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The impact of design on research teams in health services

A case study of the significance of the design artefact for interdisciplinary research and the generation of theoretical and applied lines of inquiry

Keywords: visual communication design, decision aids, patient communication, health services, design artifacts, experience maps, design research process, cancer treatment, shared decision making

The development of patient communication tools in health services research often requires the skills of a designer who will give the tool its final, usable form. However, research teams frequently overlook the demands of implementation and focus instead on the delivery of content to the patient. In the study considered here, shared decision making in cancer treatment, research was initiated by an interdisciplinary team without the participation of a designer. Once a designer began working on the team, the benefits he/she brought to the production of the designed artefact were evident. Design improved the team's effectiveness through better communication, and allowed for further studies based on application and theory. Researchers responded positively to design and saw the potential for its application to a range of health research.

1. Background

This project came about at the invitation of a bio-ethicist, a bio-informatics scholar, and a cancer researcher and clinician. The oncologist Dr. Larry Cripe is the primary investigator, and the impetus of this project is his experience in the clinic. Dr. Cripe and his team had been working on a decision-making tool (the Roadmap) for patients with acute myeloid leukemia (AML), a form of cancer most commonly found in 70 and 70+-year-old individuals (MedLine Plus 2017). The initial design challenge of this project was the creation of a tool to facilitate patient-decision making. Decision aids are becoming increasingly prevalent in medicine due to greater emphasis on doctor-patient communication to shift treatment priorities toward more patient-centred outcomes (Ernecoff et al. 2016). Many projects, including this one, are intended for screen-based media, to facilitate decision-tree interactivity.

Dr. Cripe is frequently faced with the task of delivering the initial cancer diagnosis to his patients and presenting them with a range of treatment choices. For patients in the advanced stages of the disease, Dr. Cripe also presents the option of supportive care, which focuses on providing comfort to the patient rather than disease control.

Patient-oncologist communication have multiple goals: exchanging information, building relationship, making decisions, and supporting patients emotionally (Arora 2003). The available evidence suggests that oncologists struggle to achieve these goals, especially

when the outlook for the patient is poor and death is the most likely outcome. Several factors can hinder effective communication. In this project it was the difficulty of providing patients with information relevant to their decisions that hindered effective communication. Multiple studies of patients have demonstrated that **patients quickly feel overwhelmed by the volume and complexity of information** and often **recall only a small fraction of the potentially relevant information**. Therefore, the original aim was **to develop a *more efficient means to disclose the necessary information* and *a means to disclose information in a way that would support patient decision making***. The perceived benefits of a more efficient means of disclosure include more accurate patient recall and *increased time for the oncologist to provide emotional support and discuss how decisions are made to assure the decisions are consistent with patients' fully-informed preferences*.

2. Shared understandings

The clinical experience of the physicians on the team, which was also reflected in the literature, suggested the following:

1. Qualitative studies of patient experience reveal that patients do not identify as important the elements of shared decision making valued by physicians (Koehler, Koenigsmann, & Frommer 2008).
2. Patients tend to trust the expertise of the physician and feel that only through them they can get a better *treatment* (Nissim).
3. Patients believe that the desire to live and the urgency of the diagnosis lead them to devalue information and accept the physician's recommendation without much evaluation (Leppin et al. 2017).
4. Patients demonstrate poor recall and feelings of being overwhelmed (Nissim).

3. Problem definition

During the design process, we found that progress was being delayed by lack of focus and weak continuity between meetings. Our concern as designers therefore was team mechanics: without clear communication within the team, we could not move forward with the design. After two meetings, it became clear that there was no shared model for the project at hand. When asked why he had asked designers to join the research team, the PI/oncologist on the project answered: "We were stuck" (Larry Cripe, personal email, June 12, 2017).

3.1 Framework

At the beginning of the project, the doctors used an unstated framework based on their content knowledge and desire to make an artefact, specifically, a decision tool in the form of a touch-screen app. Based on previous knowledge, largely first hand and experiential knowledge, according to Dr. Cripe the initial framework for the project looked like the example depicted in Figure 1.

DOCTORS
Problem definition
"How might we improve patient experience based on these 4 situations?"
Patient knowledge
Through lens of doctor
Patients make their decisions based on (1) Risk, (2) Uncertainty, (3) Values, (4) Goals
Two patient groups, treatable and palliative
Theoretical framework
Bioethical principles

Figure 1. Study framework with medical considerations only

The creation of artefacts through the design process led to the emergence of another framework (Figure 2) that integrated perspectives outside those brought by the doctors.

DOCTORS	DESIGNER
Problem definition	
"How might we improve patient experience based on these 4 situations?"	"How might we collaborate with medicine to improve patient experience?"
Patient knowledge	
Through lens of doctor	No knowledge
Patients weigh their decisions based on (1) Risk, (2) Uncertainty, (3) Values, (4) Goals	
Two patient groups, treatable and palliative	
Theoretical framework	
Bioethical principles	User-centred principles

Figure 2. Study framework integrating perspectives outside those brought by the doctors

4. Methodology & design process to develop the solution

– "What are you doing here?" Member of study team, medical anthropologist
– "I'm making the 'thing.'" Member of study team, designer

At the initial meeting, it became clear that the team was tangled in their own content and had not looked at user input for direction. Fortunately, audio tapes of several patient consultations were available. With this patient data, and the information obtained through informal interviews with Dr. Cripe and his clinical team, we were able to design a patient experience map.

4.1 Map

The map traces patients' experience over time from the onset of symptoms through inpatient therapy to their release home. It shows doctor/patient interactions and patients' thoughts and emotions triggered by communication with the doctor (Figure 3).

By revealing the experience of the patient, the map brought a new form of knowledge to the project, and in doing so, validated the design process. The team had approached the experience of the patient only through the experience of the oncologist during office visits. The map enabled the team to engage with each other through the patient experience as it progressed over stages. The map also provided a shared framework for discussion of the broader themes that had already emerged in the pre-design integration stage, such as physician trust. Critique of the map gave the interdisciplinary team specific points to focus on.

4.2 Worksheets/simulations

Worksheets were to be used during office visits to aid with the retention of information, and as a tool for general reference/information while treatment decisions were being made. Content was initially conceived by the oncologist based on experience. Later, however, content was modified significantly based on role-play simulations of patient visits, in which members of the study team unfamiliar with AML played the role of patient and family member, with the oncologist proceeding as in standard appointments. Worksheets were initially designed to ensure that the patients could discuss the
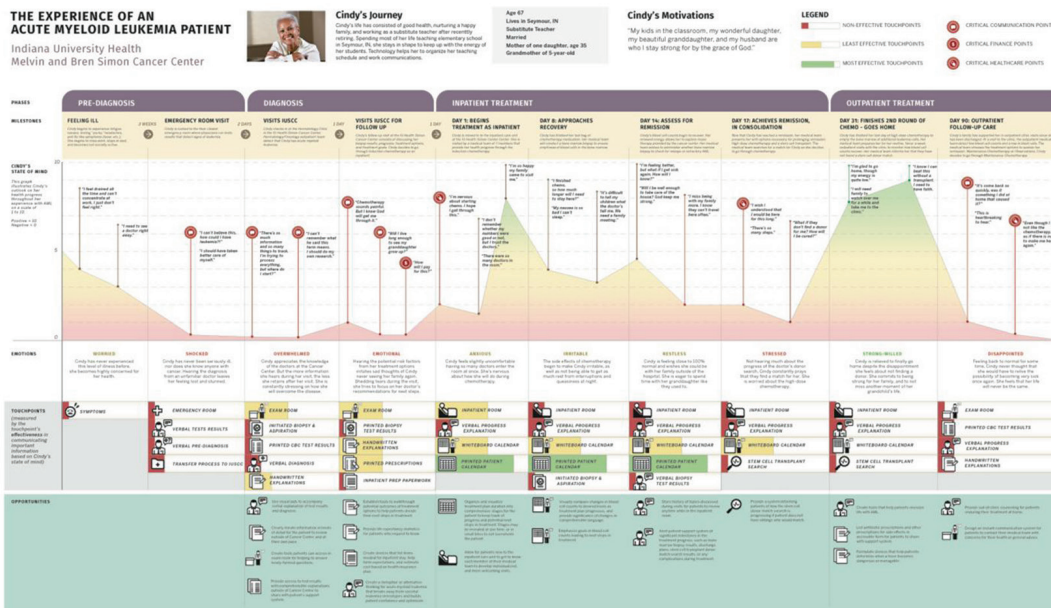
Figure 3. Patient Experience Map

issues they wanted during their appointment (agenda); understood their treatment options and potential side-effects; and were informed of options at different decision points in their treatment.

The simulations had a marked effect on the conception of the worksheets. The original intent was for the worksheets to efficiently share materially important information with the patient, with informed consent (i.e., permission for treatment) and shared decision making as the dominant paradigms. The worksheets were to serve as neutral ground between oncologist and patient and provide the patient with an informative document they could take away with them. The content was generic information (e.g. "What is AML?"); patient-specific information (e.g. test results and an explanation of what they mean: "here is how we know you have AML"); and

communicating the implications (prognosis: "You have AML and you are likely to be cured (or die).")

The simulations, first and foremost, convinced us that *the efficient transfer of complicated, voluminous, and threatening information* is not possible. Although we progressively refined and limited the amount of information, patients in our simulations were still overwhelmed in the first few minutes of the conversation. We also learned that the content on the worksheet may distract patients, so we are working on how to integrate the worksheet without taking the patient's attention away from what is being said during the conversation.

All in all, our user-centred approach to worksheet development has led us to focus on process rather than outcomes. Rather than trying to provide the patient prognostic estimates we are *training the patient and*

oncologist so that they know how to navigate together whatever happens in the future. Thus, instead of trying to reassure people that their chance of dying is too low to worry about, or trying to caution people that their chance of dying is so high that any treatment would likely be ineffective or could make them feel worse, we are saying let's figure out how to navigate the future regardless of the outcome. We are exploring narrative techniques to identify bigger themes that can help patients come to an understanding of their illness on their own terms, so that rather than focussing on AML they can focus on themselves, their priorities, and their lives. In essence, our focus shifted from creating an AML Road Map to be followed, to creating a patient-traveller, better equipped to make decisions confidently along their journey.

4.3 Process

Our working method is a hybrid process that reflects the doctors' content expertise and the process expertise of the design team (see Figures 5 and 6). Once again, the underlying platform for progress is an artefact,

| MY AML ROAD MAP | Goals for Treatment & Care | Option Grid | |

Goals for Treatment & Care

Key Questions	Treatment		Care	
	Achieving Complete Remission	**Achieving Cure**	**Optimizing Quality of Life**	**Achieving Personal Goals**
What does it mean?	Normal blood counts No blasts in the blood Less than 5% blasts in the bone marrow Feeling well	A cure is when there's a complete remission for five years or longer.	Your quality of life is the extent to which your life is satisfying, enjoyable or meaningful. We will think about your quality of life in terms of how you feel physically and emotionally.	Personal goals reflect who you are and what you hope to achieve in the future.
How is this achieved?	Intensive inpatient induction chemotherapy Less intensive outpatient induction chemotherapy Clinical trials may be an option	Further intensive chemotherapy Allogeneic stem cell (bone marrow) transplant	In order to provide you with the best quality of life, we will work together to identify and respond to distressing physical and emotional symptoms. Care directed at symptoms is called supportive or palliative care. you will receive palliative care wether or not you choose chemotherapy.	Start by engaging in personal reflection and talking with family and friends about what's important to you. Next, we will discuss your personal goals and decide how best to align them with your treatment goals.

Figure 4. Worksheet example

DOCTOR	DESIGNER
	1. Gather user/patient data
	2. Design patient experience map
	3. Frame problem
1. Write decision aid content	4. Write content
2. Design decision aid artefact	5. Design artefact
3. Test	6. Test
4. Re-design	7. Re-design
5. Implement	8. Implement
6. Evaluate	9. Evaluate

Figure 5. Doctor process vs design process

Phase	Effect on process
1. Patient data gathering	**(pre-study)**
2. Patient Experience Map	**Facilitated communication (un-stuck team process); defined overall scope**
3. Worksheet development	**Solution finding**
4. Testing	**Checking effects, efficacy**
5. Revision	
6. A/B testing	
7. Revision	
8. Implementation	

Figure 6. Our hybrid process (**bold indicates completed steps**)

increasingly the site of patient/doctor communication, a hardcopy tool that adds a visual component to the doctor's appointment, currently delivered face-to-face with visual aids. Both doctors and designers had intended on employing a design process in the study, the key difference being the patient journey research and exposition.

5. Evaluation/impacts

We are currently in the design development/testing stage of the doctor/patient intervention, so evaluation of the tool in use is still ahead of us. So far, however, the design process itself has taught us two things that have implications for design research: 1) that a design-centred intervention can be a generative model for Basic/Applied research, and 2) that design-centred processes that bring teams together around designed things ("thingness") facilitate generative interdisciplinary discourse within academic teams.

5.1 Intervention-centred model for basic/ applied research

Since the start of our involvement with the project, the study team has consistently spun off a range of questions touching upon each of the disciplines represented in the team. This has led to an understanding of this study as a generator of not one but two distinct paths of inquiry, Basic and Applied, wherein 'Basic Research' is research without a specific application in mind, and 'Applied Research' is conducted to address a practical problem. This split understanding is one of the contributions of our work.

The Applied path relates to the refinement and efficacy of the patient intervention itself. Intervention development (the AML Road Map) was initially conceived as the sole aim of the project. Significantly, because the project centred around the production of an artefact/object rather than the generation of

new knowledge/scientific discovery, the project was not viewed as an act of research. We lacked a formal hypothesis, and without a strictly determined basis for establishing evidence, the design itself became the measure of progress. We applied best practices in graphic, service, and experience design, and assessed their efficacy with members of the study team. The scientific team fed into our work raw data from recorded patient consultations, their knowledge from cancer literature and from established principles of bioethics. We were guided by the questions "Are we doing the right thing?" and "Are we doing it in the best possible way?".

The Basic path was an emerging area of general inquiry that was identified at every stage of review. Questions such as "What is the impact of negative health news on comprehension of information?" stood as potential areas for further theoretical inquiry and speculation, related to but beside the original intent of the project. Questions such as this suggest the integration of additional disciplines into our inquiry (such as health communication), and open the door for research in other fields. The Applied activities 'spin off' Basic lines of inquiry for research/knowledge generation, and have the potential to pull other fields into discourse, facilitated by design. We intend to address the 'Basic' area separately and are keeping track of its implications for research as we make the artefact.

5.2 The significance of things

Both the efficacy of the intervention in the Applied path and interdisciplinary integration of the Basic track rely on the persistence of the object. Perhaps the first notable outcome of the AML Road map intervention is how the introduction of a physical object impacted the team. The design became the locus of attention, discussion, decision-making, and idea generation. The physical presence of a visual object, rather than being viewed on screen,

had a galvanizing effect on our research partners, potentially because deliberate engagement with the object through sight and touch provided a common reference point regardless of specialization. We believe that it is stimulating for research teams to create interventions governed by design processes rather than solely through content knowledge. This is because the physicality of the object directs attention away from disciplinarity (silo-ed, specialized, or disease-centred ways of thinking) and toward utility and patient perspectives. We also speculate that embodying disciplinary knowledge in a tool is a novel way for many researchers to engage their expertise. The significance of the "thingness" seems to suggest an alternative approach to design. One which considers the design process design "thinging" rather than "design thinking", which emphasizes engagement with design to make ideas manifest and accessible. The extent to which design can provide a platform for discourse is a significant 'Basic' research question we hope to explore in ongoing research.

6. Implications for design education and practice

Often designers enter into collaborative projects with the understanding that the end outcome or artefact is their primary output. This project suggests that the benefits of design emerge much earlier in the process, through its impact on team efficiency in terms of communication and its potential to extend and refine questions of application and basic research.

Implications for design education and for design practice carry into the self-conception of the designer/design identity. I would like to suggest that design focused on the end-user brings opportunities for team-building and disciplinary innovation specifically because the disciplines take a 'back seat' to the user experience. Rather than creating a vessel into which

silo-ed researchers pitch-in to create a more comprehensive carrier of disciplinary content, the design process creates a more communicative, better coordinated team by shifting the focus from content to context, and from comprehensive coverage to effectiveness. Implications for design education are clear: in addition to competency in design methods and best practices, designers also need to be prepared to work in interdisciplinary teams as 'ring-leaders' or 'shepherds,' engaged in acts of creating that reel people in, scoop up stragglers, appoint or propose tasks, and keep everyone going in the same, shared direction. Replication of design's capacity to fashion better communication and better interventions depends on fidelity to design methods in research and design methods in craft. One of the most basic and broadest goal of design education is to attain mastery of the practice, and this is still essential for working with interdisciplinary teams. It is imperative that the design's functionality reflects both the research interests of the team and the perspective of the user. To this capacity I would add the importance of awareness of design's 'thingness' as a galvanizing force for communication across disciplines (Frascara & Noël 2014). If a designer wants to make a big impact on research they need to be able to see design as an external force that disrupts disciplinary inquiry to focus on relevance *while* expanding horizons for interdisciplinary practice.

7. Conclusion

As design thinking infiltrates both medical education and research, designers must keep in mind that the tools they bring along with them should not be relegated to either crafting deliverables or facilitating processes of innovation and iteration. Design can help engage researchers in their disciplines in new ways. It enables researchers to draw upon their expertise in the creation of a patient-centred tool, rather than erect an edifice of expertise, centred on validating its own authority. This is perhaps the longest standing contribution design can make to research. Designed products can help experts talk to each other confidently and without reservations.

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