INTERWOVEN CARE: CREATING OPPORTUNITIES FOR RICHER CONVERSATIONS BETWEEN CASE MANAGERS AND PATIENTS

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21ST CENTURY HEALTHCARE

Interwoven Care: Creating Opportunities for Richer Conversations Between Case Managers and Patients

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Acknowledgements

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Abstract

This thesis project developed patient-centric tools to address whole-patient assessments to reduce potential hospital readmissions. The project was an integrative design project mapped under the framework of the Double Diamond Design Methodology. It was conducted for heart failure patients with clinicians, hospitals and an insurance company. A three-part toolkit was developed to create opportunities for patients and case managers to discuss, document and track concern areas beyond the patient's medical needs. The toolkit acknowledges patient, clinician and healthcare system expectations.

Keywords

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Figures

INTRODUCTION AND RATIONALE

Healthcare Delivery is a Wicked Problem

Think about your last healthcare experience: What thoughts ran through your mind? Were you thinking only about your health? Or were you thinking about missing your child's practice? Or the cost for the tests proposed? How many times did you discuss these concerns with your clinicians? These conversations are important yet rare in a healthcare setting.

This project highlights one approach to study and propose interventions in the healthcare space to create opportunities for broader concern driven conversations. The project was done by the author with and for St. Joseph Mercy Health System, Ann Arbor (St. Joseph) to address issues in care transitions.

Healthcare delivery itself is a complex system. It cannot be addressed from one point of view or expertise. Healthcare system interventions require multiple points of views, expertise, and approaches. Hence, healthcare delivery is a wicked problem.

Wicked problems are unconstrained, thorny societal issues that ethically, charge at us to act, yet are never readily solved (Rittel and Webber 1973). It is the integrative designer's task to develop process-driven, collaborative approaches to cross-disciplinary projects situated in the crux of wicked problems.

The following terms will be used and defined throughout this project as follows:

1. Patient - "A person receiving or registered to receive medical treatment" (Oxford English Dictionary 2005)

2. Caregiver - A person who supports the patient through their medical treatment. Often a close family member.

3. Clinician - "A person qualified in the clinical practice of medicine, psychiatry, or psychology" (Merriam-Webster Dictionary 2017).

4. Clinician team - A team of clinicians, each member with a specialized role. A Clinician team could include physicians, nurses, case managers, residents, pharmacist.

5. Case manager - "A person (social worker or nurse by training) who assists in the planning, coordination, monitoring, and evaluation of medical services for a patient with emphasis on quality of care, continuity of services, and cost-effectiveness" (Merriam-Webster

Dictionary 2017).

6. Hospitalist - "A dedicated in-patient physician who works exclusively in a hospital." (Oxford Living Dictionaries 2017)

7. Designer - This word designates a student in the University of Michigan's Master of Design program.

8. User - A person who uses a product or service.

9. E-advisor - E-advisors are a group of volunteers, who have had positive or negative experiences as patients and caregivers. They volunteer their time to advocate from a patient and caregiver perspective.

Whole-Patient Care

Hospitals are guarded spaces; patients come to the hospital because they are sick. The healthcare system is expert at treating medical problems. At the hospital, patients get to be temporarily away from their life and all the factors that make it up, to concentrate on their health. However, the causes of illness may have roots in aspects of their lives other than medical issues. A patient's illness may be connected to other physiological problems: emotional, psychological, cultural, behavioral, social, financial or legal causes. These factors are often not addressed during their hospital stay. Many of these factors that have an impact on health are private and possibly taboo concerns for patients; hence they may never be discussed. Patients may themselves be unaware of the connection between all these factors and their health.

It is important for the patient's clinician team to be aware of these factors that may be the cause for:

1. A patient's current hospitalization

2. Failure for the patient to maintain their health once they leave the hospital

3. Future patient readmissions to hospital

Purpose and Goals of the Project

St. Joseph's heart failure team was looking to identify ways to assess their patients better. Their aim was to be able to determine factors that may be of concern to the patient during hospitalization. Through the identification of the concerns earlier, a clinician team at the hospital could address them during the hospitalization, which in turn would help in reducing patient readmission rates. Readmission rates, from a hospital system point of view, are crucial as they are connected to hospital incentives, which fund hospitals to maintain standards of care and to generate profits for the hospital.

While this project aligned with the bigger goal of St. Joseph to identify ways to improve patient assessment, the project also had the following project-specific goals:

1. Identify the current system used for patients and caregivers to discuss patient concerns with the clinicians.

2. Discover how the concerns are discussed between patients, caregivers, and clinicians.

3. Track how the concerns are addressed.

4. Identify challenges and opportunities in the system that accommodate a hospital-proposed modification to the case manager's role.

5. Propose new tools that would initiate, facilitate and document communication of patient concerns with the case managers.

REVIEW

Contextual Review

This project does not aim to solve all the problems in care transitions but proposes a small incremental change in service to the heart failure patients by the clinicians housed in St. Joseph. The project aims to create an impact on the local team as well as the larger healthcare system in the future.

Healthcare System and Care Transitions

Healthcare is not housed in one location or set at one time. For patients, a healthcare experience is like a relay race made of systems, providers, technologies, diagnostics, procedures, therapies, ambulance rides, waiting rooms, discharge summaries, and hospital beds. The transitions between these healthcare experiences are where small yet crucial details can create possible errors. This project demonstrates the critical nature of these details during patient care transitions.

The following information demonstrates the importance of one condition, heart failure disease, to a health provider like St. Joseph. In 2016, for the first time in twenty-six years, deaths caused by cardiovascular diseases went up in the United States. Seventeen percent of US healthcare spending and about thirty percent of Medicare spending goes toward cardiovascular diseases (America's Health Ranking Annual Report 2016). Heart Failure is a type of cardiovascular disease. A study determined that between 2007 and 2008 nearly all heart failure patients were readmitted within a year of leaving the hospital, out of which, 47% of readmissions were within 30 days of discharge (American Hospital Association 2011). Better management of the patient's condition is crucial because most readmissions for heart failure patients are caused by the same or similar diagnosis to previous admissions (American Hospital Association 2011). Jencks et al. found that about $17 billion out of the approximately $26 billion spent on readmissions by Medicare are avoidable (Jencks et al. 2009). Three critical breakdowns during care transitions were identified: 1) communication breakdowns, 2) patient education breakdowns, and 3) accountability breakdowns.

According to data from the Michigan Department of Health and Human Services through 2014, heart diseases were the leading cause of hospitalization, with congestive heart failure as the top hospitalization which could be prevented through better management for the condition (Michigan Department of Health and Human Services

2014). Michigan was ranked at 34th place in 2016 by the United Health's annual report ranking America's health (America's Health Ranking Annual Report 2016). The overall score for Michigan was even lower than the nationwide average. With about 289 deaths per 100,000 population, Michigan has one of top ten recorded death rates due to cardiovascular diseases (America's Health Ranking Annual Report 2016). Cardiovascular diseases are the biggest area where local health systems need to allocate resources.

Integrative Design and I-MPACT Collaboration

Collaborative Quality Initiatives (CQI) by Blue Cross Blue Shield of Michigan (BCBSM) are initiatives where the CQI partners with hospital and physician groups to identify opportunities for improvements in specific areas of healthcare delivery.

The Integrated Michigan Patient-Centered Alliance for Care Transitions (I-MPACT) is BCBSM's first patient focused CQI. I-MPACT is also the first CQI to integrate patient and caregiver participation along with teams of hospitals and physician organizations. Every year four to six hospital clusters (hospital + physician group) form a cohort to develop new interventions. Through the years upto 70 hospitals across the state of Michigan will be part of I-MPACT. I-MPACT aims at working with the hospital to assess patient risk for readmissions and adjust plans to reduce those risks (I-MPACT 2016).

The I-MPACT team approached the University of Michigan, Penny W. Stamps School of Art & Design, Masters of Design (MDes) in Integrative Design students (designers) to identify and develop new approaches to tackle this CQI. The designers initial role was to partner with I-MPACT to facilitate the creation of problem statements and provide recommendations for developing potential interventions. Later the designers took on different roles to work on a range of specific problems identified during the CQI.

Collaboration with St Joseph Mercy Hospital, Ann Arbor

In 2016, Truven Health Analytics announced St. Joseph as one of the top 100 hospitals in the US (Truven Health Analytics 2017). St Joseph is also one of the participating clusters in the first I-MPACT cohort. The St. Joseph cluster identified heart failure patients as a target population to improve care transition experiences and formed a team to address heart failure issues. Through St. Joseph's work within I-MPACT, the heart failure team identified a need to assess their heart failure patients better for the patient's concerns, support system and provide education and allocate resources based on those factors. Such an assessment requirement meant the patients needed to be evaluated for aspects of their lives beyond physical health. The heart failure team had identified the kind of information they would like to know from a patient, based on their experience and current literature. However, the heart failure team had not identified the content nor the medium for this information to be gathered, communicated, facilitated or documented.

The author of this project collaborated with St. Joseph's heart failure team to identify and create opportunities to facilitate and document the needs of the patients better. Outcomes from this collaboration formed the basis for this project.
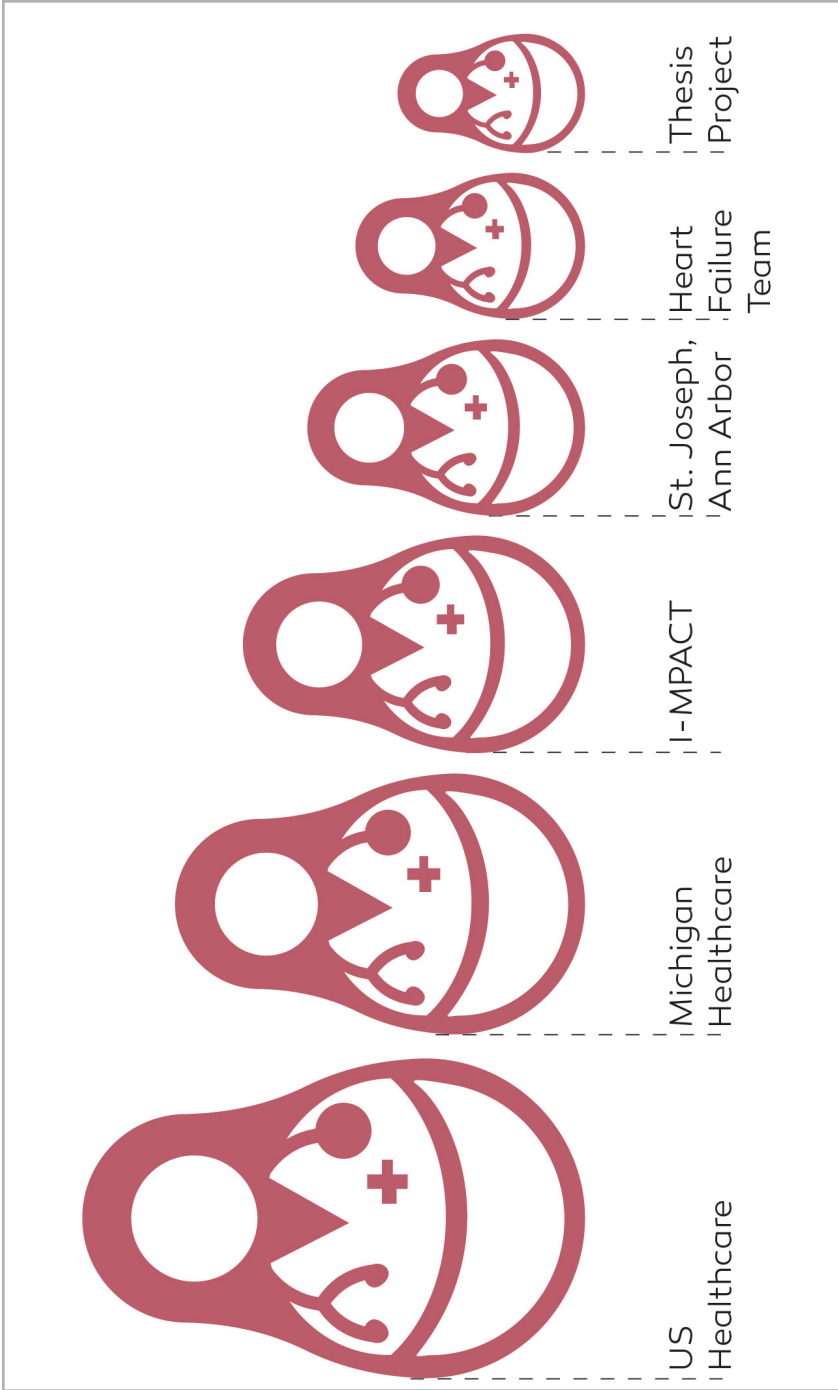
US Healthcare

Michigan Healthcare

I-MPACT

St. Joseph, Ann Arbor

Heart Failure Team

Thesis Project

Figure 01. Understanding the Context

Literature Review

Key Concepts

Patient-Centered Care Theory

Patient-Centered Care focuses on treating a patient as an individual and identifying their needs of care. Richardson et al. defined patient-centered care as care that is "providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions." (Richardson et. al. 2001 , 3). The intention of patient-centered care is to allow patients to be drivers for their care (Reynolds 2009). This philosophy resonates with human-centered design, and studies have drawn parallels between the two approaches (Johnson et. al. 2004). The system exists to serve its primary users, the patients, and their wellbeing. Shared decisions where patients can understand their options and clinicians can figure out what is important to the patient and caregivers is highlighted by research as the "pinnacle of patient-centered care" (Barry and Edgam-Levitan 2012).

Patient Complexity

The World Health Organization (WHO) defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." (WHO 1995). This definition of health broadens it to include factors that build up the complexity in a patient's life, beyond physiological health. Below are some practices and frameworks that address patient complexity.

The Mayo clinic's Minimally Disruptive Medicine (MDM) team has developed a theory-based model where the care is planned to think of what is the least "burden of treatment" for the patient (Leppin, Montori and Gionfriddo 2015). Through their "cumulative complexity

model" the team highlights how social factors and clinical factors play a role in a patient's care. The model aims at understanding the patient's complete life, acknowledging the complexity and ambiguity that comes with it.

Safford, Kiefe and Allison created the vector model of complexity as a quality measurement model comparing how different determinants of health (socio-economic, cultural, environmental and behavioral) may affect the biological factors of health (Safford, Kiefe and Allison 2007).

Palliative Care is one field of care with acceptance of patient complexity and providing whole-patient care as the field's core belief. WHO defines palliative care as an "approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering using early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual"(World Health Organization 2006). The Canadian Hospice Society identifies eight categories of care that need to be recognized and addressed for every patient to improve their quality of life. Their eight categories are "disease management; physical care; psychological care; social care; spiritual care; practical care, end of life care; death management and loss/grief care" (Ferris et. al. 2013, 5). The Clinical Practice Guidelines for Quality Palliative Care by National Consensus Project for Quality Palliative Care defines seven aspects of care. Their seven aspects of care are "physical; psychological and psychiatric; social; spiritual, religious and existential; cultural; care at the end of life; ethical and legal aspects of care" (Dahlin 2013, 1).

Psychosocial assessments are used by nurses, case managers, social workers, psychologists, occupational therapists and other clinicians to "evaluate a person's mental health, social status, and functional capacity within the community" (Oxford Concise Medical Dictionary 2015). Based on these needs they develop their care plans.

An occupational therapy practice framework identifies five aspects to support engagement and participation of health. These five domains are "occupation (activities, education, work, etc.), client factors (values, body structures, etc.), performance skills (motor, social interactions skills, etc.), performance patterns (habits, routines, etc.), contexts and environments (cultural, social, etc.)" (American Occupational Therapy Association 2014, 4).

Case management uses psychosocial assessments for various types of behavioral health assessment, medical case management, HIV-related support, etc. These assessments do not have a standard framework but do have a common pattern of questions. All the questions are multiple choice. The categories of questions include housing situation, education, support and dependents at home, insurance, financial situation, transportation availability, etc. In defining the priorities of patient needs and concerns; most psychosocial assessments are driven by the clinician and not by the patient.

Example Case Management Forms

Boston Public Health Commission, HIV/AIDS Services Division: HIV Case Management Assessment Form (Boston Public Health Commission 2008):

The form looks at assessing patients in medical, adherence and insurance issues; financial, housing and legal; transportation; mental health; support system and relationships; sexual health and alcohol and drug use. In the end, based on the answers provided by the patient, the case manager creates a summary for each category, tracking assessments at six month intervals. Each category is tagged as minimal, moderate or intensive based on the answers. The questions are asked of the patient, but the form provides cues to the case manager to check on the patient.

Massachusetts Department of Public Health, Office of HIV/AIDS
Boston Public Health Commission, HIV/AIDS Services Division

HIV CASE MANAGEMENT ASSESSMENT FORM

Completing the first page of this document, along with the Joint HIV/AIDS Client Information Form, fulfills the funders' requirements of intake.

Client Name:	Client Code:
Address:	Social Security Number:
Case Manager:	Date of Assessment:

Who at this agency may contact you? _____

How may we contact you?

Home Phone Message OK?	☐ Yes ☐ No ☐ Yes ☐ No	( ) _____ - _____
Cell Phone Message OK?	☐ Yes ☐ No ☐ Yes ☐ No	( ) _____ - _____
Work Phone Message OK?	☐ Yes ☐ No ☐ Yes ☐ No	(___) _____ - _____ x _____
Mail	☐ Yes ☐ No	Address:
E-mail (complete special release)	☐ Yes ☐ No	E-mail address:

Figure 02 . HIV Case Management Assessment Form - A

	LEVEL OF NEED SUMMARY			

Section	Score (by 6-month assessment intervals)			
	Initial assessment	/ /	/ /	/ /	/ /
Medical, Adherence, and Insurance				
Financial				
Housing				
Legal				
Nutrition and Basic Needs				
Transportation				
Mental Health				
Support System and Relationships				
Sexual Health				
Alcohol and Drug Use				
Level of Case Management *A = minimal* *B = moderate* *C = intensive*				

Figure 03. HIV Case Management Assessment Form - B

Diabetes Initiative Case Management Assessment Form (Prescription for Health Diabetes Project 2004)

The diabetes initiative was set up with support by the Robert J. Wood foundation to help patients self manage their diabetes. The case management assessment form looks at identifying the patient's diagnosis, transportation support, literacy levels and family support system and their age, community resources and condition management. The form also has an action list to help case managers document and act on patient needs.

Care Management Workbook, New Jersey State Human Services (Division of Medical Assistance and Health Services 2015)

The Care Management Workbook provides an overview on case management roles, responsibilities and resources. The workbook provides a list of questions to ask patients during assessment. Areas of questions include demographics, history, functionality, nutrition, developmental concerns, support/community resources, psychosocial history, other supplemental questions and reflection questions for the case manager. The questions rely on the case manager to verbally ask these questions as a part of the assessment, take notes of the conversation and document the conversation in the electronic medical records.

All practices and frameworks discussed above in the patient complexity theory accommodate the broader definition of health as defined by WHO. They involve a patient-centric approach in planning care based on documentation of factors in a patient's life which may affect their health. However, they do not mention how the complexity levels are decided and who reports them. Particularly in the vector model, where the complexity will be determined by the patient's status (e.g. homelessness may get higher complexity rating than having access to a house). As discussed, patient-centered care aims to be patient-

	Case Manager Initial Assessment Page 3		
Actions taken:			
Diabetic Flowsheet updated	YES	NO	
Research consent form signed	YES	NO	
Pharmaceutical Drug Assistance Form completed	YES	NO	
Portable Record updated	YES	NO Other (ex. Pt. forgot/lost)	
Calendar updated	YES	NO Other (ex. Pt. forgot/lost)	
Pt. Referred for social support	Yes	NO	

If yes, to what person or organization (ex. CHW, home visit, provider notified)

_____

_____

Figure 04. Diabetes Initiative Case Management Assessment Form

	QUESTIONS
1	What is your name (member)?
2	What is your primary telephone number?
3	What is a secondary telephone number we could use?
4	In case of an emergency, what is the name and telephone number of a person we can contact?
5	What is the primary language spoken in the home?
6	What is your current address?
7	Who is providing the information to complete the assessment (include name and relationship to member)?
8	Is there a guardian involved?
1	Who is your current primary care provider or family doctor? (Provide name and telephone number)
	What was the date of last appointment?
2	Do you see any specialists? (Provide names and telephone numbers)
	What was the date of last appointment?
3	Do you see a dentist? (Provide name and telephone number)
	What was the date of last appointment?
4	Which of the following medical conditions do you/have you had? (Select: Asthma, Chronic Obstructive Pulmonary Disease, Tuberculosis, Seizures, Memory Problems, Depression, Schizophrenia, Congestive Heart Failure, Heart Disease, Hepatitis, Diabetes, Kidney Failure, On Organ Transplant List, Paralysis, Multiple Sclerosis, HIV/AIDS, Stroke, Lead Poisoning, Sickle Cell disease, Cancer w/treatment, Hemophilia, Other)
5	On a scale of 1 to 5, with 1 being "poor health"; 2 being "fair health"; 3 being "good health"; 4 being "very good health"; and 5 being "excellent health", how would you rate your overall health during the past three months?
6	Which medications are you taking, including over-the-counter medications and supplements?
	Do you need any help taking your medications?

Figure 05. Case Management Workbook

driven. Which means a patient's scale needs to be compared to their own life and base points. Each patient is different and having a standard scale for them may work for the system but may not work for the patient.

The first two case management assessments formats are forms with questions composed for the patient. However, they have information directed towards the case manager, providing mixed directions for the ownership of the form. The questions are framed as an information seeking strategy and not as a support for the patient to identify their needs. Specifically in the HIV assessment form the case manager may fill out these forms as the conversation proceeds, indicating the form as a note taking tool more than a conversation tool. The questions are mostly multiple choice, pointing more towards a checklist for medical record documentation than a conversation tool. The forms fail to provide an overview in the beginning before questions are being asked.

The care management workbook completely relies on the case manager to initiate a conversation, ask the right questions and document the conversation. The questions are open ended and seek information. The framework expects the case manager to remember the order of conversation and the patient to comprehend the question without any physical artifact for reference.

In all three case management assessment formats, the conversations are case manager initiated. The quality of conversation depends on the trust patients have with the case manager to discuss private and possibly taboo issues. The patients are also expected to remember all details of their lives at the point of conversation. The case manager may not have enough time with their workload, to allow the patient to think about their problems, before communicating. As the flow of the conversation is directed by the form or case management script in case of the workbook, the order and time allotted to a certain category may not necessarily reflect the depth of the problem.

Care Transitions

The Joint Commission Enterprise, which accredits and certifies health organizations, defines care transitions as "...refer to the movement of patients between healthcare practitioners, settings, and home as their condition and care needs change" (The Joint Commission Enterprise 2012, 3). It highlights healthcare as a process instead of interactions with health systems. Such care goes beyond entry and exit from a hospital. So, care transitions are more like a game of hand-off where the care responsibility keeps on shifting between the clinicians, the caregivers, and the patients themselves. The spaces in between these handoffs can be uncertain and are often dependent on possible paper and digital trails. The only person who may be constant through these experiences is the patient, who may or may not be entirely aware of what they are going through. Such uncertainties are errors waiting to happen, leading to possible readmissions to a hospital.

Framing and Sense-making of Complexity

Moving from System's Perspective to Patient-Centered Perspective

Schon defines framing, as a interpretation of a problem (Schon 1983). The way the problem is described allows influencing possible interventions. Typical healthcare interventions are system-centric and data driven. The core task for this project was to move away from quantitative data-centric perspectives to more qualitative patient driven perspectives. Identifying the patient as the primary driver for defining a problem statement for the I-MPACT project, allowed for more patient-centric interventions.

Paton and Dorst introduced the concept of "the designer as a collaborator" (Paton and Dorst 2011, 7), which aligns with the aim of participation required for the project. Contrary to participatory design where users are involved in the design process, this project allowed for

the author to collaborate as a team member in the heart failure team.

The project was situated in the US healthcare system following the rules set under the Affordable Care Act (ACA), contextualized in St. Joseph's heart failure system and temporally based on the organizational modifications planned by the heart failure team. Under these realities, the author could identify a high-value problem to tackle. Interventions in healthcare, just like any other wicked problems, works on the scale of better or worse instead of good or bad (Rittel and Webber 1973, 163). The project proposed to make a small incremental change, which potentially would have an impact to make real change. The author created tools for people to understand their context. It allowed for affordance to elicit the quality of conversation that does not typically happen.

Double Diamond Design Methodology

This thesis project employed the Double Diamond Design Methodology. This methodology is a "simple visual map of design process" created by The Design Council, UK (Design Council, UK 2005). The methodology involves identifying possibilities through divergent thinking followed by narrowing in on ideas through convergent thinking. There are four phases in this methodology.

Discover: Exploring various aspects of the problem space.

Define: Identifying specific insights leading to a problem statement.

Develop: Generating concepts and prototypes to tackle the problem statement.

Deliver: Evaluating concepts to finalize and further develop the key concept.

Design processes are iterative and not linear. However, setting them in a framework like the double diamond design methodology, allows
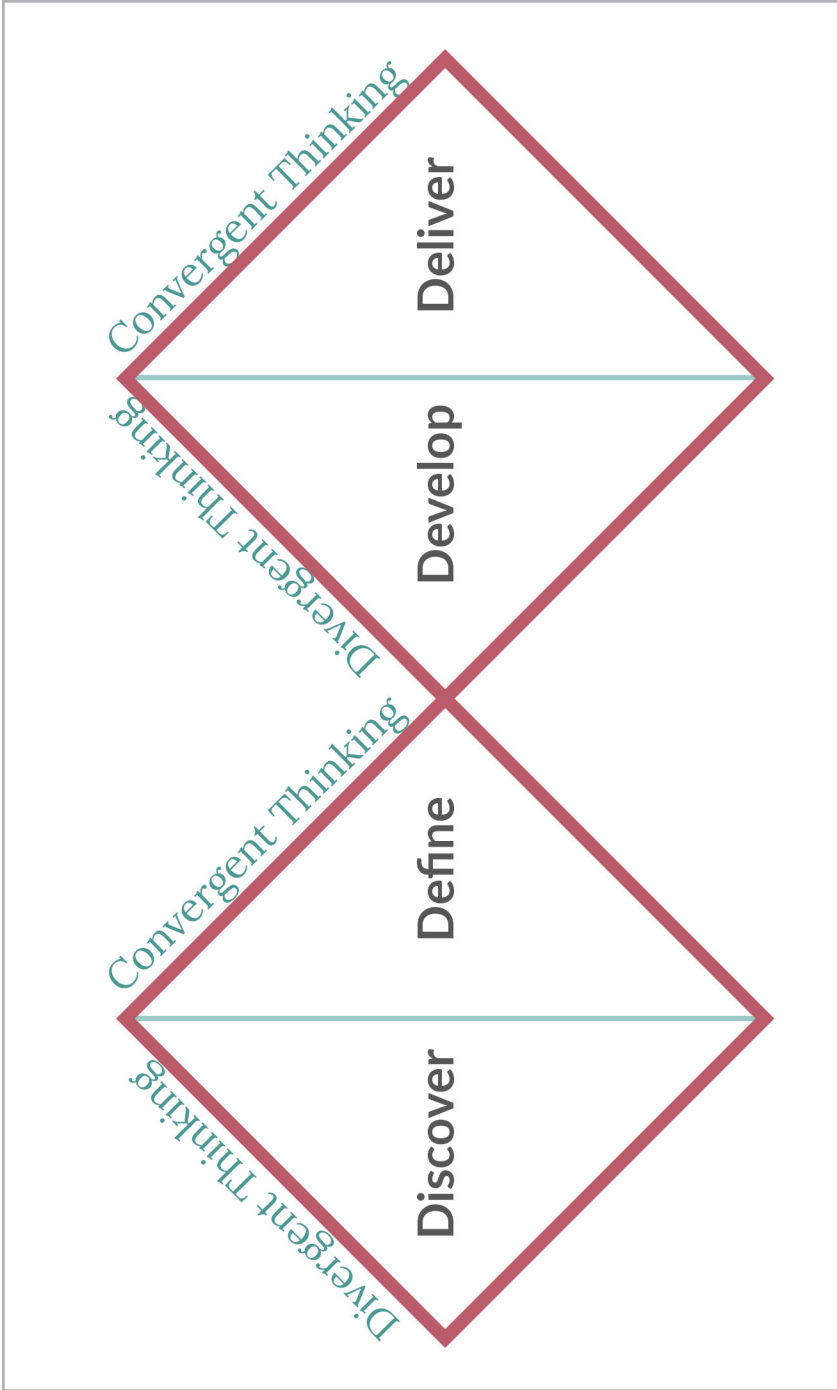
Figure 06. Double Diamond Design Methodology

designers to describe the frame of thinking, whether divergent or convergent; while deploying a planned design method.

Relevant Programs

This section presents six programs and projects that tackle issues in care transitions and provide a possible patient-centric approach to these issues.

The Joint Commission identifies three nationwide initiatives that address multiple issues in care transitions. The three initiatives are:

1. Better Outcomes for Older Adult Safe Transitions (BOOST) by the Society of Hospital Medicine

BOOST aims at providing expert training to a hospital in improving their care transitions. BOOST mentors work with the hospitals for a year to identify their patients who are at high risk for rehospitalization along with their current care transitions processes. Once the high-risk patients are identified, hospitals implement interventions developed by BOOST to specifically address issues which may go wrong in the care transition process (Society of Hospital Medicine).

2. Re-Engineered Discharge (RED) by Boston University Medical Center

The Re-Engineered Discharge (RED) project works in developing interventions and improving hospital discharge processes to reduce hospital readmission rates. Their intervention calls for a nurse discharge advocate to meet with the patients after their discharge, to set up appointments with the patient's primary care physician (PCP). Pharmacists reach out to the patient's post-discharge to discuss medications. Both nurse discharge advocate and pharmacist connect

with the PCP to discuss medication lists and any other problems (Jack et. al. 2013).

3. The Care Transitions Intervention by University of Colorado, Denver

The Care Transitions Intervention (CTI) is based on qualitative research done with and for patients and caregivers. The CTI works with "Transitions Coach" nurses to follow up with patients post discharge, providing them with tools to manage their health. The follow-up includes one home visit and three phone calls with the patient after discharge (Coleman et.al. 2006).

All three interventions discussed above have been shown to assist in reducing possible readmissions. However, they rely heavily on addressing the medical needs and concerns of the patient, and not the other needs that may cause readmissions. There is a gap for formal interventions in the space of identifying and addressing the whole patient needs and concerns to avoid readmissions.

Other Similar Programs

4. Designing and Delivering Whole-Person Transitional Care: The Hospital Guide to Reducing Medicaid Readmissions by the Agency for Healthcare Research and Quality (AHRQ).

This is a set of tools for hospital system administrators and clinicians, specifically designed or modified to address readmission issues for Medicaid patients. Amongst the tools, is a "Whole Person Transitional Care Planning Tool." This tool prompts the discharge planner to identify nine potential post-discharge need areas and work on an action plan based on the needs. The nine need areas are 1) access to ambulatory care, 2) access to behavioral healthcare, 3) functional status, 4)

unstable/inadequate housing, 5) financial insecurity, 6) food insecurity/
access, 7) social connection/ isolation, 8) legal issues, and 9) language
or literacy issues (Boutwell et.al. 2016).

*5. Reflection Document by Mayo Clinic's Knowledge Evaluation Center:
The Patient Revolution Project*

The Patient Revolution Project works towards developing tools and
activities that provide a space for patients to discuss their life and
goals. One of their projects is a reflection document, which allows for
a patient to go through "dimensions of their lives" like family, friends,
work, etc. The patient then marks the document indicating if those
areas are "satisfaction or burden" for them. This tool is designed to be
used in the waiting rooms for the patient to prompt a conversation
with their clinician (The Patient Revolution Project 2016).

6. Asthma Discharge Action Plan Tool by IIT Institute of Design

The asthma discharge action plan tool relies on communication
between the patient and the clinician instead of being a formal
document only for the clinicians. The new tool uses simple terminology
and illustrations to help patients and caregivers understand their care
plan better.

The three tools discussed above highlight ways to accommodate a
patient's complexity, while managing their care. The whole-patient
transitional care planning tool looks at nine areas of needs, but the
format of the document is clinician-driven and relies on the clinician's
understanding of the patient's needs. On the other hand, the reflection
document is entirely patient-centric, but relies on the patients to
initiate conversations about their "dimensions of life." Even though

the asthma discharge action plan tool is clinician-driven, it is done in a format patients, and caregivers can understand. Informed by these examples, this project looks at designing a patient-centric communication tool, which is facilitated by the clinician. (Erwin et. al. 2016).

DESIGN PROCESS

The first part of the project was done with and for I-MPACT, where the aim was to build an understanding of the US healthcare system and a shared understanding with the hospitals to identify an appropriate problem statement for this broad context. This part of the project was conducted by a team of six designers. The later part of the project was conducted individually by the author with the St. Joseph heart failure team to develop a problem statement relevant to their particular context and then identify approaches to address this more specific problem statement.

The Double Diamond Design Methodology, discussed in the literature review, was employed in both parts of the project. The specific methods are discussed as they relate to the four phases of the Double Diamond Design Methodology and are not described in any chronological order. As discussed in the literature review, the design process was iterative and nonlinear.

Discover

Pilot Observations

Observations were done by unobtrusive shadowing of clinicians to see clinicians interact with patients. Observations were conducted at five locations in the state of Michigan: four hospitals, and one skilled nursing facility as a part of the I-MPACT project. The author and five other designers enrolled in a volunteer program at the five hospitals to get clearance for the observations. The volunteer program requirement included orientation sessions for observation etiquette, required vaccinations, and emergency-situation training. Nine observation sessions were conducted in units chosen by the participating hospitals. These included two short-stay units, one heart failure unit, one progressive care unit, two inpatient units, one skilled nursing facility, two patient rooms and one clinician conference room. The observations were divided between six designers, who visited locations in groups of either two or three. The clinicians who were being shadowed introduced the designers to the patients to maintain full disclosure. The most common introduction was "this is (first name), a student at University of Michigan's Art & Design school. They are following us to understand the discharge process and suggest changes based on their observations."

Clinicians were asked questions after the observation sessions to

Figure 07. Pilot Observations at St. Joseph

clarify details about the process, medical terms or their point of view on interactions. Handwritten notes documented the process and conversations.

At the end of the observation sessions, the patients who seemed eager to share their experiences were revisited by designers and the clinician. The clinician would ask the patients about their willingness to have a phone conversation with the designers, post-discharge. If the patient agreed, written consent with contact details was obtained from the patient. A visiting card with a photograph of the designer and

conversation questions was handed to the patient as a reminder about the call.

Follow-up Phone Interviews

Patients were called by two designers, two to three days, post-discharge. One designer engaged in the conversation with the patient and the other designer documented the conversation. Patients were asked to describe how they felt leaving the hospital and going home; what they expected about taking care of themselves and how that was different when they got home; and if there was anything that would have made the transition easier. Patients who could not be reached on the phone were left a voicemail and were called the next day again. In the case that they were not reachable on the second attempt, they were not called back. The conversations were documented in notes for further analysis.

Semi-structured Interviews

E-advisors are a group of patients and patient family members (caregivers) who advise I-MPACT. These are people that have positive and negative experiences as patients and caregivers. They volunteer their time to advocate from a patient and caregiver perspective to I-MPACT. Twelve e-advisors were contacted through email with a link to a Google Form, out of which ten e-advisors responded. Seven in-person interviews and one telephone semi-structured interview were conducted. Interviews were done in teams of two designers, one asked the questions and the other documented the conversation. E-Advisors were invited to describe their interaction with the healthcare system, specific experiences in the medical settings and experiences beyond medical settings, for example, at home, pharmacy, etc. E-advisors were asked for written consent to audio/video record the interviews.

Figure 08. Follow-up Phone Interviews

Figure 09. Semi-structured Interviews

Recorded interviews were transcribed for analysis.

Clinician Observations

Four different clinician roles were observed as a part of the project. The observations and the interviews were conducted individually by the author in two locations: St. Joseph Mercy Health System's, Ann Arbor heart failure unit and the University of Michigan Health System's inpatient unit. In total, eleven observation sessions of about four hours each were conducted with two hospitalists, two case managers, four bedside nurses, one cardiologist and the cardiologist team (cardiologist, residents, interns, nurse manager and pharmacist). The clinician observation sessions were kick started with a verbal orientation from the clinician describing their day's plan, workload, and specific preferences while they interacted with patients. After the orientation session, the observation sessions were conducted. Clinicians were asked questions about the patient interactions at the end of each observation session.

Patient Observations

A total of four patients and two caregivers made up the patient observations for the project. For the observations, the clinicians approached patients to check their willingness to be observed and their interest in engaging in a conversation. The observations were conducted individually by the author. Verbal consent was obtained from the patient before the observation. Patients and caregivers were asked questions in free-time between clinician interactions.

Both, the clinician and the patient observations were documented by handwritten notes. Six categories were documented using the AEIOU Framework (described below). Additionally, the time for interactions was documented.

Figure 10. Clinician Observations

Figure 11. Patient Observations

AEIOU Framework Observation Areas (Martin and Hanington 2012, 10):

Interactions: What was the reason for the interaction? What was communicated to the people involved in the interaction?

Environment: Where did the interaction take place? How were people placed during the interaction?

People: Who was involved in the interaction? How did their involvement change the nature of the interaction?

Activities: What was the reason for the interaction? What activities were the priority for the people involved in the interaction? How was that communicated through body language and/or through actions?

Objects: What artifacts assisted or distracted the interaction?

Time: How long did the interaction last?

Administrative Observations:

A nurse manager and a quality improvement specialist at St. Joseph identified one heart failure collaborative practice team's meeting to be shadowed by the author. Additionally, a conference call based training session was observed. This call discussed insights from St. Joseph's sister organization on implementing care transition interventions. Finally, one open-ended meeting was conducted with the quality improvement specialists and the author to define bigger system drivers and financial models that have an impact on the context of the project. The meetings were documented in handwritten notes.

Figure 12. Administrative Observations

Define

Workshop Parameter Framing

A team of six designers worked together to define the elements of a collaborative workshop with four hospitals and one skilled nursing facility based on pilot observations and semi-structured interviews. The workshop was designed to help subvert organizational hierarchies, re-frame patient discharge experiences and shift hospital-centric points of view to a patient-centric point of view.

Insight Framing

The observations done for the project were used to build an analytical framework. Observations and semi-structured interview evaluations defined the needs, opportunities, and constraints for patients, clinicians, hospital system administration, and especially case managers. Recordings and notes about interactions led to generating insights, while the activity, environment, people, objects and time usage defined lenses for analyzing the interaction. Insights about patient needs and constraints were given priority over insights about case managers and other clinicians.

Patient Narrative Sorting

Patient narratives that pointed to the patient concerns were identified from the patient and the clinician observations. Transcripts from the e-advisor interviews were revisited to build on the narratives. A concern framework was generated based on the categories defined by the whole-patient assessments and the patient complexity models discussed in the literature review. The concern framework helped in sorting patient narratives into ten categories: physiological, emotional, psychological, cultural, behavioral, social, mental, financial, legal
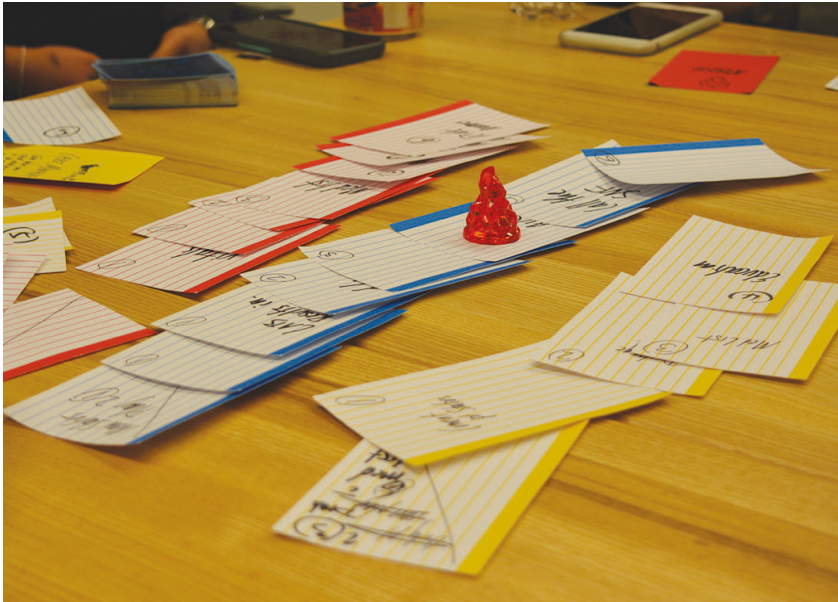
Figure 13.Workshop Parameter Framing

B ◀ ▶ E	Involved	What Happened	Insight
7.05-7.2 5 am	Handoffs between hospitalists	Conversation opening Vitals: Updates from yesterday	relied on narratives before morning physician meets patients.
7.05-7.2 5 am	Handoffs between hospitalists	Discussions points and decisions"As long as he is feeling better today" "From his standpoint....he can be dischardged today" "he said his first developed when he had..." "He then had a surgeon..." "He was here not too long ago..."	Nature of conversation is narrative, chronological and sometimes providing personal perspective. The style of narration moves to reporting when it comes to vitals, medicines, etc.
8.18 am	Hospitalist & Patient	Pt: "They keep on testing me, I wonder how many blood draws do they want to do?"	Patients not aware of tests done on them. On other hand maybe there is a lack of coordination amongst different care team members to call for tests.
	Hospitalist & Patient	Pt: "I still cant figure out why they cant give me the (pain meds)..The dertimtologist can definitely not give me that. I feel pretty bad, I have two sons at home...I need help. Its not getting any bettter. All this is new...my arms, my vagina. Thats what is making it worse, its not getting any better	Patients may not be aware of why certain medications are given to them and certain not given

Figure 14. Insight Framing

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Work & Colleagues

Beliefs & Traditions

Insurance, Money & Legal

Diet & Exercise

" *I have started a new job at school, 12 hours of working and managing 290 kids has been difficult. That is making me come back to hospital"*
— Michael, 39 years

" *My grandson wants to join the navy and serve the country like me. I need to get out of homelessness and be healthy for him."*
— Willie, 61 years

" *If my insurance is not paying for an automatic bipap, what is the point of me getting better?"*
— Martha, 73 years

" *They send my food. I didn't feel like eating it. But I am under [quarantine] and its a different level of complexity."*
— Adam, 48 years

Figure 15. Patient Narrative Sorting

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Home, Family & Friends

"I will move in with my daughter. But I need to go to therapy first before I go to her house. She won't be able to take me to therapy."
— Lily, 75 yearsv

Body & Health

"My heart failure is a new diagnosis. I also am trying to deal with COPD, back pain and diabetes. These added diseases are not helping!"
— Nancy, 78 years

Mind & Feelings

"The only thing I wish the hospital would help me manage other than my symptoms is anxiety."
— Heather, 67 years

Habits & Actions

"After the surgery and rehab, I have stopped drinking, but every once in a while I still smoke."
— Philip, 54 years

*Names changed to protect privacy of the patients

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and environmental. The concern framework was later modified to recombine the ten categories into eight categories: physiological, psychological, environmental, cultural, behavioral, financial & legal. The decision on the final eight categories was made in consultation with a case manager.

Expectations Mapping

Once all the insights were generated, the key insights were categorized from three points of view; the patient, the clinician and the healthcare system. A diagram mapping expectations of the patient, the clinician, and the health system was generated based on these key insights. The patient needs were given priority over clinician and system needs.

Develop

Kick-off Workshop

After the pilot observations, a workshop was planned for the participating hospital clusters. Each participating cluster had a representative team from various roles including physicians, specialist physicians, hospitalists, nurse managers, quality improvement members and even e-advisors. The day's activities were planned in such a way that there was a level field of contributions from these roles. The day of the workshop was divided into two parts. Through the first half of the day, the representative teams went through a series of activities including interacting with the e-advisors patient panel, playing a specially designed game of 'hand-off,' and mapping out a patient journey of the care transitions. Based on these activities, the representative teams defined a problem statement.

In the second half of the day, the representative teams identified
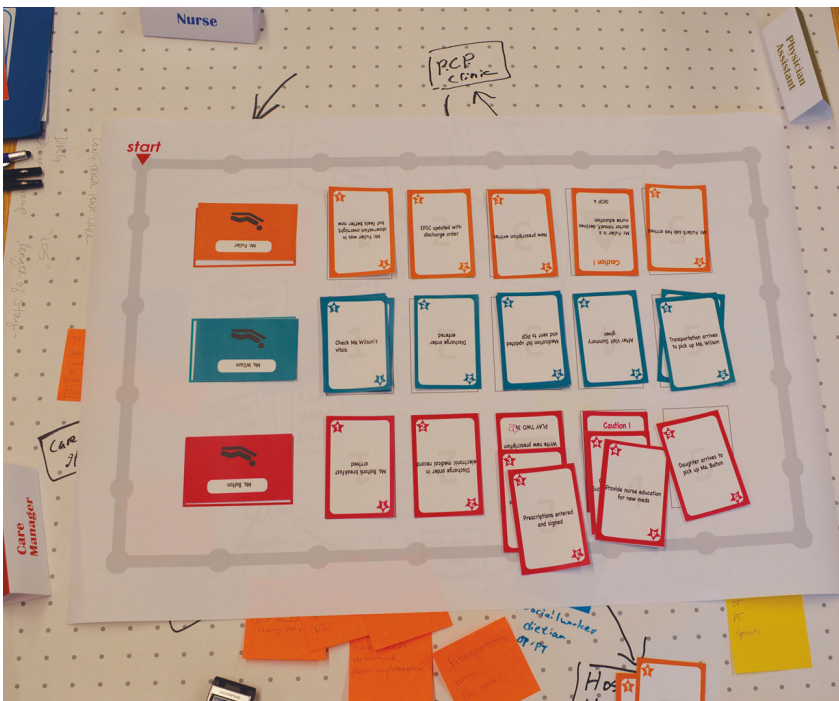
Figure 16.Kick-off Workshop-A

Figure 17. Kick-off Workshop-B

possible interventions and pathways by which the interventions could be implemented. The teams then presented their problem statements and possible interventions to other teams.

Design Concept Generation

Based on the expectation map and the eight assessment categories, potential concepts were generated. The concepts had three objectives: initiate conversations, facilitate guided frameworks for conversations, and document concerns. Paper prototypes of the concepts were created to test them. A patient-centric outcome was desired; hence patient needs were given priority over case manager needs in defining the pros and cons of a concept. A concept for a concern assessment diagram was selected based on the pros and cons of all concepts. The concept for the concern assessment diagram includes a radial diagram that represents possible concern areas in a patient's life. The patient can mark each concern area as high, medium or low.

Prototyping

Once the final concept of a concern assessment diagram was identified, it went through multiple refinements. Digital, as well as physical prototypes, were generated to test usability. Through the series of prototypes, the prototype was refined in five key areas: content, visuals, product naming, ownership of the tool, and the medium in which the tool would be distributed.

Building a Toolkit

The concept of a concern assessment diagram was further developed into a complete toolkit with three tools. The toolkit included a printed concern assessment diagram to be used by the patients, a concern
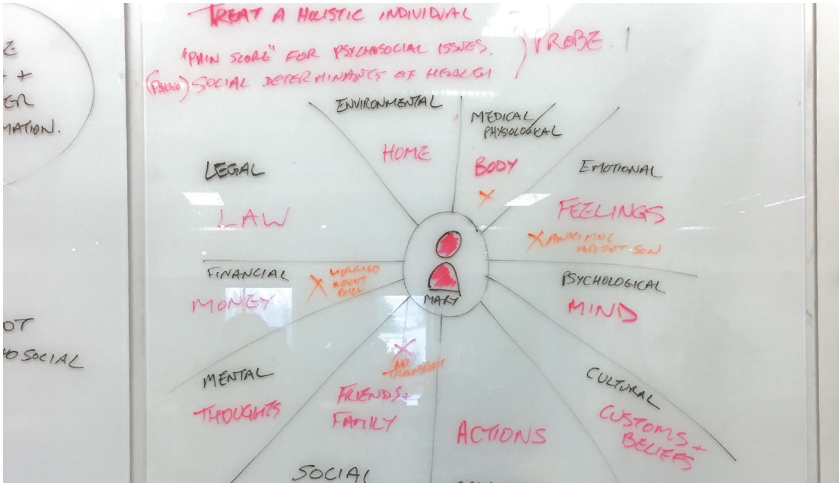
Figure 18. Design Concept Generation

Figure 19. Prototyping

reflection booklet to be used by the patients, and a digital concern tracker to be used by case managers.

The concern reflection booklet was developed on the same framework of concern areas defined in the concern assessment diagram. Content for the concern reflection booklet included questions driven by the AHRQ whole-patient assessment toolkit, discussed in the literature review, and various psycho-social assessments for case managers, also discussed in the literature review. The concern reflection booklet questions were kept open-ended, yet targeted to the concern areas. The content for the concern reflection booklet was evaluated with patients and social workers.

The digital concern tracker was proposed as a communication platform for hospital case managers to communicate patient concerns through software to the primary physician group and cardiology case managers.

Toolkit Evaluation

The toolkit concept was evaluated with semi-structured interviews with an e-advisor, semi-structured interview with a case manager and a co-creation workshop with medical social work students.

Semi-structured Interviews

Individual advisor meetings were organized with one e-advisor and one case manager to engage in an in-depth evaluation of the toolkit. The advisors were asked to evaluate the content and the visual organization of information on paper prototypes of the concern assessment diagram and the concern reflection booklet. For the concern assessment diagram, the advisors were asked to discuss three points: relevance of the categories represented in the diagram, specific concerns they wished to discuss under each category, and visual preferences for the design of the diagram. For the concern
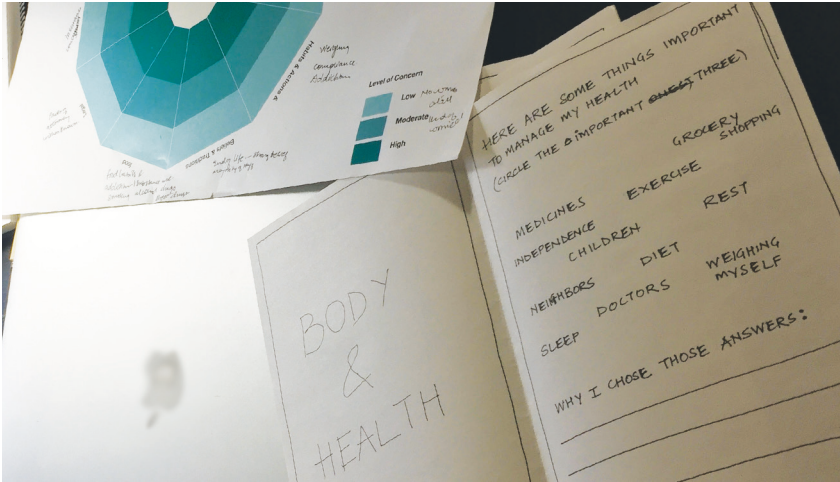
Figure 20. Building a Toolkit

Figure 21. Toolkit Evaluation- Semi-structured Interviews- e-advisor

reflection booklet tool, the advisors were presented with three possible booklet options: one with open-ended questions, one with multiple choice questions, and one with mixed questions. Finally, the advisors were asked to comment on possible names for the tools, willingness to use the tools, ownership and sharing concerns, and possible means to introduce the tools. The e-advisor was asked for a written consent for video/photo documentation of the semi-structured interview. The case manager was asked for verbal consent before video/photo documenting the semi-structured interview.

Evaluation workshop

Medical case managers at a hospital can either be nurses or social workers by training. The project was presented at a University of Michigan School of Social Work class. The class subject matter for these 20 social work masters' students concentrated on behavioral, psychosocial and ecological aspects of health and disease. At the end of the presentation, students were divided into four groups of five, asking each group to review two categories of concerns. They were given prototypes of the concern reflection booklet, AHRQ's whole-patient assessment, and a copy of the concern assessment diagram for reference. The students discussed the questions in the concern reflection booklet and identified other possible questions during thirty minutes. At the end of the discussion, one member from each the group presented to the whole class. The discussions and presentations were video documented after verbal consent from the class.

Deliver

Presentation of Concern Assessment Diagram at Collaborative Wide Meeting

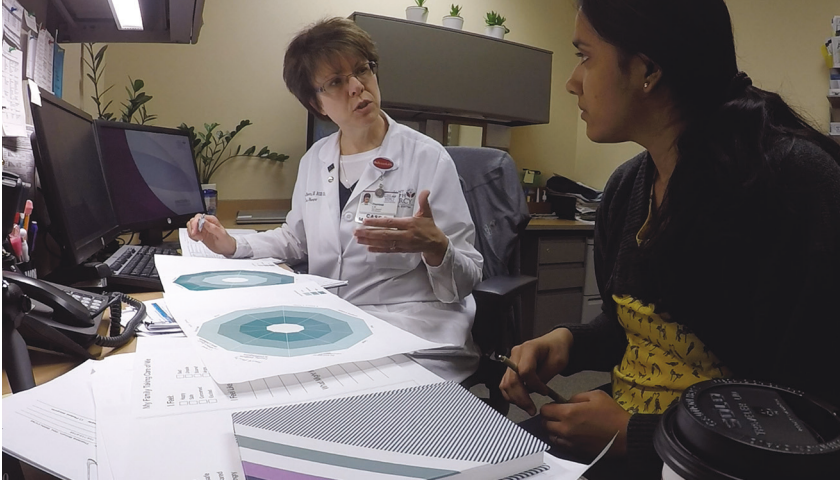A prototype of the concern assessment diagram was taken to an

Figure 22. Toolkit Evaluation - Semi-structured Interviews - Case Manager

Figure 23. Toolkit Evaluation - Evaluation Workshop

I-MPACT update meeting known as a collaborative-wide meeting. At a palliative care breakout session, the concern assessment diagram was presented. The breakout session group consisted of four physicians, five nurses/case managers, and one patient advisor. Comments on the tool from the breakout session were presented by the moderator of the session to the larger audience of the meeting. A digital copy of the concern assessment diagram was sent to all the participants. The presentation and comments were documented in handwritten notes.

Presentation of Concern Assessment Diagram at IHPI

The Institute for Healthcare Policy and Innovation (IHPI) is a collective of about 500 healthcare professionals, researchers, and their partners to address problems in healthcare. The project was presented as a part of the collective with five other designers, at one of their weekly meetings. The meeting was attended by around 40 IHPI members. Participants were each given a copy of the concern assessment diagram as a handout. The presentation was followed by an informal discussion with the participants. The discussion was documented in handwritten notes.

Graduate Exhibition

This thesis project was presented as a collective, along with the work of five other designers at a graduate exhibition. Six projects in total formed six approaches to tackle problems in care transitions. This project was presented as an 8' x 8' printed display. Copies of the concern assessment diagram were available as a handout for the visitors to document their concerns and to share with their own clinicians.

Figure 24. Presentation at Collaborative Wide Meeting

Figure 25. Graduate Exhibition- A

Figure 26. Graduate Exhibition- B

RESULTS

The goal of the pilot observations was to build a general understanding of how the US healthcare system works, who the players are, their relationships, and hierarchy. The project partner, I-MPACT, was specifically interested in the discharge process and issues that may happen before, during and after discharge from the hospitals in the state of Michigan. The insights from the observations helped identify parameters of a design workshop for participating hospital clusters. The workshop helped the participating hospitals identify issues of care transitions in their hospital and define possible intervention to address

these problems.

Five key insights from the pilot observations that framed the workshop were:

1. Searching for a discharge process was a difficult task. The designers could not find a "typical" process for discharge between different hospitals and possibly not even between the different departments of the same hospital. They began by looking for the discharge process and ultimately identified discharge as a series of events that occur before a patient leaves the hospital. As many as fourteen different people can be involved in a discharge.

2. The physician was identified as the key decision maker on when a patient is ready to be discharged, providing a discharge order. The clinician team then works on their set of tasks to get the patient discharged.

3. Patients see only a small portion of the steps for getting discharged. So, when they were asked specifically about discharge, they usually did not have any complaints about it. From their point of view, the discharge process includes getting a medication list, arranging for a ride and getting home.

4. It is when patients were probed about points beyond the act of discharging they had stories to share. These included the need to gain a better understanding of their medications from a primary physician, a difference in medications provided by the pharmacy and the medications mentioned in the patient's discharge list, and others.

5. Beyond discharge, care transition is a broader concept that needs to be highlighted. Care transitions can happen in-hospital and outside the hospital. Clinicians within the hospital "hand-off" responsibility of care between nurses, case managers, physicians, and specialists. Patients see individual people while clinician team

members identify themselves by their various roles. Beyond the hospital, the responsibility of care transfers between caregivers, primary physicians, consulting specialists, home care staff and patients themselves. Right communication is crucial at every step of transferring care responsibility, within a team, with other teams and to the patient and caregivers. Ineffective communication during transfer of care responsibility leads to possible inefficient care for the patient.

Identifying the Appropriate Intervention

The problem statements and intervention areas were developed over a period of four months. This development process was done within the healthcare teams, without any involvement from the design team. Specifically, for St. Joseph Mercy Health System, Ann Arbor, the goal was to reduce 180-day readmissions for heart failure by a certain percentage by a specific date. Increase the median number of hospital free days within 180 days for heart failure admission by a specified date.

To achieve these, they identified the following interventions:

1. Standardize follow-up appointments for all patients. One week after discharge, set up an appointment with the cardiologist, and two weeks after discharge, an appointment with the primary physician.

2. Expand palliative care services to heart failure patients.

3. Develop a standard whole-patient assessment to understand the patient better and develop a curated care plan.

While the first and second interventions were well defined regarding execution, St. Joseph's heart failure team decided the third

intervention required modifications in organizational structures as well as processes. From the pilot observations, it was highlighted that the high-value problem for care transitions lies in identifying and addressing problems which were connected to care transitions not only the discharge process. St. Joseph collaborated with the author to identify new ways to assess the requirement from a patient-centric point of view and develop a new assessment tool. To build a better care transitions model, St. Joseph collapsed two types of case management roles into one integrated case manager. This person would be the ablest to act on the whole patient care plan for the patients. Unfortunately, it is not always the case that the people holding this new role would have adequate training and experience to engage patients in conversations that can build trust, elicit and capture whole patient information. Any intervention planned for building better assessment for patients would have to also accommodate the variability in experience levels of the case managers.

Opportunities and Challenges for New Assessment Tools

Observations and interviews resulted in the following interactions:

1. 67 clinician-patient interactions were observed while shadowing the clinicians.

2. 18 clinician-patient interactions were observed while shadowing the patients.

3. Approximately 120 pages of handwritten notes were taken during observations.

4. 147 pages of e-advisor interview transcripts were generated.

The goal of the patient, clinician and system observations and interviews was to identify the parameters for developing new assessment tools. Insights from the observations and interviews defined potential opportunity areas and challenges for the tools from patient, clinician and healthcare system perspectives.

Patient Perspective

The following insights came from the patient observations described in the 'discover' phase:

1. Being in a hospital is intimidating and stressful for patients and caregivers. When patients come to the hospital, they and their caregivers may be more concerned about how the diagnosis and treatment affect other aspects of their lives along with the medical concerns.

2. Clinicians in the hospital rotate for shifts, and it's hard for patients to keep track of all the clinicians. Such rotation makes it confusing and challenging for the patients and caregivers to maintain a trusted relationship with members of their clinician teams in the hospital.

3. When the clinicians visit the patient rooms, they plan their agenda for the conversation prior to entering and document the conversation after exiting the patient's room. The patient and the caregiver do not take part in setting the agenda or defining what is being documented. When clinicians walk in with a planned agenda to identify or address problems, the agenda takes priority over building a relationship of trust with the patients and caregivers.

4. A patient's day in the hospital is planned according to the availability of different clinicians over the patient's preference. When a clinician enters a patient's room with questions, a patient is expected to remember the details of their diagnosis or needs.

The clinician may miss out on getting some crucial information, which the patient may not have communicated during that interaction.

5. When e-advisors and current patients were asked who they trusted the most within their clinician team, the nurse was always in the top three. Nurses are the role patients interact with the most.

6. If a patient had not voiced a social concern or had a medical equipment requirement, they might not even be aware that they had a case manager assigned to them.

Clinician's Perspective

The following insights came from the clinician observations described in the 'discover' phase:

1. At St. Joseph, a bedside nurse manages around four patients, which affords them the time to check in on patient needs formally every hour. Such continuous interactions may be the reason it was the most trusted role for patients.

2. With around fifteen to twenty patients, a case manager has one of the highest numbers of patients to manage. This affects the time that they can spend with the patient. Case managers usually look out for cues during interdisciplinary rounds to identify any patient concerns or needs. They visit a patient's room when such needs or concerns are highlighted.

3. All clinicians spend a bulk of their time documenting to electronic medical records (EMR). They spend effort on quality documentation, as this is tied to insurance coverage for a patient. However, they also recognize the importance of actual time spent with the patients and therefore may fill in only those areas of the

EMR they get audited on. The notes section is a crucial form of communication with the future shifts of clinician teams.

4. Even within a clinician team, the roles are very hierarchical which may lead to certain roles feeling left out or unheard during interdisciplinary rounds or in the electronic record communications.

5. When clinicians communicate with the patients, the caregivers or within the team during handoffs, the conversation is anecdotal in nature. Such conversations highlight certain aspects of the patient's life which are not connected to their disease. However, such information may be lost over electronic documentation as electronic records may not have a formal place to document it.

6. With the modified role of integrated case manager, there is anticipation as well as curiosity between the case managers to figure out how their roles will play out. They are excited to have reduced patient load at the same time evaluating possible challenges that may occur with the new types of workload.

Administrative System Perspective

The following insights came from the administrative systems observations described in the 'discover' phase:

1. Healthcare system administrations must keep track of incentive models and ratings to keep up with standards of care and profits for their system. Reducing readmissions is one way they can help increase their ratings and incentives from insurance organizations. To reduce their readmissions rates, the St. Joseph heart failure team identified the need to define and possibly address concerns in the patient's life that would assist in maintaining their health.

2. St. Joseph was on a hiring freeze when the project was initiated. This meant that the team could not implement the successful

"transition coach" model discussed in the literature review for addressing the concerns of the patient. They identified case managers as a resource to assist patients in care transitions. St. Joseph could negotiate with their primary physician and cardiology physician group's case manager to build a better plan for care through improving communications channels.

Expectations Mapping

Expectations from the proposed toolkit vary for the three key stakeholders in the following way:

1. Patients need space to reflect on their concerns before sharing them with clinicians. They also need to have trust in the clinician to share private and possibly taboo concerns.

2. Integrated case managers will vary in experience; they will need tools that assist in facilitating conversations with patients to discuss their private life matters. This will help bring a level field amongst case managers ensuring that they can provide a similar and improved quality of care.

3. Health systems need to identify and track possible patient health maintenance issues so that they can keep their readmission rates down and insurance industry-offered incentives up.

Results from Concept Generation

Four possible concepts to initiate conversations between case managers and patients were created. These concepts were analyzed for their pros and cons based on criteria defined in the expectations map. A final concept was selected as the one with the least number of
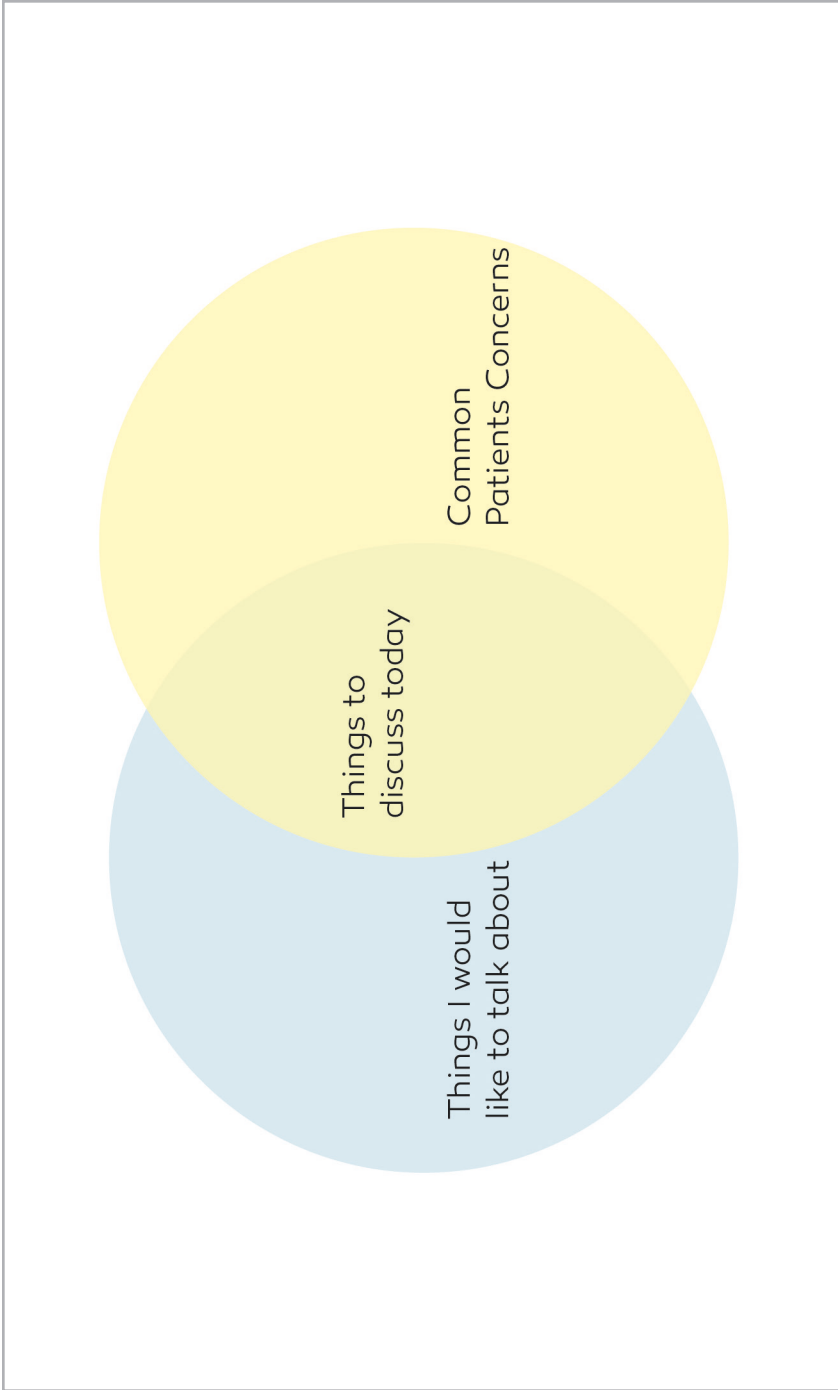
Figure 27. Design Concept #1 Venn Diagram of Concerns

cons.

Design Concept # 1 Venn Diagram of Concerns

An interactive activity between patients and their case managers. A chart of two intersecting circles, one circle for the patients to write the topics that concern them, and a second circle for the case managers to write about concern areas which they would like to discuss. After both members have written their concern points, based on the topics which intersect, a conversation is initiated.

Expectation mapping led to the following pros and cons for design concept #1:

Pros:

1. Both patients and case managers get an opportunity to contribute to the conversation.

2. Patients understand that they are not alone with the concerns.

3. Time spent with the patient provides an opportunity to build a relationship of trust.

Cons:

1. Prioritization of topics is not individualized for a patient, as case managers have the power to guide the conversation around the general patient needs.

2. Patients are expected to generate their concern areas; they may miss out or may not bring up certain concerns.

3. The act of writing requires case managers to dedicate additional time to initiate the conversation.
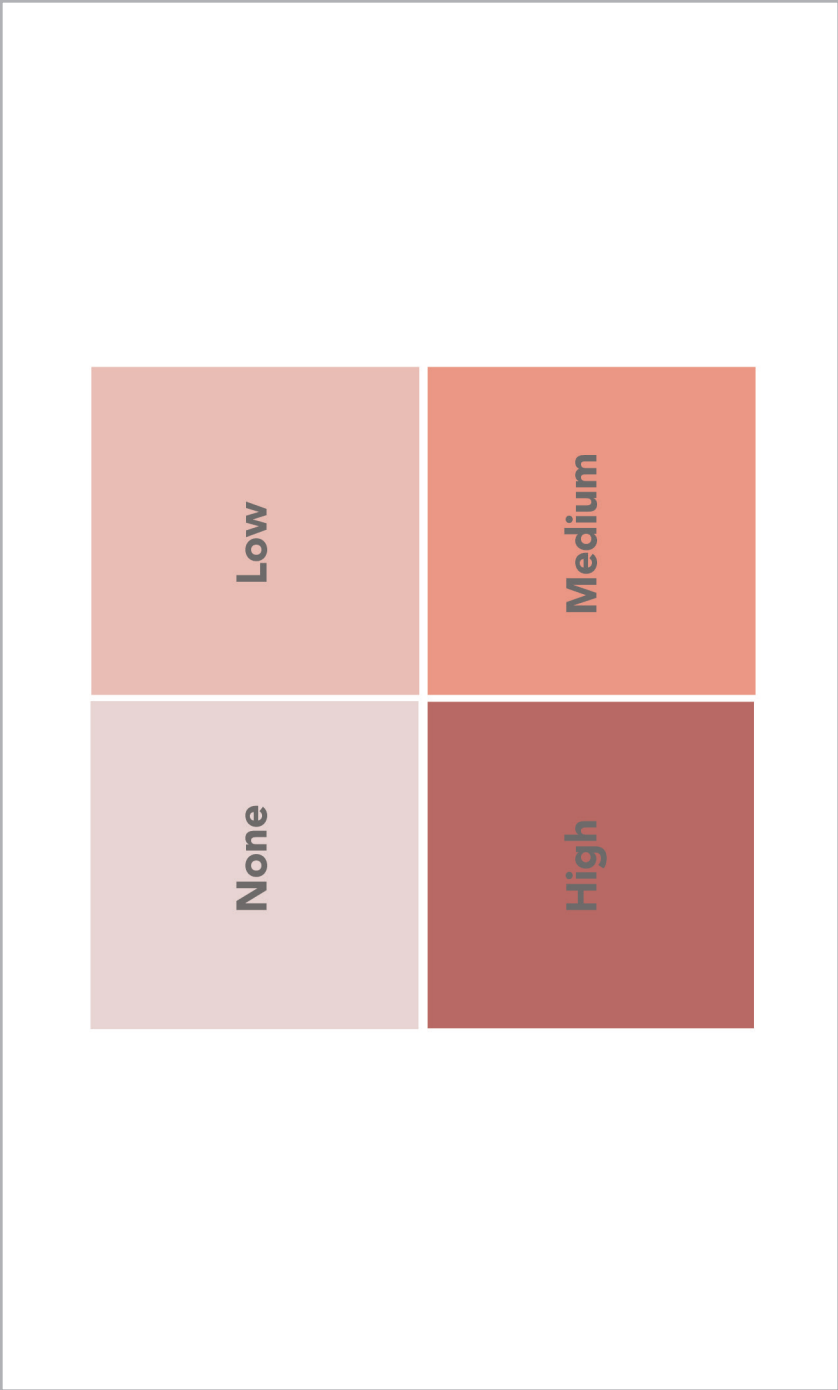
Figure 28. Design Concept #2 Concern Quadrant

Design Concept # 2 Concern Quadrant

Patients are asked to write down concerns in four quadrants, low to high. The quadrants decide the priority in which concerns are discussed with case managers.

Expectation mapping led to the following pros and cons for design concept #2:

Pros:

1. Patients have full ownership over the concerns they would like to discuss.

2. The quadrants provide a visual assistance, building a shared understanding of concern levels for both patients and case managers. This helps in prioritizing conversation.

3. Case managers can allow patients quiet time to reflect on their concerns before initiating a conversation.

Cons:

1. Patients are expected to generate their concern areas; they may miss out or may not bring up certain concerns.

2. If patients see certain high concern areas are not addressed, that may not help in building trust with the case manager.

Design Concept #3 Personal Framework

A graphic of concerns using a personal framework where individual to social concerns are placed along a scale on the x-axis and reflective concerns to action driven concerns are placed along a scale on the y-axis. Eight categories are mentioned as cues in the appropriate quadrants. The patient can list specific concerns under each of the quadrants.
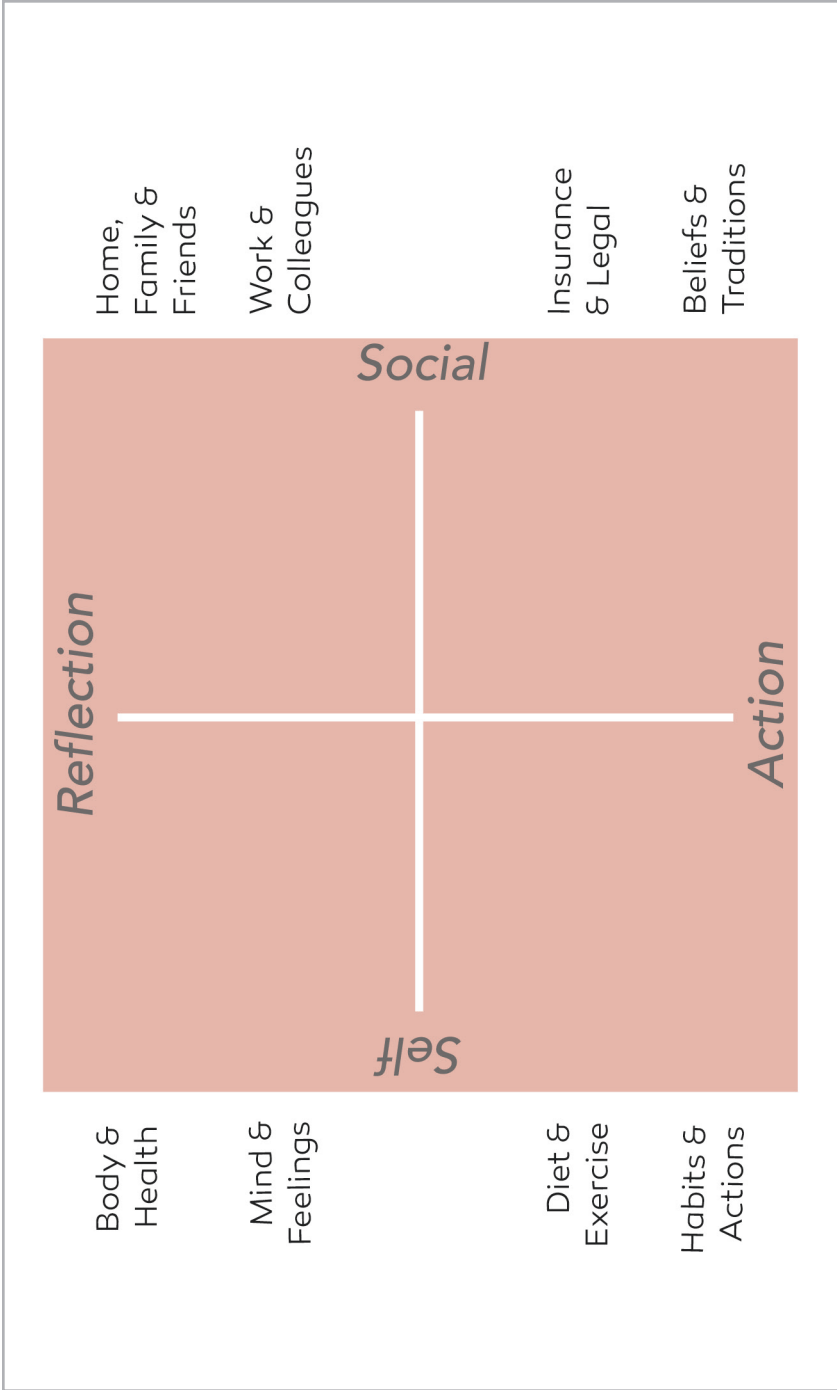
Figure 29. Design Concept #3 Personal Framework

Expectation mapping led to the following pros and cons for design concept #3:

Pros:

1. The axes put a visual structure on the patient's life. This will help them understand if their concerns are individual or social in nature and driven by their thoughts or actions.

2. The eight concern areas provide reflection cues to the patient to think about their concerns.

Cons:

1. The framework is highly abstract and conceptual. It requires a high level of understanding from the patient's side.

2. The framework does not prioritize concerns.

3. The framework treats all concerns in the same quadrant with equal importance.

Design Concept #4 Concern Assessment Diagram

A radial representation of patient concern areas. Each concern area is divided into three parts low, medium and high. A patient can mark their concern levels for each area. Case managers can prioritize conversations based on concern levels.

Expectation mapping led to the following pros and cons for design concept #4:

Pros:

1. Simple visual representation of a patient's life.

2. Concern areas provide cues for a patient to reflect on each area.

3. Case managers can allow patients quiet time to think about their

Figure 30. Design Concept #4 Concern Assessment Diagram

concerns before initiating a conversation.

Cons:

1. Distinct colors for concern areas suggest that levels have a start and end.

Design concept # 4, the concern assessment diagram, was selected as the final concept for further development as it had the fewest cons.

Design Concept Refinement

Conceptually, the concern assessment diagram was viable for the patients and the case managers to initiate and discuss their concerns. The following content and visual changes helped make the concept more patient-centric.

Content Changes

The terms used for concern categories were academic and possibly difficult for patients to connect with their lives. They were modified to terms used in daily life. For example, the social category was modified to home, family, and friends; the psychological category was modified to mind and feelings, etc.

Visual Refinement

Concern levels were represented in the concern assessment diagram in different colors giving a message that there was a beginning and end for each concern level. This was converted to a gradient to provide a more refined scale.
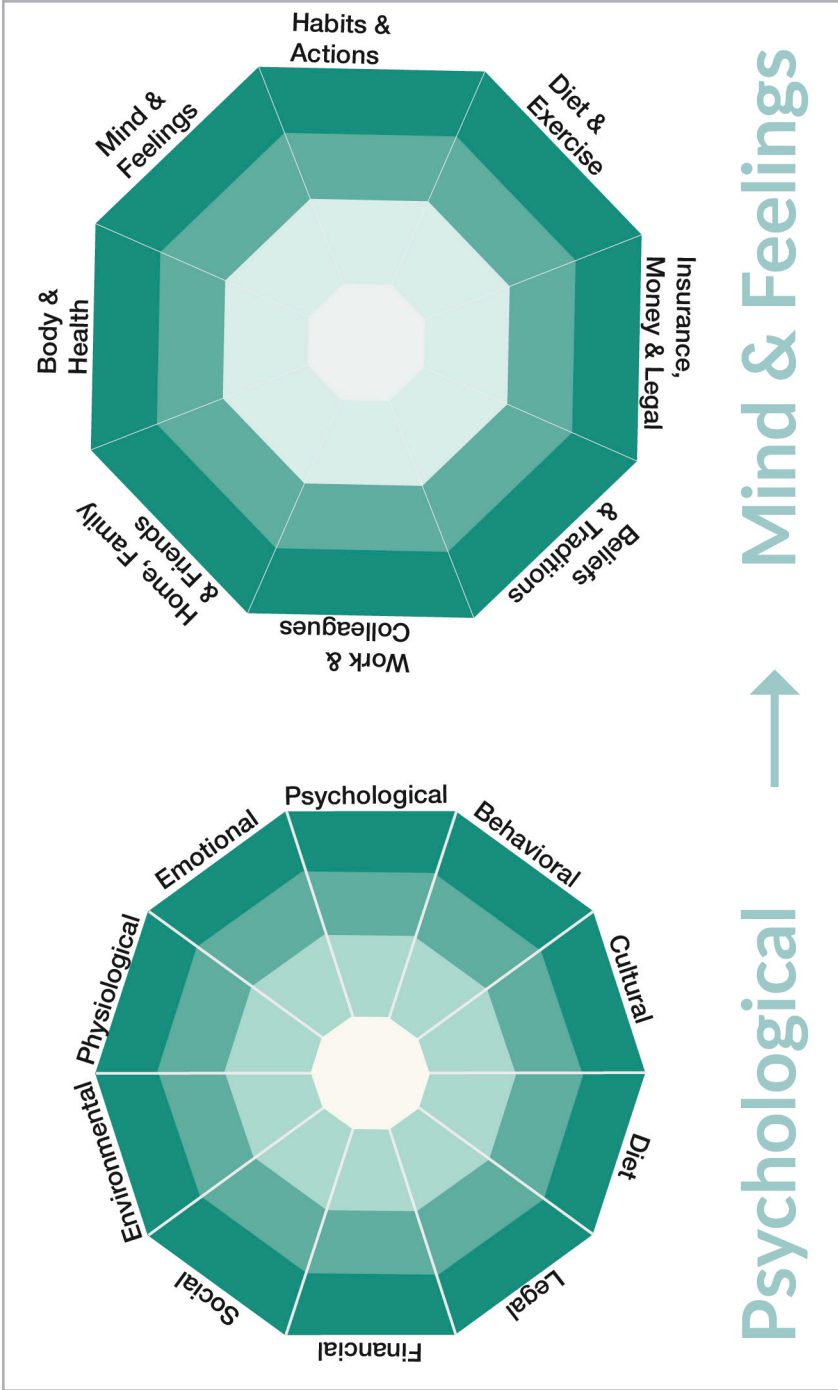
Figure 31.Content Changes

There were two options for the direction in which the scale should move. Whether the highest concerns should be outside and lowest closer to the center or vice-a-versa. Based on opinions from the e-advisor, the case manager and the quality improvement specialist, it was decided that the gradient would show low-concern outwards and high-concerns closer to the center.

St. Joseph's brand color is a deep red, so there was a proposal from the heart failure team to brand the tool in the same color. However, the red mass at the scale of the diagram was too strong and reminiscent of blood. Other colors from the St. Joseph brand palette were also tried, but none of the colors helped in creating smooth yet distinct visual transitions for people with low vision.

On the color wheel, teals, turquoises, and blues are colors at the opposite zone of warm orange and red tones. They are also popular colors for medical scrubs. Identifying colors in this palette helped to achieve a gradient that was easily discerned and without negative connotations. A turquoise gradation was finalized for the tool.

Building a Family of Tools

Concern Assessment Diagram

The concern assessment diagram did the job of allowing patients to initiate conversation on the broader concern categories. It did not assist in facilitating and documenting specific concerns. There was a need to expand the toolkit to accommodate these requirements.

Concern Reflection Booklet

A concern reflection booklet was conceptualized to ask the patient specific questions under each concern area. The content of the question was driven by the whole-patient assessment tool and various psycho-social assessments used by the case managers. Instead of
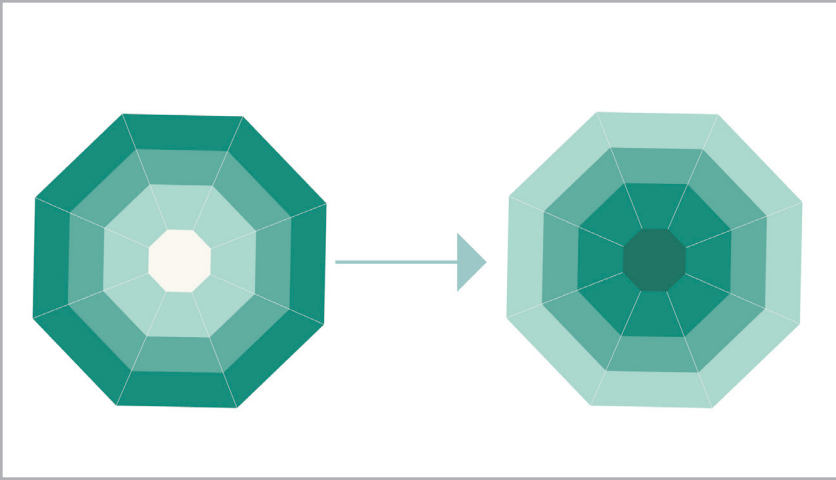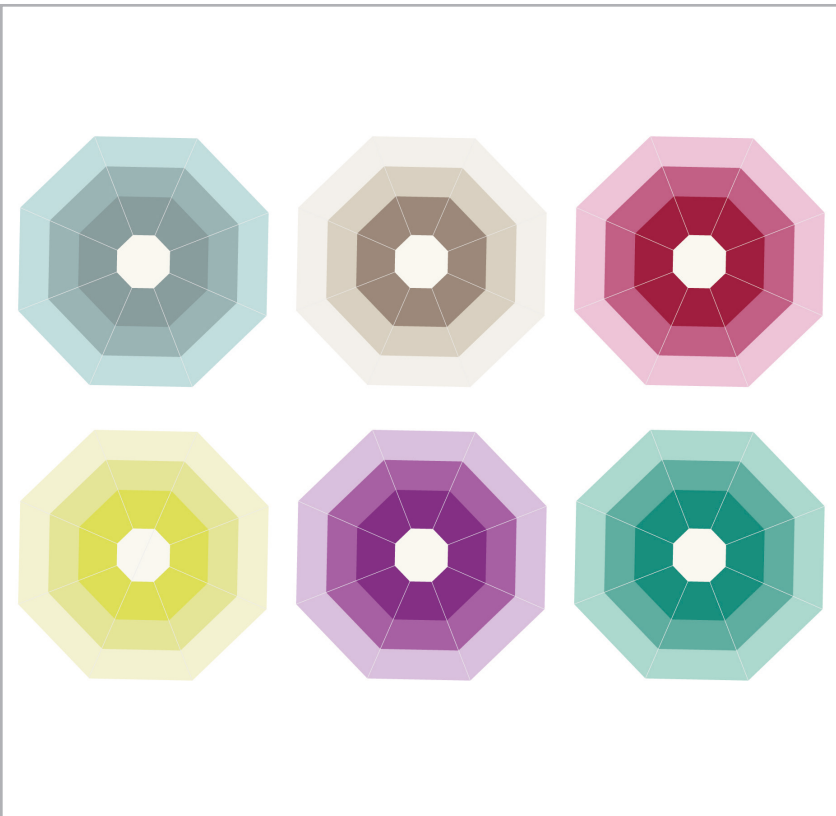
Figure 32.Visual Refinement - Concern Direction

Figure 33.Visual Refinement - Identifying the Right Color

asking general questions, patients were asked specific questions which can assist them in understanding their concerns better. For example, instead of asking if they were unemployed, an hourly worker or a permanent employee; the concern reflection booklet asks whether their work, volunteer or daily tasks require them to stand for long hours, concentrate on the screen, etc. The questions were kept in the first person so that they appear to be points of self reflection for the patient instead of a clinician asking them to the patient for documentation. For example, instead of asking "what medications are you taking," the question was framed as: "I take the following medications." The questions were also kept open-ended to avoid lead-ins to an expected answer.

Digital Concern Tracker

St. Joseph is currently building a communication platform for in-hospital case managers to communicate through a software program to the primary physician's case managers and cardiologist's case managers. A digital tracker is proposed to track a patient's concerns over time; through patient interactions with different health systems. This can help identify concern trends for a patient. Any fluctuations in the concerns can provide an opportunity to check if the fluctuations affected physical health and possibly caused further hospitalizations.

Naming the Toolkit

The name of the toolkit had to be inviting for the patient, acknowledge the complexity of the patient's life and create an affordance to how the tool is meant to be used.

Interwoven was finalized as a name as it suggested multiple elements coming together to form something new. These elements of one's life are individual yet connected. Unbalance in one of the elements affects the harmony of the whole. The term is an acknowledgment of the

meetup Yantra

whatsnew forma

Tellmemore. grafik

All ears akruti

Ponder skima

muse figurme

compose kaava

sketchme Naksha

mymap Saacha

Blueprint

Meli

Figure 34. Naming the Toolkit

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complexity of not forcing someone to share their concerns unless they are comfortable.
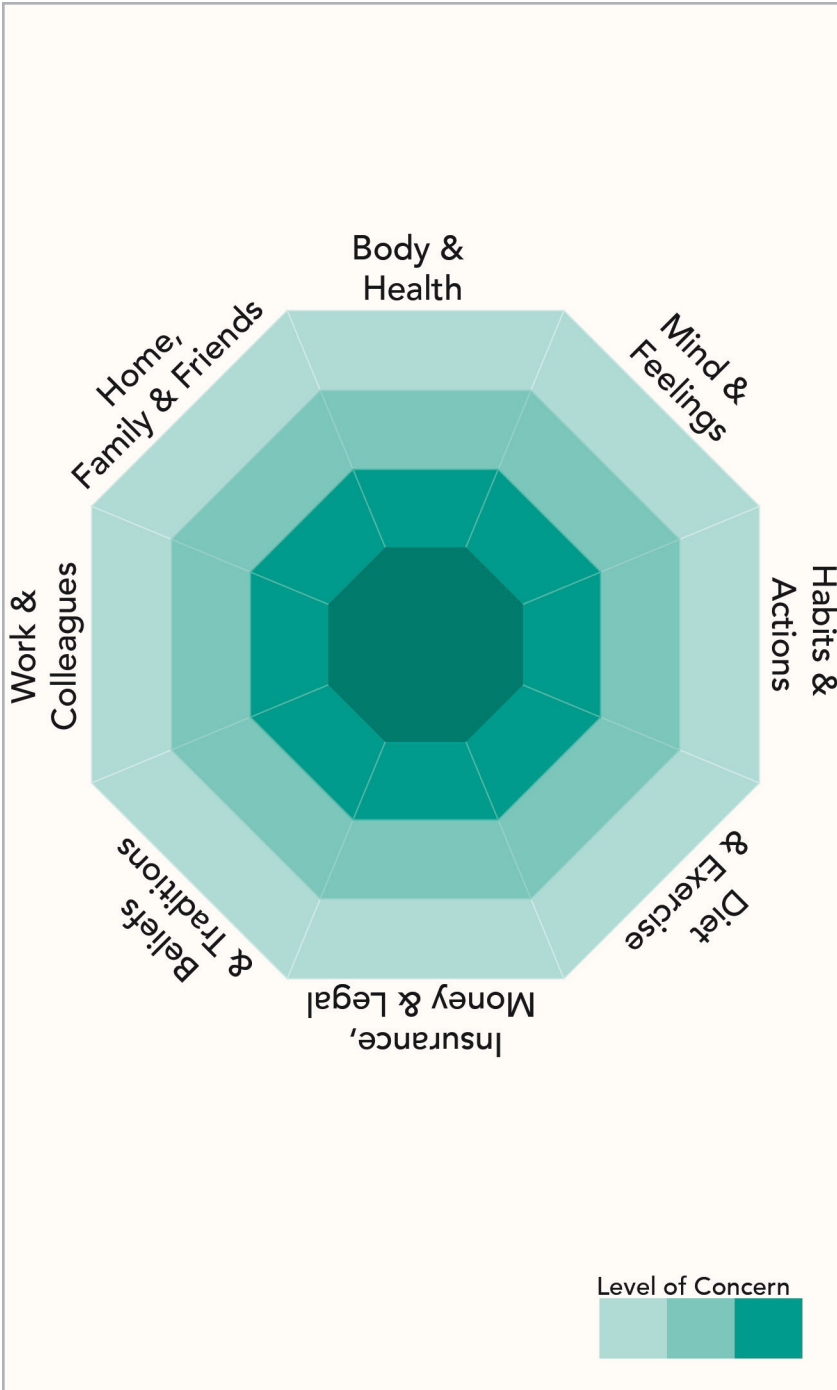
Figure 35. Concern Assessment Diagram

Final Design Deliverable

The primary result of this thesis project work was 'Interwoven,' a set of three tools that explicitly acknowledges eight factors in a patient's life that may affect their health and wellness. This toolkit opens the scope of discussion in healthcare settings between the patients and their healthcare providers. The eight factors framework includes physiological, emotional, psychological, cultural, behavioral, social, financial and legal concerns of the patient. These tools were designed to facilitate and capture conversations about a patient's complex reality. If patients can better communicate their concerns, there is a greater chance they will better engage in their care. Additionally, if clinicians are better able to build a comprehensive understanding of a patient's concerns and needs, they will be able to create a more appropriate care plan.

The toolkit includes:

A Concern Assessment Diagram

The concern assessment diagram asks patients to self-identify the level of concern for the eight possible factors. For each factor, the patient indicates a high, medium or low level of concern. A case manager uses this diagram to start a discussion with the patient on factors that might be beyond their medical health.

A Concern Reflection Booklet

The concern reflection booklet contains in-depth, disease-specific questions for each factor that may be a concern to getting better. The concerns may include medicine management strategies, occupational requirements, housing conditions, unstated feelings, etc. The questions are open-ended but ask patients to think about specific actionable

Figure 36. Concern Reflection Booklet

Figure 37. Digital Concern Tracker

reasons for their concerns.

A Digital Concern Tracker

The digital concern tracker is a proposed digital tool used by both inpatient and outpatient case managers to maintain a shared record of the patient's concerns. Data visualization within the tracker can better show trends, allowing for more immediate responses to patient needs. The digital concern tracker needs to be further developed based on the software capabilities of the healthcare system.

Few hours after...

Case Manager introduces herself to Lily. Hands her the Interwoven Toolkit. Says will meet her back in a day.
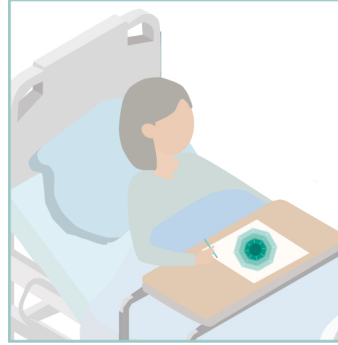
During the day...

Lily goes trough the assessment diagram and the reflection booklet. Fills most of the booklet.

Lily admitted

72 Yrs, Lives Alone
Manages: Diabetes,
Congestive Heart Failure
admitted for heart pain

Figure 38. Use Case Scenario: Lily's Story

One day later...

Case Manager comes back, spends time with Lily to understand her concerns. Discusses possible solutions.

Later that day...

Case Manager documents Lily's concerns to the concern tracker.

Lily discharged

DISCUSSION

This project proposes the 'Interwoven toolkit', (toolkit) consisting of a concern assessment diagram, a concern reflection booklet, and a digital concern tracker, designed to assist in identifying, documenting and tracking patient concerns that may be beyond their medical care. The aim of this toolkit is to create opportunities to build a relationship between the patients and the case managers by encouraging the patients to discuss matters that concern them openly. Continuous communications and tracking will help case managers and other clinicians to understand their patients better. Such understanding

would help clinicians address their patient's complex needs to avoid future re-hospitalizations.

The concern assessment diagram captures the complexity of a patient's life to build a shared visual understanding between a patient and a case manager. The concern reflection booklet allows for a patient to think about their complex needs based on reflections on specific tasks or actions in their daily life, in eight concern categories. The digital concern tracker allows for documentation of the concerns over time, allowing case managers to track connections between the complexity levels of a patient's life and its possible connection to their health. The tools in the toolkit are complementary yet self-contained. Each tool can be introduced as an individual intervention if future changes in the healthcare system demand for it.

In patient-centered care, a patient's needs and values drive the decisions of care. The toolkit looks at identifying possible patient needs and values through their concerns. The concern assessment diagram and the concern reflection booklet are patient-reported, ensuring that the patient's concerns are captured in the patient's words and not the clinician's interpretation of them.

The complexity models, the palliative care framework and the psychosocial assessments discussed in the key concepts section, try to accommodate patient complexity to define the level of care needed. However, it is unclear who reports and interprets the complexity, whether it's the patients or the clinicians. Both the complexity models and the psychosocial assessments may define a patient's complexity in comparison with other patients, and not on the patient's baseline. The interwoven toolkit will provide complementary information to these programs to help the clinicians identify the complexity factors from the patient's point of view.

Four major programs discussed in the relevant programs section (BOOST, RED, CTI, and AHRQ), ask for process modifications in the

system to implement the program. The tools used in these programs can be roughly divided as clinician owned for hospital interactions and patient owned for some post-discharge interactions. They also look at tracking patient health for a set period after discharge and not at identifying the cause of hospitalization. The toolkit can be complementary to the tools used in these programs. The concern assessment diagram and the concern reflection booklet will assist in determining the possible concerns which may have caused the current admission and may cause future readmissions, in a patient-reported format. The digital concern tracker will help in keeping track of the changes in concerns, through a network of supporting health systems and not only one hospital system.

The categories in the toolkit are simplified to spoken language from the academic terminology. In this translation, some of the categories may lose out on subtle differences that the spoken language may not accommodate. For example, from the palliative care framework, psychological and psychiatric care may have different implications for the severity of care requirement, care recommendations, costs, etc. However, in the toolkit, the categories are simplified to 'mind and feelings' concerns for both, psychological and psychiatric care needs. In such situations, it would be the case manager's job to analyze and recommend specific care needs to the patients.

The toolkit also reframes categories for better comprehension of concerns. For example, the environmental and social factors are combined and divided to form 'home, family and friends' and 'work and colleagues' categories. This division makes it easier for the patient to imagine their concerns in those contexts. For the patient, the concerns in the work environment might be completely different than concerns in the home environment. This puts the onus on the case managers to identify which parts of the concerns pertain to the social category and which concerns pertain to the environmental category.

Both the examples discussed above highlight the need for case manager's good interpersonal skills to identify and address specific patient concerns. The toolkit acts as a catalyst to create an opportunity for a conversation, but the success of the conversation still lies on the relationship building skills and the communication skills of the case manager.

Contextual Opportunities and Challenges

St. Joseph Mercy Hospital, Ann Arbor

St. Joseph's heart failure team was looking to identify problem areas in care transitions and implement possible interventions for the identified problem areas. Current programs in care transitions ask for additional resources such as a transition clinician (for example transition coach in the CTI program), to help patients with their transitions from hospital to home. Due to the current hiring freeze, the heart failure team could not implement these programs and had to look for resources within their organization. They identified the case manager as their primary resource to tackle the problem area. They were also able to negotiate a communication channel between their primary care physician group and their cardiology physician group. The case managers have a particular advantage over the transition clinician because they can be involved in planning the patient's care right from the point of admission and not from the point of discharge. The case managers at the primary care physician group and the cardiologist physician group form a network, which divides the workload and provides different touch points to document concerns. However, the transitional work is in addition to the current workload, which may burden the case manager if the patient case load on them is not reduced.

The toolkit allows for the case managers to have multiple touch

points with the patients. The administration expects case managers to complete assessments within 24 hours of the patient's admission. The case manager's days are complicated. A day's plan is often modified based on patient needs, making it difficult to prepare patient assessments within 24 hours from admission. The toolkit allows for the case manager to initiate the first point of contact within the 24-hour time frame just by introducing themselves and the toolkit. The case managers can then better plan their assessment time during the patient's hospital stay.

The clinician teams are interdisciplinary yet hierarchical. The concern points mentioned by individual clinicians may be ignored by certain other clinicians based on the hierarchy. By creating the concern assessment diagram and the concern reflection booklet to be patient-reported, takes out the interpretations by the clinician and provides substantial evidence to direct the care plan. This may help with addressing some of the hierarchical communication within the clinician team. However, the patients may have shared some aspects of their lives based on the trust of the case manager. The patient may not feel comfortable with their information being shared with other clinicians. The case managers will have to use their training to identify which information shared by the patient can be documented in the electronic medical records (EMR) and passed on to other clinicians.

The EMR generates a lot of different data per patient. The current systems require case managers to look through multiple entries and may miss out on certain details. The system does not have allocated space for all the concern categories, which may lead to case managers forgetting to document certain points based on their conversations with the patients. The development of the digital concern tracker will help clinicians better comprehend the patient concerns over time and with different healthcare systems. However, the assessments will add on to data generated per patient, which will add on to the amount of information required to be comprehended per patient to create an

appropriate care plan.

The discover phase of the design process highlighted patient narratives which provided specific examples for each of the eight concern categories. However, each patient may have multiple concerns making the patient concerns more complicated. During the conversation, the patients may under-report a particular concern category, or the case manager may only concentrate on high concern categories, missing out on addressing other crucial categories.

The discover phase identified multiple patient stories where the patient had multiple hospital experiences. Such patients have understood the current information requirement by the clinician, leading to them reporting the information as required by the clinician and not as per their preference. Such patient reporting can result in the patients missing out on significant changes in their lives and communicating their personal concerns.

The discover phase also identified that most patients do not look through the reference materials nor document in the health tracker books once they leave the hospital. The process for implementing the toolkit will have to be such that the concern assessment diagram and the concern reflection booklets are asked to be filled during the hospital stay. Even if the patients manage to go through the concern reflection booklet, the conversation with the case manager would not be entirely new. The patients would have had an opportunity to reflect on the key concerns before communicating with the case manager.

Sharing the documentation of concerns with a caregiver may vary from patient to patient. A patient may open up about concerns with their caregiver in an individual session with the case manager. In such situations, they may not want their caregivers to see the filled tools. On the flipside, a caregiver may be able to highlight certain concern areas a patient might not discuss with them. The case managers will have

to be sensitive to these preferences and decide on the involvement of caregiver during the conversation. Similarly, how the tools are documented and stored may be dependent on the patient-caregiver relations. The healthcare administration will have to decide whether the filled tools stay with the patient or with the case manager.

Broader Healthcare Systems

Most challenges faced by St. Joseph would be shared by other healthcare systems while implementing the toolkit. Other healthcare systems may present their unique healthcare opportunities and challenges. If other organizations do not have restrictions in hiring transition clinicians, they would be able to create dedicated clinician roles for addressing patient concerns in the hospital and beyond. Similarly, if EMRs are being set up or modified for an individual healthcare system, they will be able to include the digital concern tracker in their EMR.

The patient complexity is beyond the disease and will be shared by all patients dealing with different diseases. Therefore, the concern assessment diagram can be applied beyond heart failure patient groups. The deliver phase identified interest in the toolkit from clinicians practicing palliative care, social work, psychology, cancer care and even medical device companies. The concern reflection booklet, however, will need to be modified as per the disease group. For example, with heart failure patients, the booklet concentrates on working conditions, diet and lifestyle choices of a patient. With other disease groups, some other categories may be more crucial to the ones mentioned for heart failure.

Ethics Statement

This project is classified as a quality improvement project and does not fall under IRB requirements for the University of Michigan. However, the research is conducted keeping in mind all IRB requirements. Written consent was obtained from the e-advisors to interview and video/photo record. Patient privacy was ensured, and no patient indicators were documented. No audio or visual data directing to the currently hospitalized patients were recorded. Clinicians provided a verbal consent before being observed. Health Insurance Portability and Accountability Act (HIPPA) standards were followed through all stages of the process.

Limitations of the Study

The study was conducted for a specific situation: heart failure patients at St. Joseph Mercy Health System, Ann Arbor. The toolkit is designed for scenarios where it's implementation is made possible because of hospital-proposed modification to the case manager's role. The study was designed and implemented using a patient-centric approach based on qualitative design research methods. Alternative approaches to studying design have not been explored. The tool has not been tested for other disease groups and locations.

The designed toolkit does not work independently; it relies on the patient to report accurate concerns and clinicians to identify correct solutions, case-by-case, based on the reported concerns. The project's design process did not study HIPPA's directives on what patient information could be shared with other clinicians and what information can be documented. The discover phase of the design process, only looked at interactions with heart failure patients who are cognitively able to communicate and document their concerns. The study did not look into patients who may have language barriers, cognitive

difficulties or are not willing to communicate their barriers.

The author of the project does not have experience in any healthcare specialties nor its system management. If anything, the author is closer to being a patient than a healthcare specialist. While this provides a fresh outsider perspective, the point of view may overlook other relevant work or policy changes in the domain.

FUTURE WORK

Through evaluations and presentations, the project identified willingness amongst patients and clinicians to use the proposed tools. The following future work is required to implement the toolkit:

1. Testing the concern assessment diagram and the concern reflection booklet: St. Joseph's Heart failure case managers need to be trained in using the concern assessment diagram and the concern reflection booklet from the toolkit. A pilot study needs to be implemented to test the concern assessment diagram and

the concern reflection booklet with heart failure patients. The concern reflection booklet questions are based on literature that is currently available for whole-patient assessments. The questions may need to be modified according to patient requirements.

2. Developing and testing the concern tracker: A digital communication channel between case managers at St. Joseph and case managers of primary physicians and cardiology specialist needs to be set up where they can communicate patient data. The digital concern tracker needs to be developed as per the software capabilities of the communication channel. The digital concern tracker needs to be piloted with the heart failure case manager and primary physician or cardiologist case managers.

3. Modifications on the toolkit documentation will have to happen based on Health Insurance Portability and Accountability Act's (HIPPA) directives on what could be shared with other clinicians and what should not be shared. Implications on patient insurance status also needs to be further studied.

4. Implementing in broader healthcare settings:

   i. The toolkit is currently designed for heart failure patients at St. Joseph. However, the concern assessment diagram received interest from fields such as palliative care, social work, psychology, cancer care and even medical device companies to assess their patients' needs. Such parallel applications for the concern assessment diagram need to be tested, and the diagram needs to be modified as required.

   ii. Questions in the concern reflection booklet are currently designed to address heart failure related concerns. To implement it in other disease areas, would require modifications and the addition of new questions.

   iii. The digital concern tracker was proposed for a context where

the system was setting up communication channels between inpatient and outpatient case managers. This may not be the case with other departments and health systems. However, many health systems and corporations are currently working on connecting health records between different health systems or even proposing patient-held health records; this would be an ideal platform to implement the digital concern tracker.

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