Learning from Specialists’ Communication Strategies to Inform the Design of Tools for Clinician–Patient Communication

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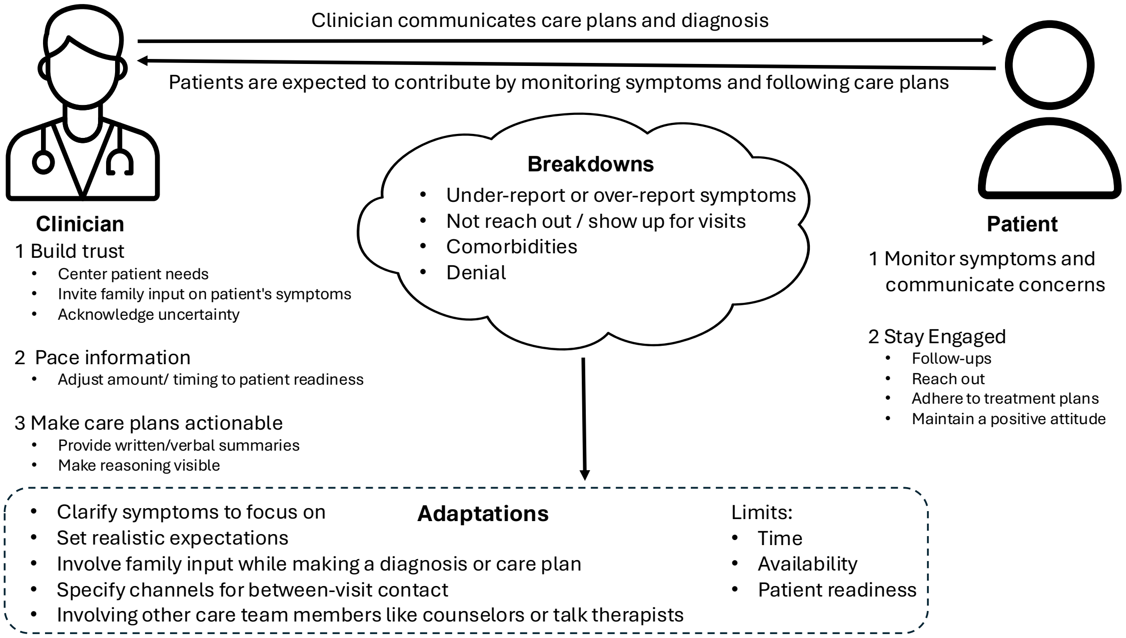

Fig. 1. Clinicians employ layered strategies (building trust, pacing information, making care plans actionable) and expect patients to contribute by monitoring symptoms and staying engaged. Breakdowns such as under/over-reporting, denial, or not reaching out lead clinicians to adapt (clarifying symptoms, involving family or other care team members). These adaptations are constrained by limits of time, availability, and patient readiness.

Communication between clinicians and patients is essential for managing chronic diseases. Effective communication supports treatment adherence and improves quality of life but is challenging: clinicians need to convey evolving prognoses and treatment limits under time constraints. Our research furthers the health community’s understanding of how movement disorder specialists adapt their communication strategies when explaining subjectivity/uncertainty and when patients struggle to keep up with care plans. We report findings from interviews with six movement disorder specialists in the United States, United Kingdom, and Nigeria. Specialists described layered strategies: building trust by centering patient needs, pacing information to patient readiness, and framing care plans for shared understanding. Specialists also expect patients and families to monitor symptoms and follow care plans, but are limited when these expectations fall short. We identify human-centered techniques (including technology design) that support clinician-patient communication for chronic conditions like movement disorders.

CCS Concepts: • **Human-centered computing** → **Empirical studies in HCI**.

Additional Key Words and Phrases: Clinician-Patient Communication, Digital technology, Human-centered healthcare

1 Introduction

Effective communication in the clinical setting improves patient satisfaction, shapes adherence to treatment and leads to better health outcomes [2, 36, 40, 46]. When clinicians effectively communicate results, patients adhere to treatment plans [46]. When patients communicate symptoms, clinicians can make better decisions [36]. In chronic care, communication carries multiple responsibilities: clinicians must not only deliver information but also guide patients and families as they take on ongoing responsibilities such as tracking symptoms, following treatment plans, and coordinating care [10, 33]. Yet effective communication is difficult to achieve. Patients often struggle to articulate their symptoms or process complex medical information, while clinicians must translate uncertainty and clinical reasoning into terms that patients can understand [36].

Poor communication between clinicians and patients can cause misunderstanding about treatment and follow-up, leading to worse outcomes, readmissions, and even legal risks [20]. Researchers have explored tools to aid communication—from systems that visualize patient data [15, 25] to designs that support shared decision-making [7, 37]. These studies highlight the promise of technology for supporting communication, yet also show its limits: self-tracked data often fails to meet clinical needs [41], electronic health record (EHR) screen-sharing does not guarantee shared understanding [3], and communication challenges persist in contexts where data is incomplete, ambiguous, or contested [7].

Movement disorders provide a compelling context for examining these challenges. These neurological conditions—including Parkinson's disease, essential tremor, and dystonia—are chronic, progressive, and their clinical presentations are often complex, variable, and at times unusual [1]. With no definitive test available, diagnosis depends on how the clinician gathers patient history, examines, and interprets patient symptoms [16]. This reliance on clinical judgment makes it difficult for patients to understand how specialists arrive at a diagnosis and forces clinicians to communicate uncertainty as part of routine practice [38, 43]. These challenges are compounded by cognitive changes that can accompany movement disorders, which can complicate gathering reliable reports from patients [36]. Clinicians must extract subtle histories, frame uncertainty and make clinical reasoning visible in the absence of objective data [38, 43].

Prior HCI and health communication research has approached related problems from other angles: pediatric contexts that emphasize family involvement [37], efforts to make numerical or data-driven findings understandable to patients [15], aligning care with patient values in multiple chronic conditions [7], and mitigating implicit bias in clinical interactions [5]. However little is known about how specialists in chronic, progressive conditions communicate when diagnosis and treatment depend heavily on subjective accounts. Nor is it well understood how clinicians adapt when patients do not meet expected responsibilities for their care. This gap matters because specialists' ability to tailor and adjust communication directly shapes whether patients remain engaged over the long course of illness—and highlights opportunities to examine how technology might support them.

In this paper, we address these gaps through semi-structured interviews with six movement disorder specialists practicing in the United States, United Kingdom, and Nigeria. Our analysis focuses on two research questions: (1) *How do specialists communicate complex and uncertain aspects of care to patients?*, (2) *What contributions do specialists expect from patients and how do they respond when these expectations are unmet?*

We find that specialists use layered strategies—building trust by centering patient and family concerns, pacing information according to patient readiness, and making care plans actionable—to manage complexity and uncertainty in diagnosis and treatment. At the same time, they expect patients to contribute by monitoring symptoms and engaging in treatment and daily management; such roles are often hard to sustain. Clinicians adapt in some ways, such as clarifying which symptoms matter most or offering layered explanations, but they face limits in time and resources.

From these findings, we outline opportunities for human-centered techniques (including technology design) that can help specialists tailor information delivery and support patient participation across the care journey. We highlight opportunities for health researchers to design tools that reduce incidental burdens while preserving the human aspects of care. This paper contributes empirical insights into how movement disorder specialists communicate in conditions defined by observations rather than definitive tests, including how they articulate expectations for patients and adapt when those expectations break down.

2 Related Work

We review work at the intersection of human-computer interaction (HCI) and health communication, focusing on long-term chronic conditions, and identify gaps in two areas, clinician–patient communication strategies and patient contributions to care.

2.1 Clinician–patient communication strategies in chronic, progressive conditions

Clinician-patient communication is influenced by multiple factors: clinicians' needs (to gather information for diagnosis and care plans) [6], data available (subjective reports vs. quantitative/objective test results) [40], and patient needs (emotion, understanding, and values) [24]. Clinicians often ask targeted questions to gather information that supports diagnosis and care planning. When patient descriptions are vague or incomplete, clinicians may adapt by probing deeper to narrow possible diagnoses [38]. Clinicians also communicate diagnoses and treatment plans; clear explanations increase the likelihood that patients follow recommendations [46]. Available data and medical results further influence communication. In some contexts clinicians can point to quantitative data or test results to anchor discussions. However, many chronic and progressive conditions diagnosis rely on observations and clinical judgment [33], requiring clinicians to then make their reasoning visible to patients [32]. Finally, patient needs and readiness also affect how clinicians communicate. In pediatric contexts, for example, clinicians simplify routines, build rapport, and use less technical language to match the knowledge level or emotional readiness of children [37].

Due to the need to gather data from patients and explain clinical information to them, understanding communication challenges in clinical interactions is important. For instance, clinicians face twelve challenges in explaining quantitative medical data to patients, including low patient numeracy, emotional reactions and data uncertainty [15]. These challenges are compounded in many health disorders including those that require long term chronic care—where concrete objective data are often absent. In such cases, clinicians rely on understanding and interpreting patient reports and their own observations in the clinic [44]. Clinicians also describe "communication friction," where patients do not share health experiences that could guide treatment. For example, clinicians have reported frustrations because patients sometimes did not share important problems until it was too late to act [10]. Additionally, conditions with variable prognoses can make it difficult for clinicians to communicate clear outcomes to patients [21]. Instead, they need to communicate uncertainty.

In such conditions where quantitative data is rare and observations, patient narratives, and clinician interpretation are key, how do specialists communicate? Our study addresses this gap by examining how specialists in movement disorders communicate, highlighting strategies they use to share diagnoses and care plans in the absence of definitive tests. By doing so, our research contributes to ongoing efforts in understanding and supporting patient–clinician communication [2, 7, 17, 35, 36].

2.2 Missing patient contributions in clinical settings

Patients are expected to play an active role in clinical care by communicating information that clinicians rely on to make decisions. They describe symptoms, track medication effects, and report on side effects, all of which help guide diagnosis and treatment adjustments [33, 41]. Patients also communicate to coordinate care priorities with clinicians and family members [7]. Without these forms of patient communication, clinicians would lack critical context for tailoring care. When patients communicate symptoms clearly, clinicians can make better decisions [36]; when patients understand treatment instructions, they are more likely to adhere to care plan [23, 36]. Effective communication thus underpins patients' ability to carry out beneficial tasks and engage in their care.

In long-term, chronic, and progressive conditions, communication becomes even more important because patient contributions are harder to sustain. For instance, onset speech impairments reduce patient ability to partake in clinical dialogue [27]. Patients need to monitor subtle or fluctuating symptoms over time, adhere to complex treatment regimens, and stay engaged across repeated visits [41]. Families often assist by observing daily changes, managing medications, or reinforcing treatment adherence [7]. However, communication in these contexts is difficult: patients might not bring up important symptoms because they do not understand it or they might not know its relevance for diagnosis [39]. Patient-generated data is often incomplete, inaccurate, or misaligned with what clinicians find clinically useful [41]. Additionally, there are mismatches in information-sharing priorities: patients may withhold emotional or contextual factors they see as irrelevant, even when providers view them as critical [22]. At the same time, emotional distress or cognitive decline can further constrain what they are able or willing to share [10]. People with chronic conditions often filter or withhold aspects of their experience due to stigma, time limits, or competing priorities [27]. At other times, patients and clinicians emphasize different priorities—patients focus on emotional needs and clinicians focus on factual details—leading to breakdowns when these priorities diverge [35].

Despite these insights, little is known about how clinicians adapt when patient contributions fall short. Do they clarify instructions, reframe expectations, or adjust the care plan? Most studies describe what patients struggle with, not what clinicians do in response. Our study fills this gap by examining, from specialists' perspectives, what contributions they expect from patients and families, and how they respond—or cannot respond—when those contributions fall short. Understanding clinicians' adaptive strategies can inform the design of useful tools and techniques. By foregrounding clinician perspectives, we highlight how they adapt—or cannot adapt—to sustain care in long term chronic conditions.

3 Background

Movement disorders are neurological conditions that affect a person's ability to control body movements [12]. Common examples include Parkinson's disease, essential tremor, and dystonia. In the United States, over 1.1 million people are currently living with Parkinson's disease, with approximately 90,000 new diagnoses each year [31], and prevalence is expected to double by 2040 due to the aging population [29]. These conditions are progressive and, for most, there is no cure; treatment aims to slow disease progression, manage symptoms and help patients maintain independence for as long as possible [9].

Diagnosis for most movement disorders is clinical—that is, based on a specialist's observations, physical exams, patient history and how the clinician interprets all these data—rather than a single definitive test [1]. Clinical presentations of movement disorders are often complex, variable, and at times unusual [1]. Subtle fluctuations in symptoms can be difficult for patients to describe, while clinical observations may be open to interpretation [26]. This reliance on subjective accounts and careful observation makes communication a central component of care. Patients and families must convey subtle changes, while clinicians must explain diagnoses, treatment options, and prognoses under conditions of uncertainty [2].

Movement disorder specialists are neurologists with specialized training in these conditions. They are the primary clinicians responsible for diagnosing and managing movement disorders [12]. These specialists face distinctive communicative demands: they must coordinate care over years, work with patients and families to monitor symptoms, and make decisions often without definitive tests. Studying their practices will provide insights into how communication operates in chronic, progressive conditions where medical data is subjective or uncertain—highlighting why movement disorders are a critical domain for understanding and supporting clinician–patient communication.

4 Methods

We conducted semi-structured interviews with six movement disorder specialists, who had 5-20 years of clinical expertise in diagnosing and managing movement disorder conditions. Our goal was to understand how they communicate with patients and families, and what they expect of patients. Automated transcripts were generated, verified for accuracy, and analyzed using thematic analysis which were then coded with codes clustered through affinity mapping. From this analysis, we derived design claims linking communication challenges to opportunities for technological intervention.

4.1 Participants

Six participants were recruited: five participants were based in the United States, and one had worked in both Nigeria and the United Kingdom. We recruited participants through snowball sampling [18], beginning with professional colleagues and asking them to share our recruitment materials within their networks. Participants had between 5 and 20 years of clinical experience in diagnosing and managing movement disorders such as Parkinson's disease, essential tremor, and dystonia. We chose to focus on movement disorder specialists because they are neurologists with advanced training in diagnosing and treating neurological conditions. Their expertise places them at the forefront of communicating complex diagnostic information, treatment options, and long-term care planning to patients and families. Additionally, patients who receive care from movement disorder specialists experience better outcomes compared to those managed solely by general neurologists [31]. Table 1 provides an overview of participant demographics and practice settings.

4.2 Data Collection

As part of an overarching study, interviews were conducted to examine specialists' diagnostic workflows and decision-making processes. All interviews were conducted via Zoom. Each session was scheduled for approximately one hour, though participants frequently provided rich accounts that extended beyond this time. In two cases, interviews were split

Table 1. Overview of interview participants. PD- Parkinson's disease, ET- Essential tremor, HD- Huntington's disease, PSP- Progressive supranuclear palsy, MSA- Multiple system atrophy, DLB- Dementia with Lewy bodies, FND- Functional neurological disorders

ID	Common conditions treated	Experience
P1	PD, ET, dystonia, tics and Tourette's syndrome	8 years
P2	PD, HD, tremors, chorea	7 years
P3	PD, tremors, balance problems, gait difficulty, stiffness, memory	14 years
P4	PD, Parkinsonism, ET, dystonia, chorea, tics	20+ years
P5	PD, PSP, MSA, DLB	12 years
P6	PD, ET, atypical Parkinsonisms, FND	4–5 years

into two sessions to accommodate participants' schedules. Interview lengths ranged from 42 to 110 minutes (average 70 minutes). With consent, all interviews were recorded in audio and video formats. The study received approval from the Institutional Review Board (IRB) of the authors' institution. For this study, we draw on the same dataset to determine how specialists communicate movement disorder–related information to patients; and the contributions they expect patients to make in long-term care.

4.3 Data Analysis

We transcribed the interviews using Otter.ai [30] and manually reviewed each transcript for accuracy. We analyzed the data using inductive thematic analysis [42], which is well-suited for identifying patterns in underexplored domains such as specialist communication strategies. The first author coded transcripts using Atlas.ti [4], exported codes to a collaborative online platform Miro [28], and conducted affinity mapping to cluster them into broader themes. Codes and emerging themes were iteratively discussed with two co-authors to refine interpretations and answer the research questions. Building on the thematic analysis, we identified design claims—analytic statements linking clinicians' communication challenges to opportunities for technological intervention. We then generated design possibilities for potential useful tools and techniques. Our analytic approach combined with a design perspective allowed us to uncover current issues and to generate possibilities for novel approaches to improve on them.

5 Results

Our study examined how movement disorder specialists communicate in contexts where diagnosis and care are defined by subjectivity rather than definitive tests. Specialists described layered strategies for shared understanding: they attempt to build trust by centering patient needs, pace information to patient readiness, and present care plans in ways that patients and families could act on. They also emphasized the need for patient contributions—such as monitoring symptoms and staying engaged in care—while acknowledging the limits of what patients can reliably provide and the challenges clinicians face in adapting when these contributions fall short.

5.1 Strategies specialists use to communicate care information to patients

Specialists described three main strategies for communicating with patients. They build trust by centering patients' needs, inviting family input, and being candid about uncertainty. They adjust the amount and timing of information to match patient readiness. They present care plans in ways that support shared understanding and decisions. We describe each of these strategies in detail below, along with a summary of the strategies described depicted in Table 2.

5.1.1 Building trust by centering concerns, inviting family input, and being candid about uncertainty. Clinicians attempt to build trust by centering patient needs, asking open-ended questions, and encouraging families to add details that may shape diagnosis and care planning. Apart from providing important details, these practices signal to patients and families that their voices matter in the clinical process.

As one specialist explained:

> *"...asking them questions about why they're here, about their symptoms, about everything...as well as asking collateral information from family members or friends or someone else that's with them in the room"* (P1)

Another explained that they start broad before moving to specifics, making sure patient concerns are centered first.

> *"So I pretty much have my standard list of questions that I ask the patient when I'm doing a history. The general—What brings you in? What are you most concerned about? And then specific to their movement disorders. What symptoms have you noticed?"* (P3)

Clinicians also described deliberately including family perspectives into the conversation.

> *"So in that interaction, most of the effort... was based on talking to the patient and talking to his relatives who were involved, and asking them a series of questions about these particular movements, the context of these movements, then a set of related problems that had nothing to do with the movement."* (P4)

> *"when I evaluate patients with movement disorders, I use the history obtained from the patient and family members or friends"* (P5)

A further account highlighted the act of paying attention—not only to what patients say but also to clinicians' own priorities, and then balancing both in treatment decisions:

> *"In the history taking I want to pay attention to what their concerns are, while also asking questions that delve into what I'm concerned about, and then try to make decisions on both treatment and diagnosis around both..."* (P6)

In addition to listening to the patient's and family's voices, the specialists described being upfront when certainty was lacking. Since most movement disorders are diagnosed clinically rather than through definitive tests, specialists often needed to acknowledge uncertainty while guiding families through the process:

> *"I'm also honest with them...right now, I'm not sure which one of those it is...over time, we'll have more information that will help us determine which of those it's more likely to be."* (P1)

Another specialist echoed this approach when discussing prognosis, emphasizing that it is better to explain variability than give false reassurance:

> *"...If you want to hear about prognosis, I will tell you on the basis of what's been published... but that doesn't mean it's going to be relevant to you individually, because there's such variability."* (P5)

Table 2. Summary of communication strategies specialists use with patients (Section 5.1).

Theme	**Strategy**	**Participants**
Building trust	Ask questions that center patient needs	P1, P3
	Involve family voices in history	P1, P4, P5
	Pay attention to both patient concerns and clinician goals	P6
	Being upfront about uncertainty	P1, P5
	Offer optional steps to build confidence	P3
	Reinforce trust with nonverbal cues	P5
Adjusting information	Delay difficult topics until patients are ready	P5
	Involve counseling or multi-disciplinary teams when needed	P2,P5
	Separate conversations when family wants more detail than patient	P5
Making plans actionable	Provide written/verbal summaries, checklists, handouts	P2, P4, P5, P6
	Use clear, conversational language and walking through plans aloud	P3, P6
	Make reasoning visible (diagnostic tests, spoken thought process)	P1, P6
	Promote collaboration by outlining treatment options	P1, P3, P5

Some specialists also offered optional steps, such as scans or temporary changes to medication, not because they were required for diagnosis but to help families feel more confident in the assessment:

> *"...I let them know that we could follow up...with a DAT scan or a medication trial...whichever they prefer...I didn't need it to make the diagnosis...but more to help them come to terms with it."* (P3)

One clinician also noted that nonverbal choices could reinforce trust—such as sitting face-to-face, keeping eye contact, and holding a hopeful but realistic tone:

> *"You want to share diagnoses or treatment plans where you're sitting down, looking directly at the patient and their family... minimize or hopefully eliminate medical terminology...be realistic, but always leave the door open for hope...not false hope, but hope."* (P5)

In summary, specialist attempt to build trust through layered communication: asking questions that center patient needs and draw in family voices (P1, P3, P4, P5, P6), and paying attention to both patient priorities and clinical concerns (P6). Specialists are also upfront about uncertainty (P1, P5), sometimes offering optional steps to build confidence (P3). Even small nonverbal choices—such as eye contact and tone—also reinforce this trust (P5).

5.1.2 Adjusting the amount and timing of information based on patient readiness. Clinicians adjust how much information to share and when to share it by gauging patient and family readiness. They assess readiness through emotional and cognitive cues—such as signs of distress, denial, or information overload—and adjust communication accordingly. For example, repeated consultations with multiple neurologists may signal that a patient is in denial rather than seeking a second opinion. In such cases, specialists may involve other care team members—such as psychologists or counselors—to provide additional support and help patients process the diagnosis.

> *"When you tell the patient that you have this, and he's not convinced...you won't give up on that kind of patient. Those are the kind of patients that need an MDT [multi-disciplinary team] review to counsel appropriately"* (P2)

> *"...you want to be very attuned to the patient's needs in the moment...on a gut level, you want to kind of have the sense of is this patient really anxious, are they in denial about the diagnosis? That could be a reason that I am the third or fourth neurologist they're seeing, not because they didn't trust their other neurologists, not because the communication wasn't there, simply because they don't want to believe the diagnosis, so they keep seeing other doctors, hoping to hear something different, and that's something that you want to pick up on. That really might merit from a referral to psychology, a talk therapist or a counselor"* (P5)

Clinicians also navigate differences between patient and family information needs. In cases where family members seek more detail than the patient wishes to hear, clinicians may hold separate discussions to respect patient preferences while still supporting family or caregivers.

> *"Sometimes the family wants to hear more information than the patient themselves... If the patient wants to hear X, you share X... then you either go outside after the visit or... set up a separate time to meet with the family to discuss the additional information."* (P5)

In addition, specialists may withhold discussing long-term implications (e.g., assisted living needs) early in the diagnostic process to avoid overwhelming patients—introducing such topics gradually over time:

> *"When I first diagnose somebody, I probably will not choose to talk about setting up, looking at long-term care or continuing care facilities...I might save it for follow-up visits."* (P5)

In summary, specialists adjust both the timing and depth of information: involving other professionals when denial blocks acceptance (P2, P5), separating conversations when patient and family information needs diverge (P5), and delaying difficult topics until patients are ready (P5). These adjustments help prevent overload, respect patient preferences, and help families engage in care.

5.1.3 *Presenting care plans in ways that support shared understanding and decisions.*

Clinicians use verbal and written forms of communication to make care plans easier to follow over time. Written summaries, such as after-visit summaries, act as a reference for patients between appointments. These summaries often provide step-by-step checklists, allowing patients to work through recommendations—such as medication schedules, therapy follow-ups, or lifestyle adjustments—at a manageable pace.

> *"At a practical level, we talk, and I give...written instructions...start this medication at this dose this many times a day, and then after so many days, increase the dose or change this, change that. So, yeah, it's a combination of verbal and in writing, typically." (P4)*

> *" I treat every after visit summary...as a checklist. My treatment plans are anywhere between 5 and 20 items long per visit, and so don't expect to implement everything at once. Put it on your refrigerator and check something off, like one thing or two things a week."* (P5)

In both verbal and written communication, clinicians aim for straightforward, conversational language, avoiding medical jargon and matching the tone they use during appointments so that instructions feel familiar. At the same time, they work to build shared understanding by making their reasoning visible—showing relevant diagnostic test results when available or walking through their thought process out loud during the visit.

> *"I provide a written plan...I try to keep it as concise but informative as possible, so not a lot of big words...straightforward, using the same language I used when I spoke to them, I tend to not be overly techie or scientific when I'm speaking... I like a more conversational approach"* (P3)

> *"...I go through my thought process and plan out loud with them, giving them multiple opportunities to ask questions. I then have it all written down in language that is suitable for patients..."* (P6)

> *"If we have any tests, I show them...I pull out the images and the pictures and show them you see how this looks abnormal. This looks like a period, instead of it looking like a comma shape. This is consistent with Parkinson's"* (P1)

Some clinical facilities provide handouts in multiple local languages or prepare patient folders with curated resources that patients can explore later.

> *"in my facility, we made a simple note on Parkinson disease...its in pidgin, Yoruba, Igbo, Hausa. So we share this for all our patients whenever they come, and then we counsel them based [on that]."* (P2)

> *"And then we also have a ton of information in our rooms, as well as new patient folders...I also then tend to provide, which includes things like websites, additional educational resources and information on medications, treatments, etc."* (P6)

Decision-making is seen as a collaborative process. Specialists outline the available treatment options, explain the trade-offs, and invite patients to choose according to their preferences or values. They may provide recommendations when asked, but emphasize that the patient directs the decision-making, with the clinician acting as a guide.

> *"As your doctor, it's my job to let you know all of the options, and it's up to you to choose which one you want. And when I talk about the options, I talk about the pros and cons of each of those options. And if patients want my opinion about which one I think is best, I tell them, most people respond the best to this type of treatment. So this would be the one that I would recommend starting with, but these are the other options if you prefer one of the other ones instead."* (P1)
>
> *"The management of your illness... is like a bus. You're driving the bus as the patient... it's my job to be there on the bus with you, directing you where to go, and giving you options of where the turns are, so you could make an informed decision as to where to go"* (P5)

In summary, clinicians support shared understanding by combining practical tools—such as written summaries, checklists, and multilingual handouts (P2, P4, P5, P6)—with conversational explanations that avoid jargon and walk through plans out loud (P3, P6). They also make reasoning visible, for example by showing test results (P1) or by verbalizing their thought process during the interaction (P6). Finally, they promote collaboration by outlining treatment options and framing patients as drivers of decision-making (P1, P3, P5). Together, these practices aim to make care plans both clear and actionable, reinforcing the patient's role as an active partner in long-term care.

5.2 Clinicians expectations of patients in managing care

Clinicians expect patients to take an active role in managing care. They described two main expectations: monitoring symptoms and communicating concerns; and staying engaged and following the care plan. These expectations are central to keeping track of symptoms, supporting treatment plan decisions, and maintaining continuity of care. Each expectation, however, brings its own challenges for patients, and clinicians use different strategies to address them—with differing rates of success. A summary of patient contributions can be found in Table 3.

5.2.1 Monitoring symptoms and communicating concerns. Clinicians expect patients to monitor symptoms between visits and report any changes or concerns. These reports are central to diagnosis and treatment decisions, often weighing more than formal scales—such as the Movement Disorder Society revised Unified Parkinson's Disease Rating Scale

Table 3. Summary of expected patient contributions to care (Section 5.2).

Expectations	**Challenges**	**Clinician Strategies (Participants)**
Monitoring symptoms	Patients may forget, miss subtle changes, underreport due to denial, or overreport minor issues	Clarify which symptoms to track, link to daily activities, set realistic expectations, involve caregivers (P2, P3, P4, P5, P6)
Reaching out between visits	Patients often wait until appointments; clinicians lack time to check in	Provide clear contact channels (portal, email, text, WhatsApp), supplement with pharmacist calls or home visits (P2, P3, P5)
Attending follow-up visits	Delayed visits due to late referrals, lack of specialists, cultural beliefs	Build trust to encourage return; re-examine progress and adjust care goals (P1, P2, P4, P5)
Maintaining a positive mindset	Denial, doubt, or anosognosia reduce health outcome	Offer counseling, use diagnostic tools (e.g., DaTscan), reframe conversations, encourage social support (P2, P3, P5)
Adhering to treatment	Side effects, cognitive decline, comorbidities, financial barriers	Suggest reminders (alarms), involve caregivers, strengthen trust to support adherence (P5, P6)

(MDS-UPDRS) [1]. Specialists mentioned deciding whether treatments are effective or need adjustment based on what patients describe about their everyday experiences.

> *"Ultimately, you make treatment adjustments in movement disorders on the basis of the patient's report...if the patient doesn't see a noticeable difference in their everyday life, then...I will not increase their levodopa*[2] *dose on the basis of my score, so the basis of what they report, that really what counts."* (P5)

Clinicians expect patients to monitor and report on multiple aspects of their well-being, including: i) symptoms that clinician and patient agreed to prioritize (e.g., tremor or memory), ii) issues the current medication is expected to address, and iii) possible side effects. Patient reports help clinicians assess whether the treatment is addressing the most pressing concerns.

> *"We decide which symptom we are addressing...if they're saying, I'm concerned about my memory or I'm concerned about my tremor...I'll say, okay, we'll start the medicine. I want you to take note if your tremor improves, if your thought processing improves."* (P3)

> *" so you tell the patient you know, don't focus on the tremor*[3] *, because tremor may or may not respond to this particular medicine, but your ability to move effectively should improve. So let me know if you're moving better, regardless of whether your tremor is better or not."* (P4)

> *"The [most common] side effects of Parkinson medications for Parkinson's patient is dyskinesia*[4]*...we ask them to watch out for that...so that we can adjust their medications regularly."* (P2)

Meeting these expectations is often difficult for patients. Clinicians mention that patients may forget to monitor symptoms, miss subtle changes, or underreport because of denial.

> *"There are things that are tricky...symptoms that are subtle, symptoms that the patient doesn't bring up or denies having or doesn't understand very well. And if you don't pick them up, you miss them..."* (P4)

Others may overreport or become fixated on seemingly minor symptoms, which can complicate treatment adjustments.

> *"The opposite is also true...folks that are very attentive to their body and their symptoms can make treatment more difficult, because… any small change is a big deal, and that can sort of impair either increasing medication that we know should be helpful"* (P6)

To support patients in this responsibility, clinicians use several strategies. They clarify which symptoms to pay attention to, often linking them to daily activities that matter to the patient, such as writing, walking, or eating.

> *"...you'd ask, is your writing easier? Is doing your makeup, eating all these sorts of things easier?...do you feel like your walking is easier? Are you less stiff? Do you feel like your movement is smoother, easier to perform?…"* (P6)

They also set realistic expectations based on what a treatment is likely to improve.

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[1] The MDS-UPDRS is a standardized clinical rating scale used to assess the severity and progression of Parkinson's disease. It covers motor and non-motor symptoms and is widely used in both clinical care and research.

[2] Levodopa is the most common medication for Parkinson's disease. It is converted into dopamine in the brain, helping to reduce motor symptoms such as tremor and stiffness.

[3] A tremor is an involuntary, rhythmic shaking movement, often affecting the hands, arms, legs, or head. It is one of the hallmark motor symptoms of Parkinson's disease and other movement disorders.

[4] Dyskinesia refers to involuntary, erratic, and often dance-like movements that can occur as a side effect of long-term use of Parkinson's medications such as levodopa.

> *"You tell the patient...don't focus on the tremor, because tremor may or may not respond to this particular medicine..."* (P4)

Families and caregivers can play a secondary role by noticing progress or decline that patients themselves may overlook or dismiss.

> *"If they're like, I'm not doing any better, but family members are like, you're not falling back every time you try to stand up… That's improvement."* (P3)

> *" I definitely encourage caregivers to come to appointments and ask caregivers questions too, because sometimes people are not aware of the full deficits that they have, and their caregivers may see things that they might not appreciate about what's going on."* (P1)

Through these strategies, specialists try to help patients monitor symptoms in ways that are realistic and clinically useful. This collaboration ensures that treatment decisions reflect both medical assessments and the patient's lived experience.

5.2.2 Staying engaged and following the care plan. Clinicians emphasized that patients staying engaged with their care plans is central to managing their condition over time. Patients can stay engaged in the following ways: reaching out with concerns between visits, attending follow-up visits, maintaining a positive mindset, and adhering to treatment. Each is critical for continuity of care but comes with challenges that clinicians work to address.

Reaching out with concerns between visits. Beyond the clinic, clinicians also expect patients or families to proactively reach out when concerns arise, rather than waiting until the next scheduled visit. Clinicians acknowledged that they do not have the bandwidth to contact patients themselves, which makes patient-initiated communication essential.

> *"...because of my schedule, I'm relying on the patient...If the patient doesn't send me a message or update me, I have to be honest, in this context of the conversation, I don't have the bandwidth of reaching out to them and asking how they're doing."* (P5)

> *"...it's not easy for us to call them, but they can call us and tell us how they are fairing."* (P2)

> *"I don't have the capacity to be able to talk to patients between visits, unless they were the ones to reach out with significant concerns."* (P1)

Clinicians support by giving patients clear instructions about how best to contact them between visits, such as through secure portals, email, text, or Whatsapp. Some health systems supplement this with pharmacist follow-up or home visits. However, it's not feasible in the long run.

> *"I tell them that if you do notice something is bothering you ...you can reach out to me through my chart, or call my office and let us know..."* (P1)

> *"I also am quite honest with them to tell them that I'm terrible on the phone. The order in which you will get a speedy response from me is email portal text message...so as long as they're comfortable with the first two, chances are they'll hear from me within a day or two."* (P3)

> *"I can spend 8 or 10 hours in the hospital. There is no time for me to even go to anybody's house to go and find out how he or she is doing. So the way we can do that is to put them on WhatsApp message and then let them contact us if they have any issues. I believe that is a major gap in our treatment for all."* (P2)

Attending follow-up visits. Follow-up visits are the main way clinicians track progress, hear updates, and re-examine patients. They allow clinicians to assess treatment effects and reorganize care goals as the condition evolves.

> *"The most common way is when the patient comes in for a follow up visit, they report back and you have a chance to re-examine them. That would be the standard..."* (P4)
>
> *"...I do these things when they come to see me for follow up appointments"* (P1)

However, patients do not always promptly reach out to specialists—whether for their first referral or for follow-up. Specialists noted that delays may result from late referrals, lack of access to movement disorder specialists, or cultural beliefs that keep people from seeking care.

> *"I have so many patients that were misdiagnosed… for years and years because they didn't find their way to a movement specialist, because they didn't have a movement specialist in their area, and it took them a long time to finally be referred."* (P1)
>
> *"Patients don't come early to the clinic… Sometimes they believe it's spiritual. Sometimes they believe they could use herbal mixtures...and after a few years, they don't get better, they now present to the hospital."* (P2)

Building trust with patients and families increases the likelihood that they return for follow-up:

> *"If you've built trust with a patient and family, I would say about 90% of the time they report back."* (P5)

Maintaining a positive mindset towards care. Specialists noted that patients who believe they can manage their condition do better than those who see the diagnosis as hopeless.

> *"If patients have that feeling that they can manage this, then they do far better than those that hear the diagnosis of Parkinson's think this is a death sentence."* (P3)

Challenges include denial or anosognosia[5], where patients reject or fail to recognize their condition.

> *"When you tell the patient that you have this, and he's not convinced… he is not likely going to follow your plan...Another thing...is a term called anosognosia. Anosognosia is that [the] patient has movement disorder symptoms, but they don't agree that they have."* (P2)

To support patients, clinicians involve other care team members—like counselors to help patients. They also use diagnostic tools (such as DaTscans[6]), or reframe conversations to highlight areas of progress. Additionally, they encourage patients to keep social connections and focus on meaningful daily activities that reinforce a sense of improvement.

Adhering to treatment. Finally, clinicians expect patients to follow the treatment plan, especially medication schedules. Consistency is essential for effectiveness but several barriers interfere, including side effects, cognitive decline, comorbidities, and financial constraints that lead patients to prioritize other conditions. Clinicians try to support adherence by making medications easier to remember, such as setting phone alarms, and by involving caregivers when needed. Above all, they emphasized that trust and rapport with patients and families often determine whether treatment is followed.

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[5] Anosognosia is a condition in which patients are unaware of or unable to recognize their own symptoms or deficits. In movement disorders, this can include denying or not perceiving motor problems.

[6] A DaTscan is a type of brain imaging (SPECT) that shows dopamine transporter activity. It is sometimes used to help distinguish Parkinson's disease from other movement disorders, though diagnosis is usually clinical.

> *“The camaraderie connection and trust a patient and family has in their doctor determines whether any treatment is likely to succeed or fail.”* (P5)

Clinicians mentioned that these different forms of engagement—returning for visits, reaching out between appointments, maintaining a positive outlook, and following treatment—can support patients in playing an active role in maintaining long-term care.

6 Discussion

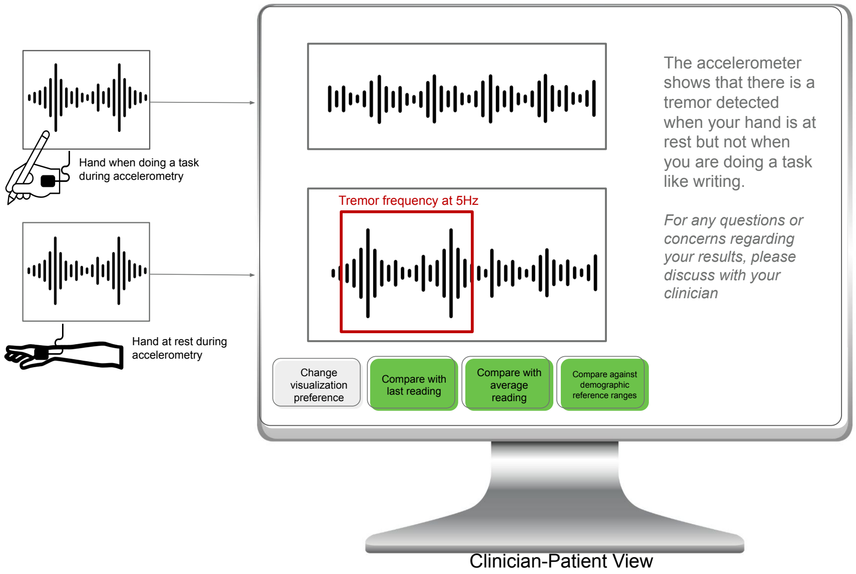
Our study examined how movement disorder specialists communicate with patients and how they respond when patient contributions fall short of clinician expectations. Specialists build trust by centering patient needs and inviting family input, while being candid about diagnostic and prognostic uncertainty. They also pace the amount and timing of information according to patients’ readinesss and make care plans actionable for patients. Specialists expect patients to monitor symptoms and stay engaged: reach out between visits, return for follow-ups, maintain a positive attitude, and adhere to medications. These expectations often break down for reasons ranging from patient-side factors—such as denial, side effects, or comorbidities—to system-level constraints, including limited access to specialists, and time/resource limitations. When patient contributions fall short, clinicians attempt to adapt in several ways: by clarifying which symptoms to focus on, involving family members as additional reporters, and specifying channels for how patients should reach out between visits. However, they face limits of time, availability, and patient readiness.

6.1 Communication when data is uncertain and subjective

In movement disorder care, diagnosis and treatment rely mainly on *subjective* data—patient narratives and clinician observations—rather than definitive tests. Specialists struggle to help patients understand how they reach their decisions and plans. They described situations where patients seemed unconvinced by clinical judgment, suggesting that the reasoning process may at times be opaque to patients. We extend prior work on communication challenges around *objective* data—such as lab results, imaging, or risk scores—where patients may struggle with numeracy, uncertainty, or overload [15].

6.1.1 Patient expectation of data and interpretable reasoning. In many areas of medicine, lab results or imaging provide outputs that help clinicians communicate with patients—clinicians can describe numeric values or imaging results compared against standard thresholds or baselines. For example, a blood glucose level above a certain cut-off indicates that one is diabetic [13], or a tissue biopsy can confirm some form of cancer [14]. However, in chronic, progressive conditions like movement disorders, diagnoses rely on subjective accounts. Clinicians recognize that patients might not always understand how those accounts translate into a diagnosis or treatment plan [26]. Clinicians noted that patients often expect more concrete proof than clinical judgment alone can provide. As one clinician explained, *“people like to see things in black and white”*. Patients’ expectations of “concrete evidence” creates tension when confirmatory tools (such as DaTscans or medication trials) are either unnecessary for diagnosis or limited in reliability.

Thus, there is a need for interpretable reasoning: ways for clinicians to make their thought process visible and meaningful in the absence of objective data. Our findings suggest that specialists already do such work by being transparent about uncertainty, voicing out their thought process, or offering optional confirmatory tests (*e.g.,* DaTscan). In clinical settings, these forms of interpretable reasoning are central to connecting subjective observations to clinical judgment. Appropriately designed tools will likely help. For example, a tool could help specialists communicate their diagnostic thought process by presenting visual and quantitative representations of motor symptoms (Figure 2). The



The accelerometer shows that there is a tremor detected when your hand is at rest but not when you are doing a task like writing.

For any questions or concerns regarding your results, please discuss with your clinician

Fig. 2. Prototype visualization tool to help clinicians interpret reasoning in diagnosis. The tool provides quantitative representations of motor symptoms. The tool shows accelerometer data from hand movements (writing vs at rest). The system highlights a detected tremor at rest (5Hz) but not during task performance, illustrating how objective traces can make the clinician's reasoning more transparent.

tool could display traces of a patient's tapping patterns alongside clinical indicators such as tremor frequency, path deviation, or amplitude changes. These representations could be shown during the interaction to illustrate the basis of the diagnosis, helping patients and families follow the clinician's thinking.

6.1.2 Clinician expectation of reports from patients. A major function of clinician–patient communication is to guide patients in contributing to their own care [10]. Specialists emphasized that patient reports are a primary source of data in making care decisions, often weighing more than clinical scales. Our findings highlight challenges in how this transpires in the real world. Patients may underreport, overreport, or track symptoms in ways that are not clinically useful. For instance, patients with chronic conditions often perform self-tracking [41] or share health information with providers [11], but clinicians often find patient-generated data incomplete or overwhelming. This showed up in our study too. One participant (P1) described tools that automatically send data from patients as *"labor intensive,"* noting they rarely have time to analyze such data with long waitlists of patients to see. Others highlighted challenges of obtaining reliable histories, especially in populations dealing with cognitive decline. A limited exception was described by one specialist who occasionally used consumer sleep data from devices such as the Oura ring in discussions with patients. However, they emphasized its limitations—far less accurate than formal sleep studies—and framed it as supplemental context used when the patient offered it.

While patient-generated data can sometimes support conversations, it doesn't always meet the standard of evidence clinicians require for decision-making. These findings suggest that patients might struggle with generating usable data. Clinicians communicate with patients to make their contributions more useful—for example, by clarifying which symptoms matter most and linking them to daily activities—-such as walking, writing, or eating. They also set realistic expectations about the effects of treatments—such as reminding patients not to focus solely on tremor as outcome measure (P4). Caregivers often notice changes patients may miss or dismiss, and prior work shows their contributions are important in managing chronic illness.

Our findings point to the need for targeted, low-burden ways of generating data: specific, actionable tasks that patients can perform with little effort that yield interpretable signals. Such efforts are similar to those proposed as *active digital phenotyping*—where patients complete brief, structured tasks that generate clinically useful data [19]. For instance, instead of a full week of wearable monitoring, a patient might complete a 30-second tapping test or a short walking trial once a month. These focused tasks yield interpretable signals—such as tremor frequency or gait stability—that clinicians can quickly review without being overwhelmed. Caregivers could also be involved to observe and validate performance, ensuring that the reports are valid and reflect daily function. At the same time, such short tests provide only a snapshot and may miss fluctuations that wearable monitoring can reveal over time, such as symptom variability across the day or changes linked to sleep and medication cycles.

6.2 Limitations and Future Work

Chronic, progressive conditions typically involve multiple stakeholders in diagnosing and managing a patient's condition—including nurses, therapists, general neurologists, and caregivers [34]. Our study focused on a single stakeholder group—movement disorder specialists. This narrow scope allowed us to explore clinician-patient communication needs in depth, but it also limits the perspectives gathered. Future research can explore how to support communication across this broader care team.

We interviewed six specialists, a sample size consistent with formative human-computer interaction (HCI) work in clinical domains [45] given the scarcity and demanding schedules of these experts. While small in number, this represents a meaningful proportion of this highly specialized field. In the United States, there are about 660 practicing movement disorder specialists, with six serving rural areas [31]. These few specialists are expected to meet the needs of over one million people living with Parkinson's disease alone—a single type of movement disorder [31]. Given this situation, we believe that recruiting even a small group of specialists to understand their communication strategies and needs is an important step forward.

The interviews yielded rich insights as we prioritized depth over quantity, and findings may extend to other chronic progressive conditions where communication relies heavily on subjective or uncertain data. However, these insights reflect only the clinician perspective on communication. Incorporating patients and caregivers perspectives will be critical for understanding how communication is experienced on both sides of the relationship, and for validating whether the strategies identified here are meaningful and effective in practice.

Most participants were U.S.-based and worked in relatively high-resource academic settings—where institutional supports for communication are relatively strong. Communication dynamics may differ in lower-resource or rural settings, or in healthcare systems outside the U.S. where family members or primary doctors may play a larger role in facilitating communication [8]. Broadening research across diverse contexts will be important for assessing the generalizability of our findings.

Finally, our reliance on retrospective interviews means we captured specialists' reflections rather than observing communication as it unfolds in real time. Clinicians may simplify or omit aspects of interaction, especially those that occur automatically or are difficult to articulate. Observational studies or recordings of consultations could complement our findings by showing how communication strategies are enacted in practice. Next steps in research include prototyping and testing communication-support tools in simulated or real consultations to evaluate how they fit into workflows and to assess their impact.

Despite these limitations, this study provides an important first step toward understanding how specialists communicate with patients in conditions where data is uncertain, and highlights opportunities for design to strengthen this communication.

7 Conclusion

This paper examined how movement disorder specialists communicate with patients and families in the context of chronic, progressive illness, where care often depends on subjective accounts. Through interviews, we found that clinicians use layered strategies—relational, informational, and pragmatic—to support care, but also face limits when patient input falls short. These findings highlight communication as a central part of care work and point to opportunities for future human centered interaction (HCI) research to better support clinician–patient communication.

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