

# Differences That Matter: In-Clinic Communication Challenges

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## ABSTRACT

We provide an integrated view of patients' and clinicians' perspectives on the communication challenges faced when patients present their medical issues to the clinicians. By combining the results of a literature review from both the HCI and medical literature with the results of clinician interviews explicitly about in-clinic communication issues, we are able to offer a more complete picture of these crucial in-clinic communication challenges. We discuss similarities and subtle but important differences between patients' and clinicians' perspectives. While patients and clinicians are often talking about the same issue, we found that they differ considerably in opinion and attitude. Drawing upon these subtle yet significant differences and ideas raised by the interviewed clinicians, we offer research suggestions for the design of future in-clinic communication tools.

## ACM Classification Keywords

H.5.m. Information Interfaces and Presentation (e.g. HCI):  
Miscellaneous

## INTRODUCTION

Extensive research has demonstrated that effective in-clinic clinician-patient communication is essential for building good relationships between clinicians and patients, as well as achieving the best results in improving people's health [49, 17]. While effective clinician-patient communication positively impacts patients' lives, misunderstandings between clinicians and patients can cause substantial harm to patients, at worst, even death [44]. Thus, it is important to work towards the improvement of clinician-patient communication; both to provide clinicians with access to the best, most focused, and richest information about the patients' conditions and to ensure patient comprehension and perception of support [49, 22, 7]. In this paper, we focus on expanding our understanding of the clinician-patient face-to-face communication challenges that occur during a day-to-day clinician-patient visit. For example, we are interested in visits in which a patient presents

their medical issues to a clinician, who tries to understand the patient, diagnose them, and suggest a possible treatment. This type of interaction happens in the circumstances in which patients need to relay information to a clinician, whether with a primary care doctor or a specialist during an in-clinic visit.

Research in HCI has shown that technology *can* help mitigate communication challenges between clinicians and patients (e.g., [47, 4, 51, 31]). However, these successes focused on specific medical problems. To explore whether a more general approach is possible, we need to expand our understanding of the communication challenges that clinicians and patients face in a day-to-day in-clinic visit. To this end, we conducted a structured literature review to gather the discussed clinician-patient communication challenges that occur during in-clinic visits. It became apparent that a large proportion of the literature focused on understanding communication challenges from the patient's perspective. To more fully grasp the whole spectrum of challenges between clinicians and patients, we additionally conducted a series of semi-structured interviews with clinicians involved in the diagnosis and treatment of patients to augment our findings from the literature survey. These interviews provided us with a better understanding of the clinicians' work practices, approaches, and their perspectives on the difficulties they face when communicating with patients.

From these two parts, we extracted seven overarching themes relating to clinician-patient communication challenges. For each theme, we compare and contrast clinicians' and patients' perspectives about communication challenges. Our key observation is that although both clinicians and patients are clearly talking about the same communication challenges, at the micro-level their opinions and *attitudes* can be different. In addition, we discuss different tools that clinicians in our study use to address the challenges. We contribute a more holistic understanding of challenges in clinician-patient communication, from which we draw directions for the design of future in-clinic communication technologies.

## POTENTIAL FOR TECHNOLOGY MITIGATION

While the importance of clinician-patient communication and the fact that it can greatly impact patients' lives and health outcomes is increasingly recognized [38, 60], it is possible that technology may help to reduce these barriers and improve the quality of communication [38, 60]. Some technologies that appear to be successful in this regard have emerged from an understanding of both patients' and clinicians' perspectives.

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For example, Ni et al. [47] explored the use of a projection-based handheld device for educating patients about their knee injury during an in-clinic visit. To inform the design, researchers conducted interviews with both physiotherapists and patients. Their technology, *AnatOnMe*, supported projecting body anatomy details on the patient's knee. *AnatOnMe* offered sufficient functionality for physiotherapists and they were keen to include more medical content for different injuries. Patients also found it engaging and fun to learn about their body.

Piper et al. [51] designed a tabletop display for information sharing between a deaf patient and a clinician. The researchers conducted interviews with both deaf patients and clinicians about the specific communication challenges they face. Then they designed a technology that presents visual information and supports keyboard entry from a deaf patient and speech input from the clinician. Evaluation indicated that such technologies might offer a substitute to using an interpreter (difficult due to cost, availability, and privacy) and facilitate medical interviews while maintaining patients' privacy.

To support sandtray therapy – a form of art therapy often used for young people – Hancock et al. [31] designed a virtual sandtray for a tabletop display to support communication between the therapists and their patients. The design of this prototype was informed by interviews with therapists and patients. The researchers found that their prototype was sufficient for therapists to gain insights about patients' psyche through their interactions with the virtual sandtray.

These examples show that technology *can be* a solution to some clinician–patient communication challenges when carefully designed by considering both perspectives. While promising, these technologies were designed for specific use cases. In order to facilitate the design of in-clinic communication technologies in a general context, we need to have a broader understanding of the challenges patients and clinicians face.

## METHODOLOGY

Our intention is to expand our understanding of the communication challenges that occur during in-clinic visits when patients present their medical issues to clinicians. To this end, we first conducted a literature survey. We found many studies interviewing patients and considerably fewer studies interviewing clinicians. While this may be due to factors such as difficulty in obtaining interview time with clinicians, it showed that a balanced view may need more clinician input, because communication always involves both parties. Also, the clinician interviews in the literature rarely consider day-to-day in-clinic visits and tend to be focused on specific medical situations such as when a clinician needs to impart a difficult fact to a patient. To learn more about the communication challenges of day-to-day patient visits, we augmented our literature review with clinician interviews about the communication issues experienced across many in-clinic visits. The literature survey and the clinician interviews provide complementary insights. By combining these, we can offer more details about clinician–patient communication and, in particular, discuss and contrast clinicians' and patients' perspectives.

## Literature Review

We started our literature search with a broad set of keywords to collect papers that investigated the challenges patients and clinicians face when communicating during an in-clinic visit. We searched PubMed, the ACM Digital Library (DL), and IEEE Xplore for all combinations of the following keywords: “physician/clinician/doctor + patient + communication/interaction + challenge/problem/issue/difficult”. This search resulted in an initial set of 2145 articles: 1781 from PubMed, 222 from ACM DL, and 142 from IEEE Xplore. We went through all the papers' abstracts and selected 312 papers that contained at least one of the search keyword combinations in their abstract.

Given our focus on day-to-day visits, we excluded articles on clinician–patient communication that happens in more extreme cases such as ICU care, surgery care, delivering bad news to patients, and end of life discussions. In addition, since we are focusing on a more general patient population, we have not included papers discussing special circumstances such as caring for patients with cognitive/physical disabilities, patients with extreme financial issues, and patients with different spirituality beliefs. We further excluded papers that only focused on the design and development of technology and have not investigated the communication requirements or challenges that patients or clinicians face. We divided these papers into four categories: patients' perspectives (22 papers); clinicians' perspectives (5 papers); both perspectives, interviews (4 papers); and both perspectives, observations (8 papers). We carefully read these papers to identify communication challenges using open coding techniques [59] which resulted in 21 codes.

## Clinician Interviews

To broaden the understanding of clinicians' perspectives on the communication challenges they face when communicating with their patients, we conducted semi-structured interviews with 10 clinicians. We interviewed a range of clinicians (both specialists and primary care doctors) who are directly involved with patients in understanding and diagnosing their condition, and suggesting treatments, corresponding to our focus on a day-to-day visit. Like 80% of the papers in our survey, we conducted interviews, in which we asked questions directly about communication challenges, since we are interested in the major challenges that clinicians are already aware of.

*Participants.* Finding physicians willing to give interview time, and with a wide variety of expertise, was a challenge. We recruited 10 clinicians (4 female, 6 male) from two different cities using snowball sampling. To maintain clinicians' requests for privacy, we do not explicitly report their length of practice but can say that we have a good spread from moderately junior to very senior clinicians. We recruited two physician pain specialists from two separate pain clinics, an established physiotherapist, a physiotherapist trainee, a neurologist, a neurology resident, and a primary care doctor, two diabetes specialists, and a chronic condition specialist.

*Why a mix of clinicians?* This set of clinicians provides a good range of perspectives from the clinician's point of view. Also, and importantly from our perspective, all these clinicians regularly do have day-to-day visits in their practice where they see patients in their office/clinic for diagnosis or treatment

		C1. ANXIETY	C2. FACTS AND EMOTIONS	C3. DIFFERING EXPECTATIONS	C4. ENGAGEMENT	C5. INCOMPLETE INFORMATION	C6. INFORMATION SOURCES	C7. MEDICAL TERMS	
CLINICIANS AND PATIENTS	CHEN ET AL. 2011 [17]								OBSERVATIONS
	WEIBEL ET AL. 2013 [64]								
	AGGARWAL ET AL. 2016 [3]								
	UNRUH ET AL. 2010 [61]								
	HUDELSON ET AL. 2013 [29]								
	SHIELDS ET AL. 2009 [50]								
	CLAYTON AND DUDLEY 2009 [19]								
	STEP ET AL. 2009 [54]								
	HAHN 2001 [27]								
	SADA ET AL. 2011 [49]								
PATIENTS	CHUNG ET AL. 2016 [18]								INTERVIEWS AND SURVEYS
	CASARETT ET AL. 2010 [14]								
	MACLEOD ET AL. 2015 [39]								
	GONZALES AND RIEK 2013 [23]								
	LIM ET AL. 2016 [36]								
	VAN WIERINGEN ET AL. 2002 [62]								
	JULLIARD ET AL. 2008 [33]								
	NETTLETON ET AL. 2005 [43]								
	KLITZMAN 2007 [34]								
	SUN ET AL. 2013 [57]								
PATIENTS	BERTAKIS ET AL. 1991 [8]								INTERVIEWS AND SURVEYS
	ABYHOLM AND HJORTDAHL 1999 [2]								
	THORNE ET AL. 2009 [59]								
	MATTHIAS ET AL. 2010 [40]								
	FALVO AND SMITH 1983 [21]								
	ROOT 1987 [48]								
	CONSTANTINO ET AL. 1991 [20]								
	ARAI AND FARROW 1995 [6]								
	JACKSON AND KROENKE 2001 [32]								
	GORTER ET AL. 2002 [24]								
PATIENTS	JACKSON 2005 [31]								INTERVIEWS AND SURVEYS
	THORNE ET AL. 2006 [60]								
	BROWN ET AL. 2007 [13]								
	SIU 2015 [52]								
	VEGNI ET AL. 2014 [63]								
	GIROLDI ET AL. 2015 [22]								
	MOFFAT ET AL. 2006 [42]								
	LOOS AND DAVIDSON 2016 [37]								
	NI ET AL. 2011 [44]								
	CLINICIANS	P8							
P10									
P9									
P7									
P2									
P4									
P5									
P3									
P6									
P1									

**Table 1. Summary of the literature review and our clinician interviews.**

purposes. Therefore, we did not differentiate between primary care doctors, specialists, or physiotherapists.

**Procedure and Analysis.** We used semi-structured interviews to let the clinicians influence the conversation and deviate from our questions. Our interview questions were general, regarding the interaction between clinicians and patients and were not related to the clinicians' field of medicine. The questions covered four main topics: 1) Clinicians' views on patients' difficulties describing their medical issues; 2) Strategies clinicians employ to facilitate communication with the patients; 3) Problems clinicians' face when presenting information to patients; and 4) Clinicians' approaches to simplify information

for patients. Given their busy schedules, we conducted the interviews at the clinicians' convenience. Eight interviews took place in the clinicians' offices/clinics, one in a public place, and one via Skype. According to the consent received, interviews were either audio or video recorded. The interviews lasted 30–60 minutes depending on clinician availability and the interview process. We transcribed and analyzed the interviews using inductive qualitative methods [59]. One researcher coded all the transcripts and another researcher independently coded a subset of transcripts. We then discussed, refined, and verified the codes. From this phase, we gathered 52 codes.

### Relating the Literature Review to the Interviews

We coded both the selected literature and the interviews. We arrived at 21 codes from the literature and 52 from the interviews. We further split up the interview codes in two groups: 22 codes describing the *challenges* clinicians mentioned, and 24 codes about the *strategies* clinicians used to address these challenges. We kept the strategy codes separate. The remaining 6 codes were not used (see later).

To reveal the major issues from both the clinicians' and the patients' challenges, we created an affinity diagram from literature codes (21) and the interview codes regarding the challenges (22). From this process, 7 themes of challenges emerged: *C1. Anxiety, C2. Facts and Emotions, C3. Differing Expectations, C4. Engagement, C5. Incomplete Information, C6. Information Sources, and C7. Medical Terms.* This process is illustrated in Table 1, where columns are the 7 themes and rows are the 39 selected papers and the 10 interview participants, ordered by similarity [50]. Papers are grouped according to whether they consider patients and clinicians together, patients alone, or clinicians alone. The dark squares indicate which themes were mentioned in a paper or by a participant.

After consolidating the codes into these seven overarching themes, we were left with 6 remaining codes. These consisted of three topics: treating patients with cognitive deficits, delivering bad news to patients, and the variation between different clinicians' performance. Given our focus on communication during day-to-day visits, we excluded the above codes. We use the strategy interview codes to inform our discussion on possible methods to address the communication challenges.

### COMMUNICATION CHALLENGES:

#### PATIENTS' AND CLINICIANS' PERSPECTIVES

For each of the seven themes of challenges that we extracted (C1–C7), we use the following structure:

- For the patients' perspectives on communication challenges, we provide results from the literature review.
- For the clinicians' perspectives on communication challenges, we combine the results from our interviews with the clinicians' perspectives found in the literature review.
- We discuss, contrast, and identify similarities and subtle differences between both perspectives.
- We present technological and non-technological strategies that clinicians currently use to address the challenge.

ANXIETY	
CLINICIANS	PATIENTS
Notice the patient's anxiety and talk about the result of anxiety	Talk about the cause – about what they think makes them anxious
Mention how a patient's anxiety leads to: forgetting details; getting lost in words, and being confused	Think the environment might be the problem - the white coat, the office, the computer

**Table 2. Clinicians' and patients' perspectives on anxiety.**

### C1. Anxiety

*Patients' Perspectives:* From the literature review, we found that *patients* sometimes find it stressful to present their medical issues to clinicians. They think stress interferes with establishing a smooth communication and sharing the necessary information with their clinicians [46]. Patients say that the lack of time is one of the factors that makes them anxious. As a result, they may not be able to share some of the information they have in mind [36]. Patients also are not happy with the way clinicians usually structure the time. They think the waiting time to see clinicians enforces a feeling of hierarchy, causing more anxiety [37]. Patients expressed their concerns about the physical set up of the room. For instance, the presence of computers can increase stress, especially when the display is not shared with the patients [18, 7]. They are unsure what clinicians are doing behind the screen.

*Clinicians' Perspectives:* From our interviews, we found that *clinicians* are aware of patients' anxiety. They expressed their concern about patients' confusion on how much and what type of information to share. Clinicians find it challenging to cut patients off when they are telling their story. They do not want to dismiss the necessary information but at the same time not all the information that patients share is necessary useful for diagnosis. The clinicians observe that patients may not know how to describe their symptoms or may get lost in trying to use the right words, resulting in extra stress on the patients.

Clinicians added that stressed patients may misremember or forget incidents related to their health: “*there is that degree of information that the patient may be expected to have but does not have*” (P2). This is even harder when patients are experiencing a symptom for the first time. To mitigate this problem, the clinicians offer help by providing examples or giving patients adjectives to describe their symptom. However, they are careful in suggesting descriptions of symptoms in order to avoid leading patients or giving patients the feeling that they are looking for *the* right answer. They are also concerned about not contributing to the patient's feeling that clinicians are dominating the interaction: “*If they can't figure something [out] by themselves, you give them a bunch of suggestions, being careful not to make someone feel frustrated or someone who has got low self-esteem, you have to be careful [to not] make them feel more inadequate*” (P3). Clinicians also feel that patients may think that the clinicians are not listening to them while they are looking at their computer: “*The electronic medical record is the third person in the room who seems to ask for more attention than the patient*” (P1). To mitigate this problem, P1 mentioned that to record a patient's history, he could use a mobile phone instead of a computer while he is talking to his patients. Since mobile phones are

FACTS AND EMOTIONS	
CLINICIANS	PATIENTS
Are mainly looking for medical information	Are looking for an emotional exchange
Feel they often get emotional information rather than factual details	Share emotions to get more attention and to make clinicians happy

**Table 3. Clinicians' and patients' perspectives on the impact of emotions on communication.**

small and movable, patients get less distracted and clinicians can maintain a face-to-face conversation with patients.

*Differences in Perspectives:* Combining the literature review with our clinician interviews, both patients and clinicians found patients' anxiety to be a problem for in-clinic communication (See Table 2). Clinicians are aware that their patients are anxious. They talk about how this anxiety affects their patients. They think that their patients' anxiety leads to forgetting details, getting lost in words, and being confused about what and how much information to share. Patients also state that they feel anxious when they visit their clinicians. However, patients do not talk about how their own anxiety might affect their behaviour. Instead, they indicate external causes for their anxiety, such as the clinical environment [57], clinicians wearing a white coat [57], and the clinicians' use of computers [28, 29, 18].

### C2. Facts and Emotions

*Patients' Perspectives:* In addition to medical help, patients seek the need to share their life situations with clinicians [53, 63]. They do not necessary expect much to be done by their clinicians rather they just need them to listen. Patients think that they will get more attention from clinicians and that clinicians will take their conditions more seriously if they share their frustrations and emotional downs [19]. Patients also like to share their happiness with clinicians when they have progressed in their treatment or recovery with their disease. They think the good news will make their clinicians happy [61].

*Clinicians' Perspectives:* Clinicians were aware that patients feel a need to share their emotional state with clinicians and the clinicians talked about trying to express their support for their patients to some extent [43, 30]. The clinicians in our study told us that they are willing to sympathize with patients to some degree and may gain useful information from patients telling their mixed story. The clinicians note that patient are often unable to articulate their symptoms because their thoughts are disorganized. Therefore, they try to narrow down patients' thoughts into a concise format, which in some cases might be complicated for patients. P1 gives the example of Twitter as way to restrict a description since patients tend to be vague and disorganized: “*Twitter forces you to really think about what you are saying cause you only have 140 characters so you are not able to include unnecessary details*” (P1). Another participant, P10, encouraged her diabetes patients to email or text message their sugar level and blood pressure numbers to get advice on their insulin intake.

*Differences in Perspectives:* Both patients and clinicians found patients' emotions to be a problem for communication (see Table 3). Patients have a different understanding of the in-

DIFFERING EXPECTATIONS	
CLINICIANS	PATIENTS
See patients who come with preconceived ideas and want quick fixes	Look for the clinicians to take patients' individual needs into consideration
Feel that patients should do the 'homework' they are given	Look for something they understand – medication they know, instructions that make sense to them

**Table 4. Clinicians' and patients' perspectives on differing expectations.**

formation that they need to share with clinicians. Previous studies showed that patients seek emotional support and recognition when they visit their clinicians [19, 61]. Patients think clinicians' emotional reaction to their complaints will give them more trust to share their medical issues [2]. As a result, they feel more satisfied with their visit [54, 9] when they share their emotions. However, clinicians are trained to efficiently interpret medical history and establish diagnosis, based on precise factual information (e.g frequency, severity). Therefore, there seems to be a conflict between clinicians thinking that patients share their emotions for "wrong" reasons and patients thinking that they share their emotions for "good" reasons.

### C3. Differing Expectations

*Patients' Perspectives:* Previous studies have shown that the most common expectations that patients have from a medical visit are: being informed about all processes [14, 64], and having their clinicians taking into consideration their individual needs [20, 21, 34, 67], age [58], gender [52, 56], and culture [6] when prescribing treatment.

For instance, elderly patients are more receptive to clinicians' treatment preferences than young patients but they have more difficulty discussing sensitive subjects with their clinicians, such as their sexual activities [36]. In some cultures people feel more comfortable and safe to be told what to do [6]. However, some patients prefer a more equal type of relationship with their clinicians [36, 6, 27]. Therefore, patients are expecting their clinicians to pay attention to their individual characteristics and treat them accordingly.

*Clinicians' Perspectives:* Clinicians think some patients have unrealistic expectations about receiving easy treatments [30]. The few studies that investigated clinicians' perspectives showed that clinicians sometimes think patients expect them to "do it all" and support patients in all aspects of their disease, including dealing with their family [25]. The clinicians in our study observed varying expectations from patients, some of which can sometimes be unrealistic. For example, P3 said "the patients tend to be a strange combination of more passive in their own health, at the same time feeling more entitled, they expect there will be a simple fix to everything and if a doctor can't provide [it], then he's not a good doctor." Patients sometimes look for options that make sense to them; "people want fancy scans where as physicians, we say all that will show you is more details about something that is irrelevant" (P3). The clinicians noted that sometimes patients come with preconceived ideas from their cultural background and expect their clinicians to follow them: "I have a sore throat, I need to get antibiotics and when you look at the culture, all want

antibiotics no matter what, antibiotics is the cure because that is what the culture says"(P1).

*Differences in Perspectives:* The patients and clinicians have divergent expectations from a medical visit (See Table 4). Clinicians in our study and from the literature mentioned that some patients are looking for easy fixes instead of self-managing their condition or changing their life-style. In contrast, previous studies revealed that patients have a different take on this problem. Patients expect their clinicians to present them with more familiar and tailored information [24] and failing to meet their expectations can negatively influence their treatment outcome [35].

### C4. Engagement

*Patients' Perspectives:* Before the 20th century, medical paternalism [62] was the most common model, where clinicians expected patients to follow their lead and apply the prescribed treatment plan [10]. Since the late 20th century, expectations of both clinicians and patients have changed towards a model of less passive patients [62, 10]. However, increasing patients' engagement in their care and in the clinical conversation still is a communication challenge. The literature identified several factors that disengage patients from a medical conversation. Patients think that sometimes the speed of information exchange is too fast, causing them to lose track of the conversation [65]. This is an even more serious issue for patients who do not speak the same language as their clinicians [36, 68]. Although there is an option to ask for an interpreter or a family member to translate, some patients are embarrassed to express their need for a translator [36] and feel like they may lose direct interaction with their clinicians [32].

Patients want to be involved in their care, beyond their engagement in the clinical conversation. They show interest in collecting and organizing information related to their disease and life style that will help clinicians become more familiar with their condition and how it affects their everyday lives [42].

*Clinicians' Perspectives:* Clinicians in our study mentioned that not all patients feel that their clinician is a partner in their health. Rather they think they just need to follow what they have been instructed to do. They might feel that they are not invited and thus avoid engaging. Clinicians told us that they expect patients to take more responsibility in managing their condition, to collect and record data that do not require labs such as medical events, list of medications, possible symptoms, chronology of their symptoms, and side effects. To amplify patients' responsibilities, P5 used a specific email address for patients emailing their data to the pain clinic reminding them that they are supposed to be ready: "The email is IamReady-ToChange@... so the actual email address is already priming the way they think about their medical encounter." In addition, three of the clinicians (P1, P3, P5) ask their patients to fill out electronic questionnaires before a visit to ensure patients' engagement and to save time during a clinical visit. Another way to engage patients in their care is to involve and inform them about the diagnosis process. For instance, P10 uses a risk calculation website to measure the risk of getting a heart attack for a diabetes patient: "When you make the process more transparent to the patients, they realize I am not just

ENGAGEMENT	
CLINICIANS	PATIENTS
Think patients are not engaged cause they are intimidated or do not have the necessary information	Feel left out because of the speed of information exchange and potential language barriers
Want patients to collect information about medical events, medications, and symptoms	Want to collect information about their life style and habits

**Table 5. Clinicians' and patients' perspectives on patients' engagement.**

looking at you saying OK "I" think you should get this pill. It is more of a "this is how I am deciding whether you should get this". I have taken all of these into consideration" (P10).

A simple solution clinicians use to address language barriers in communication is using translator applications. P1 uses Google Translate when dealing with patients who cannot speak his language. Some other clinicians do not find Google Translate always helpful since it is missing the translation for most of the medical terms. One clinician (P7) uses a special app designed for interviewing patients. The app has pre-recorded sentences for medical interviews, such as "Are you experiencing any abdominal pain?", in different languages.

*Differences in Perspectives:* Both the clinicians and patients in previous studies are just as willing regarding patient involvement in the care plan. However, there are differences between their opinions on this matter (see Table 5). Clinicians think patients avoid getting involved since they are intimidated by the hierarchy that exists between clinicians and patients [3] or do not have the information needed to get involved. However, patients see clinicians' high speed of speech, speaking in a different language, or irrelevance of the information as the main barriers [65, 36, 68]. Clinicians also think that creating and maintaining a care plan will help patients to record and remember their symptoms, so that patients would feel more engaged and less frustrated when they come for a medical visit. However, patients want to have clinicians more involved by understanding patient life situations and the impact of their condition on their life [1]. Patients think this will help them be more engaged with clinicians and in their care.

### C5. Incomplete Information

*Patients' Perspectives:* Previous studies showed there are a number of reasons for why patients may withhold information from their clinicians. They may think it is not relevant to what clinicians need to know. Patients may also have different priorities, goals, or beliefs such as their career or family, rather than living a healthy long life or just simply *getting better* [66, 39]. Prior negative experiences and mistrust of clinicians are other reasons patients may choose to withhold information [45]. Another factor causing patients not to reveal information is thinking they are an expert on their disease after having dealt with it for a long time [42]. Therefore, they may not necessarily see the value of sharing all detailed information about their disease and may prefer to manage it themselves [39, 42].

*Clinicians' Perspectives:* The clinicians in our study told us that they do not receive all the information they need from patients. They think patients are sometimes not even aware of their problem. Patients may visit them with a problem in

INCOMPLETE INFORMATION	
CLINICIANS	PATIENTS
Think patients have unknown problems and want to investigate them	Do not mention information that they think is not relevant
Want patients to have a longer and healthier life	Want to be able to live a normal everyday life

**Table 6. Clinicians' and patients' perspectives on incomplete information.**

mind, but there may be other problems. For example, P1 said: "Depression can express itself as fatigue, as pain. [For example saying,] 'I have pain in my back' but it is really depression because you don't have a job and are feeling low self-esteem, the problem is often mental health but being manifested in a physical form." Clinicians are mostly concerned with providing patients with the best treatment options to help them have a longer and healthier life [66, 39]. Therefore, they order extra tests to double check the information they received from patients and investigate possible unknown problems [40].

*Differences in Perspectives:* Both patients and clinicians are aware that patients sometimes hide or fail to communicate certain information (See Table 6). Clinicians think that patients are sometimes not even aware of their medical problem. Patients, on the other hand, think that some information is not relevant to share with their clinician. Patients and clinicians may sometimes have different goals. For instance, clinicians may want their patients to live longer and healthier lives, but the patients may want to live a normal everyday life without constantly having to think about their illness.

### C6. Information Sources

*Patients' Perspectives:* Evidently, patients see value in the information they receive from clinicians during an in-clinic visit. Previous studies have shown that patients develop different information management strategies. These include taking notes on a piece of paper or bringing another person along to help them capture the information during a visit [65]. However, patients are more interested in getting tailored information that matches with their everyday life [26], causes of their symptoms, the reasons why they developed a disease [19], and to verify the diagnosis or treatment that they received from their clinicians [8]. As mentioned earlier in "C3. Engagement", patients are becoming more proactive in their care management. As a result, they seek out this information online [11]. They mostly look online for information that can empower them with their personal needs [13, 70, 71]. This led some online forums to employ health experts as moderators to help provide clinical knowledge and avoid misinforming patients [33].

*Clinicians' Perspectives:* The clinicians stated their concerns on the negative effects of searching for information on the internet which may result in unnecessary stress on patients, a phenomena called *cyberchondria* [69]. Clinicians in our study have doubts about the credibility of all the information that patients gather, and wonder if patients have access to the necessary information. The clinicians are concerned that patients do not always look for necessary information or may not fully understand what they find. As a result, the clinicians feel they still need to inform patients in order to ensure that they have the correct information. Some clinicians think that patients

INFORMATION SOURCES	
CLINICIANS	PATIENTS
Want to educate patients about the mechanisms of their disease	Want to know about the cause of their symptoms and the reasons why they developed a disease
Want to educate patients about their anatomy	Want information that is practical in their daily lives

Table 7. Clinicians' and patients' perspectives on information sources

are often overwhelmed with the amount of information they receive during their visit. To address this issue, one of the clinicians, P10, told us that she was keen to allow patients to record their conversation. However, she was concerned with the healthcare policies on recording a visit. In addition, both the clinicians in our study and previous studies that looked at the clinicians' point of view on educational materials agree that patients will have a higher incentive to get involved in their care if they have an understanding of their anatomy and of the mechanism of their disease [47]. One clinician used the following strategy: *"I was actually taking their own smart phone and filming them doing their exercises. Because then they have it on their phone and my voice talking through it and they can see their own body doing it"* (P6).

*Differences in Perspectives:* Both clinicians and patients see value in educating patients about their disease [47]. However, clinicians and patients disagree on the material that they find useful to discuss during a medical exam visit (see Table 7). The clinicians are interested in educating patients about their conditions, anatomy, and mechanism of their disease and making sure patients understand all the necessary information. Patients may not find all this information useful, and they need to know how to turn this knowledge into everyday practice [26, 15]. As a result, not only do patients need to learn and understand this information but they also have to make an extra effort in finding ways to apply this knowledge in their lives perhaps through searching for this information online.

### C7. Medical Terms

*Patients' Perspectives:* Patients sometimes like to use medical terminology when talking to their clinicians. Previous studies showed that speaking in "surgeon-ese" [42] is as much for the patients to feel proud of their own expertise and ability to use medical terms as it is for the sake of the clinicians [42, 55].

*Clinicians' Perspectives:* The clinicians in our study think patients sometimes use medical terminology when *describing their condition*, to help the clinician or to save time. However, problems can arise from an incorrect understanding of the medical terminology: *"Every time they use a medical term I have to stop them and ask what they mean. I want to hear their story, not their story filtered through someone else"* (P3). To address this issue, one clinician tried to educate patients about medical terms and how to describe their conditions: *"Sometimes I will say a fancy word then I will have later a term that might match that, to try to teach them as we are going along. Sometimes the language that is watered down loses some of its specificity and when that happens, there could be a danger of misinterpretation or misapplication"* (P2).

MEDICAL TERMS	
CLINICIANS	PATIENTS
Think patients want to help clinicians by using medical terms	Want to appear more informed and feel proud of their ability to use medical terms
Do not trust patients' understanding of the medical terms	Want to feel that they are an expert on their own disease

Table 8. Clinicians' and patients' perspectives on use of medical terms.

*Differences in Perspectives:* The use of medical terms by patients during an in-clinic visit is a challenge. We found subtle differences between patients' and clinicians' perspectives regarding the reasons why patients use medical terms (see Table 8). Some of the clinicians in our study are skeptical when patients use medical terms and do not fully trust that the patients understand the terms. They think that patients' understanding of a medical term may be different from their own understanding, which may result in misunderstanding and misinterpretation. This is in line with past studies that have shown that patients do not always use medical terms correctly [16, 12]. In contrast, clinicians and patients disagree on the reasons why patients use medical terms. The clinicians in our study think that patients are eager to use medical terms to help clinicians and to save time in the visit. However, patients like to use medical terminology to feel proud of their expertise and appear more knowledgeable and informed [42, 55].

### DESIGN IMPLICATIONS

In this section we discuss how the subtle differences we have unearthed can be useful in formulating design directions. Being aware of the subtle differences between clinicians' and patients' ideas about communication challenges can play an important role in designing communication technologies that benefit both clinicians and patients. Both clinicians and patients raised the same issues, talking about anxiety, emotions, differing expectations, challenges of engagement, incomplete information, information sources, and the use of medical terminology. While the topics are the same, the details and thinking around these issues hold fundamental differences. These deep-seated differences pose a considerable challenge for designers who wish to develop technology that might help improve clinician-patient communication.

#### Considering a Holistic Approach to Technology Design

Both the clinicians and patients were aware that the patients' anxiety was a problem that affected the communication. In fact, the patients' discussion about anxiety pointed directly to technology. At first glance, they consider technology to be a problem and discuss how the clinicians disappearing behind the computer screen adds to their anxiety. Screens can restrict movement and interfere with work practices [41], and can impact communication between clinicians and patients [28, 29]. While one could interpret this as an indication the technology might not be a solution, it can also be taken as an invitation to change the way we think about technology use during the in-clinic visit [23]. Interestingly, the clinicians suggested trying alternate technological form factors such as using a phone, which is smaller and forms less of a barrier between the patient and the clinician. A useful design direction is to consider the set-up of the clinical consultation environment, i.e., how

technology can be used more seamlessly to ensure that it does not form a barrier between the patient and clinician.

### **Involving Patients through Information Transparency**

It is possible that increasing information transparency may contribute to reducing anxiety, encouraging engagement and reducing the amount of missing information. Patients said that clinicians recording information on their computer and not maintaining eye contact contributed to their anxiety [19]. They said they felt left out and not involved. Clinicians think that if patients could feel part of the process of data recording it might encourage them to be more involved. Clinicians suggested that allowing patients to view the screen and making it possible for the patients to follow the information that clinicians record may reduce patients' anxiety. Also, it would give them another opportunity to add missing information or bring up what they initially forgot to say. However, the amount and the type of information that can be displayed would require careful consideration since clinicians may be concerned about sharing sensitive data that could make patients worry even more.

### **Providing Alternate Ways of Exchanging Information**

In-clinic medical visits are almost exclusively a verbal exchange. To increase patients' comprehension, clinicians use technology to include alternate modalities like written words and various visuals including images, charts, and even animations. In addition, patients use various ways to exchange information that they collected with their clinicians. There is an increasing number of technologies that facilitate collecting and presenting self-generated data [48, 5]. Designing technologies/visualizations that provide both patients and clinicians with alternative ways to look at patient-generated data could be a promising approach for future work in this area.

### **Incorporating Motivational and Decision Support Tools**

Recently, expectations of both clinicians and patients have changed towards a model of more active patients [62, 10]. Clinicians expect patients to take more responsibilities in managing their condition instead of putting it all on the clinicians' shoulders. However, patients may not always see value to engage in their care. There is a need for new technological tools that assist clinicians in motivating patients to stay engaged in their care. The interviewed clinicians took various approaches to address this issue. One clinician involved patients in the diagnosis process and in calculating health risks to motivate them to take their treatment more seriously. A promising research direction would be to investigate the design of technologies and tools that provide opportunities for patients and clinicians to collaboratively input and analyze information. These tools can encourage patients to get more involved in their treatment process. Another clinician carefully named the email address she uses – IamReadyToChange – to actively promote health-related goals when patients send their information to her. Developing motivational tools could be a promising direction when designing new communication technologies to encourage patients' engagement in their care.

### **CONCLUSIONS**

From our exploration, we found that while patients and clinicians may agree on the topics of the challenges they face when communicating, they have different attitudes or reasons

for these challenges. By combining a literature review with clinician interviews, we note a series of subtle differences between patients' and clinicians' ideas about seven major in-clinic communication challenges: anxiety, emotions, differing expectations, engagement, incomplete information, information sources, and use of medical terms. In our investigation, we considered patients' perspectives in conjunction with clinicians' perspectives plus their current suggestions for possible technology solutions. In this manner, we contribute to the holistic understanding of clinician-patient communication and offer design directions for technologies that more fully support

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