bedside shift report: barriers and facilitators		19
Medical rounds: barriers and facilitators		30
What I expect	83	
Communication - interprofessional		23
Patient expectations: care process		26
Patient perception of provider knowledge and recommendation		34
You're not listening	87	
Communication - patient-provider		53
Invisible patient		17
Listen to the patient		17
Tracking my health information	69	
Information tracking: inpatient		28
Information tracking: outpatient		41
Total	533	



Bridging the Gap Pilot #2

The Influence of Hospitalization on Spanish Speaking Hispanic Patients' Chronic Disease Self-Management

Research Team: Benham-Hutchins, M., Brown, S., Donovan, E., Guevara, H., & Johnson, A.

Purpose: Elicit patients' perspectives on the exchange and sharing of information during hospitalization.

Self management methods; information and support needs during hospitalization, self management needs on discharge

Data Collection: Recruited from local oncology clinic.

Focus Group – Spanish speaking moderator, recorded and transcribed

Sample: All women, Age: 47-66 (55), chronic diseases included cancer and diabetes, comorbid conditions included hypertension, arthritis, heart, and liver disease, hospitalized 2-8 months previously for 2-14 days.

Acknowledgement: Funding – St. David's Center for Health Promotion and Disease Prevention Research in Underserved Populations
IRB approval was obtained from the University of Texas at Austin. Spanish language consents were used.



Bridging the Gap Pilot #2

Findings: Participants shared positive experiences with providers during hospitalization and the usefulness of self-care instructions. Language was not recognized as a barrier by any of the participants.

Future Research: Emotional readiness and the timing of medical information sharing.

Publications:

Benham-Hutchins, M., Brown, S.A., Donovan, E. E., Guevara, H., & Johnson, Alisha. (2018). Spanish speaking Hispanic patients' information preferences during hospitalization: An exploratory pilot study. *Journal of Participatory Medicine*, 10(4), e10782.

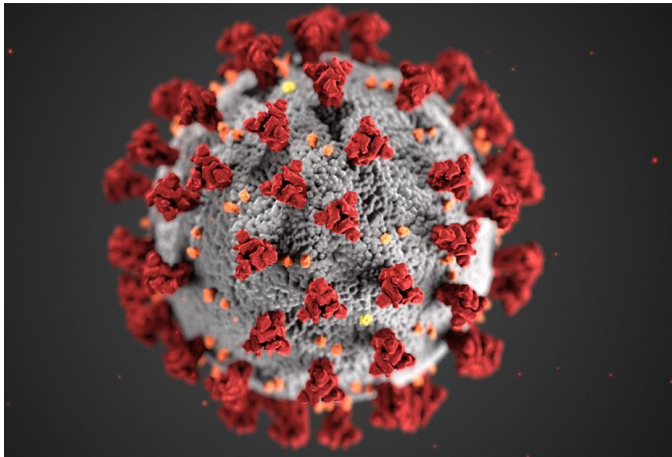
<https://doi.org/10.2196/10782>

Benham-Hutchins, M., Staggers, N., Mackert, M., Johnson, A.H. & deBronkart, D. (2017). "I want to know everything": A qualitative study on patient perspectives about sharing health information during hospitalization. *BMC Health Services Research* 7(1), 529.

doi:10.1186/s12913-017-2487-6. <https://doi.org/10.1186/s12913-017-2487-6>.



Plan: Facilitators and Barriers to Nurse and Patient Information Exchange in the Acute Care Setting



<https://www.cdc.gov/dotw/covid-19/index.html>

Pandemic: “No Visitors Allowed” – Patient/Family/Provider communication in the acute care setting during a public health emergency

Acknowledgement: Funding – TAMUCC
Just in time Covid 19 research award

Future Research

- Provider behaviors that influence patient participation on bedside handoff and medical rounds.
- Patient access and interaction with electronic medical record (inpatient portals)
- Influence of communication patterns on patient outcomes (NetFit study – secondary analysis)
- Use of Network Analysis to examine coordination of care for patients with chronic conditions



NetFit Study Publications

- Benham-Hutchins, M., Brewer, B. B., Carley, K., Kowalchuk, M., & Effken, J. A. (2017). Design and implementation of a data collection system for social network analysis. *Online Journal of Nursing Informatics (OJNI)*, 21(2). Retrieved from <http://www.himss.org/library/design-and-implementation-data-collection-system-social-network-analysis>
- Brewer, B. B., Carley, K. M., Benham-Hutchins, M. M., Effken, J. A., Reminga, J., & Kowalchuck, M. (2018). Relationship of Staff Information Sharing and Advice Networks to Patient Safety Outcomes. *J Nurs Adm*, 48(9), 437-444. doi:10.1097/NNA.000000000000064
- Brewer, B. B., Carley, K. M., Benham-Hutchins, M., Effken, J. A., & Reminga, J. (2018). Nursing Unit Design, Nursing Staff Communication Networks, and Patient Falls: Are They Related? *HERD: Health Environments Research & Design Journal*. doi:10.1177/1937586718779223
- Benham-Hutchins, M., Carley, K. M., Brewer, B. B., Effken, J. A., & Reminga, J. (2018). Nursing Unit Communication during a US Public Health Emergency: Natural Experiment. *JMIR Nursing*, 1(1), e11425. <https://doi.org/10.2196/11425>
- Brewer, B. B., Carley, K., Benham-Hutchins, M., Effken, J. A., & Reminga, J. (2019: under review). Exploring the Stability of Communication Network Metrics in a Dynamic Nursing Context. *Social Networks*.

Questions?



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