ABSTRACT
The strengthening of community care and the development of co-managed telehealth systems are vital components in addressing growing critical healthcare issues encountered worldwide. The global COVID pandemic highlights the challenges in providing appropriate co-managed home-based care in a systemic and financially viable way at scale. It is important to understand the individual, institutional, and socio-technical opportunities and barriers potentially encountered when attempting to implement telehealth systems as part of a broader social healthcare network. As part of our work designing telehealth systems for home-based physical rehabilitation, we conducted a survey and interviews with occupational and physical therapists to better understand the everyday individual and institutional reality within which our systems might ultimately be embedded. We describe the integrated personal, economic, and regulatory issues involved and propose guidelines to consider for designers of telehealth systems for home-based contexts.

CCS CONCEPTS
• Human-centered computing → Ethnographic studies; User studies; Accessibility technologies.

KEYWORDS
rehabilitation, telehealth, therapist, patient, caregiver

1 INTRODUCTION
Telemedicine and telehealth are gaining prominence as avenues for delivering participatory health and wellness at the home at scale [9]. The global COVID pandemic brings a great sense of urgency to these developments, requiring the development of co-managed telehealth systems and the strengthening of community care [8]. Aging populations are increasing worldwide [4], leading to increased need for rehabilitation services for debilitating but survivable illnesses such as stroke and degenerative arthritis [12]. Technology-assisted or smart rehabilitation in the home is emerging as a key avenue for improving health and wellness outcomes with the potential for reducing costs [15]. Smart rehabilitation in the home can provide evidence-based customization of therapy, together with the increased intensity necessary for better functional outcomes over a shorter duration. Many of the technologies and interfaces necessary for this work are advancing rapidly through consumer products including smart phones and wearable activity trackers. Technology-assisted rehabilitation can adopt and customize these technologies, thus decreasing development costs while ensuring that the technologies are widely available to the public, including underserved areas. However, the scaling of technology assisted rehabilitation in the home still faces significant challenges [16] including issues with replicating the functionality of the therapist [14], acceptance of technology systems in the home by the patient and the caregiver [3], and shifting broader healthcare policy from a patriarchal medical model to a more integrated co-managed, and person-centered model [8].

Understanding the complex and competing factors at play requires consideration of the goals, values, and concerns of diverse impacted stakeholders. In our research, we are working on designing potential telehealth systems for stroke survivors for home based physical rehabilitation. In order to ascertain the feasibility of realistically implementing a relatively low-cost system at scale, we first need to better understand the lived experience of a primary affected stakeholder - the rehabilitation therapist. To do so, we conducted a survey and interviews with occupational and physical therapists to determine the issues impacting their current practices and the likelihood that a technology-assisted rehabilitation system might support or hinder their practice. We present findings from our analysis that highlight the importance of maintaining the patient/therapist relationship, the need to empower the caregiver, and the potential for assistive systems to provide quantitative and qualitative proof of care and patient progress.

2 RELATED WORK
The convergence of shifting national and international healthcare strategies and considerable consumer growth in the digital market economy provides the potential for the disruption of top-down hierarchical hospital based healthcare strategies towards more community based, co-managed, and person-centered approaches [8]. Earlier research examined the use of wearable personal health devices such as the FitBit or Apple Watch with regards to motivation, economics, and personal health monitoring [11]. Within the context
of rehabilitation specifically, consumer cameras, wearable sensors, and augmented reality systems are proposed as off-the-shelf solutions for lightly supervised or unsupervised rehabilitation in the home [10, 19]. In addition, such consumer products have also been supplemented by the creative use of 3D printing technologies to create customized devices for diverse types of rehabilitation [1, 14, 18].

We aim to build on prior work examining the interactions of stakeholders in the deployment and adaptation of assistive technologies, examining how the desires and goals of each group impacts the way the technology is received and responded to [6, 13]. We are mindful also of the role of secondary stakeholders and the implications of our designs on them. Our approach in proposing a home based system therefore also seeks to address the key challenges experienced by caregivers, including how they may struggle to manage their emotional selves, balance their own personal health, and deal with new technologies that may fail to carefully consider their needs and values [7].

3 METHOD

Our research methodology was approved by the ethics review board at our institution, Virginia Tech, and included a preliminary survey (N=17) with occupational (14) and physical therapists (3) and follow up online video interviews with ten of those participants. The therapist participants in the survey and interview components were recruited from the local (rural and suburban) community in Blacksburg, Virginia which is a Southern state in the United States. Our work in our local community focuses on the development of assistive home-based systems for stroke rehabilitation and recruitment for participants in our survey and interview study was conducted via the posting of flyers in local hospitals and university training facilities, and by email, social media posting, and word of mouth via the occupational therapist on our research team. The participants were compensated with gift cards totalling $5 for survey participation and $20 for interview participation. The goal of our study was to better understand the experiences, values, and expectations of potential users and stakeholders of our proposed systems.

The survey instrument was administered online in Spring of 2020 and included sections soliciting information relating to demographics, work experience, everyday clinical practice, and electronic medical record keeping. 15 women and two men participated in the study. The findings from the survey were used to develop a series of questions for a follow-up semi-structured interview with some of the original survey participants (10 of the 17 ultimately participated). The interview questions explored in more depth the therapists training and education, their experiences in different clinical, community, and home based settings, their current everyday practice, their documentation strategies and use of electronic medical records, and their goals and values with regards to their patients and their employers. We adapted some of the questions of the interview protocol to include sections related to the COVID pandemic as this component of the research was conducted in Fall of 2020. Each interview lasted approximately 50-60 minutes and was conducted and recorded with permission on Zoom. The interview group consisted of nine occupational therapists and one physical therapist, and had nine female participants, which closely resembles the 92% female field [2]. The full breakdown of the interview participants is depicted in Table 1 below. The interviews were transcribed and analyzed using an inductive grounded theory [17], whereby the authors first individually used open coding to identify pertinent phenomena in the responses of two of the participants, which were then labeled by the authors using phrases as the coding unit. Working together, the authors developed concept groups from the coding labels, which the first author then used to label the remainder of the transcripts. Finally, the first author generated a list of high level thematic categories [5] that were subsequently agreed upon with the second author.

4 RESULTS

4.1 Survey

The majority of the therapist participants in our survey had experience in skilled nursing(14) and acute care(10), while only three therapists had experience with inpatient care. Seven of the therapists had experience in home health settings, and one of the therapists had approximately six months experience with a telehealth system. Based on the responses, the therapeutic time spent with patients varied depending on the practice context with acute and home health sessions typically calculated as taking 20 - 45 minutes, while in patient, out patient and skilled nursing settings took anywhere from 45 - 90 minutes per session. 14 of the therapists specified the practice setting as having the largest impact on the amount of time spent with the patient, while three of the therapists indicated the patient needs as playing the most significant role. When asked to elaborate further, therapists described factors determining the amount of time allocated as depending on "the complexity of individual patient cases" and in two cases, therapists noted the pressure of "productivity standards."

In terms of documentation of patient sessions, all therapists noted their use of electronic medical records (EMR) which were primarily used at point of service (POS). In addition, the use of paper charts and templates was noted by five of our participants who subsequently entered information from those paper notes into the EMR. Two participants described their own development of either personal "navigators for click-box documentation" or the building of a "template with some smart phrases I use to speed up the length of time spent that I customize to each patient." The documentation process itself primarily happened during and after the time with the patient, and on multiple occasions, was described as encroaching into lunch breaks, occurring during pumping times for a nursing mother, or even stretching into uncompensated hours at home. The participants described the purpose of their documentation efforts as providing proof of patient progress or barriers to progress, proof of skilled intervention, descriptions of the plan for ongoing and future treatment, and justification for therapeutic need. Insurance requirements were noted as requiring more extensive documentation, and one participant noted that "at the pro-bono free clinic, documentation is more brief due to the absence of a need to justify for insurance payment."

The results from our pilot study point us towards several tensions at play between different stakeholder needs including patient requirements, therapist productivity expectations, and insurance company stipulations. These (sometimes) competing interests can
impact the time spend on functional patient improvement and can also place additional pressure on the therapist’s everyday experience. While there are potential opportunities to develop technologies to assist with documentation and/or the automated production of “proof” of skilled intervention or patient progress, additional consideration is required with regards to the potential individual and institutional barriers that may be encountered in trying to realistically implement community and home based assistive technologies at scale. Such considerations and the results of the survey findings helped refine our interview questions, the results of which are described below.

### 4.2 Interviews

#### 4.2.1 Therapist and Patient Goals.

Determining and defining patient and therapist goals emerged as a significant theme in our interview sessions. Participants described how within a given session and in the long-term spectrum of care, their goal is primarily to teach their patients compensatory skills in order to cope with the changes in their lives and to provide them with the necessary information that they may need to adapt accordingly. This included focusing on increasing independence as noted by P8: “I’m usually working on either exercises, energy conservation, self care, mainly just kind of helping them be as independent as possible in their daily routine”, or assisting in the transfer of recovery knowledge and expertise as efficiently as possible as therapist time is limited, costly, and ultimately often terminated by insurance rules. P4 for example noted their approach as being: “I’m not your personal trainer. I’m teaching you what to do. That way you can come to me for a short amount of time and then do this on your own.”

However, the participants expressed that despite the narrow timeline, their practice is heavily guided and influenced by the patient they are working with. Our participants’ profession is very much person-centered and requires purposeful connection with patients and the development of a relationship built on trust. All of the participants in our study emphasized how fundamental the relationship that they establish with the patient is in facilitating the rehabilitation process. P2 summarized this point in stating ‘...you’re not gonna get anything out of them if you don’t...have their trust and don’t build some type of rapport’. Trust is established by the incorporation of individual patient goals and needs into the treatment plan. The therapists described how they ask their patients about what they themselves want to achieve, what key daily life functions that want to be able to do, and what skills they would most like to regain. P4 described how they “usually try to let them know, like, we kind of talk through that together saying like, what are your goals and what are my goals for you?...because that’s kind of like the buy in I feel like for a lot of patients”, while P8 explained how they incorporated their observations with the patient desires: “So then we’ll sit down at the end, and I’ll say, ‘Okay, this is what you showed me that you’re able to do. These are some things that you’re having problems with...would you like to work on this?’”

#### 4.2.2 Caregiver Impact.

Though the interviews were primarily focused on the therapist’s everyday practice and their patient interactions, many of the participants spoke about the role and impact of the patient caregiver in their own and in the patients’ lives. When discussing how they learned about the patient’s life and their levels of activity, several therapists mentioned how they relied on the caregiver to help round out their understanding of patient recovery. P10 described how they relied on the insight of the caregiver to better understand their patient’s condition, stating “If the patient is tired or something, I’ll call the spouse and say, ‘Hey, your spouse is kind of tired. Can you tell me what were they doing before? Were they dressing themselves?’”. In a more complicated case, P6 shared how they “had this patient, and he’s doing really good. And I think he got the sense that we were coming to...the end of therapy. So he tells us that he still can’t use his phone...So my student...asks his wife, can he use his phone? She’s like oh yeah, he’s using it just fine.”

Caregivers also emerge not only as sources of everyday patient information, but also as training partners for the therapists. Our study participants described the caregivers as knowledge hubs to whom therapists can pass on the information that patients may not be able to retain. Several participants described how they partially pass on their own expertise to caregivers to assist with hospital discharge, such as P8 who described how “sometimes, you know, we’re giving that education to the caregiver, and then once they get that education, then we can discharge the patient”. P7 went even further, explaining how for “some people we have to actually show them how to move the [patient’s] arms and legs to get in and out of bed and how to lift them or turn them in the shower”. In this case, the educational goal is to support the caregiver in continuing to assist with patient care.
improvement even after insurance coverage runs out. P6 described how some of their patients might need “somebody to either remind her or show her pictures, at least give the least amount of assistance so that she can maintain that mobility and that range of motion.” P5 spoke for many of the participating therapists when she stated that “...caregivers [are] a huge portion of who we [ask] about how the patient’s doing...there’s a lot of people involved...when...viewing all the information. Not just what we see, but who we talk to as well.”

4.2.3 Ethical Work Challenges. The therapists in our study directly addressed the tensions in their everyday experience between serving their patient’s diverse needs while also working within the remit of the rules and regulations of their employers and the insurance companies that they must comply with. They described how they must meet expectations including prompt documentation of sessions with patients, the maintenance of certain levels of daily efficiency, and overall standards of patient progress. When asked about the role of documentation in their practice, the participants described how they struggled to meet documentation expectations and sometimes had to find creative ways to improve their own efficiency or use time outside of work to complete documentation. In describing the requirement to do POS documentation, P2 stated “So we’re obviously encouraged to do point of service documentation, which means as the patient is doing something, you’re sitting there writing or typing...That is nearly impossible to do in occupational therapy because we are a hands on profession”, while P3 highlighted the ethical implications of POS documentation, noting “they really want all intervention notes...to be completed at point of service before you leave the house. I don’t particularly appreciate that because I don’t think that that’s an ethical use of my clients’ time...They’re cutting the value of visits and asking people to do more.” For P8, this dilemma means work encroaching on their personal time: “I’m on the road all day...so I just have to end up taking [documentation] home. And so the work life balance is not there.”

The participants noted changes in their profession over time, with P10 stating that “20 years ago, it just seemed like you might have six patients, they might all be an hour, so you don’t feel rushed. In some places now, you’ll have 12 patients for 30 minutes. So they’re trying to fit more people in but decrease their minutes. So I don’t like that because it feels like you’re an assembly line.” P6 described how even when “You could deliver the best treatment ever, but maybe like 15 minutes of it wasn’t billable, then they’re coming back and asking, ‘Why was your productivity only this this week?’”. I had these great outcomes, but it doesn’t really matter because it’s all about billable units.” For some therapists, their response was to push back on administrative rules, with P5 stating: “[my practice] was a place where I’ve been really hyper aware of the Venn diagram of us being a healthcare company and a private business. I’ve really had to advocate to get some of that time back to do some of the things that are necessary to complete the job ethically.” For several others, they developed shorthand systems to assist with efficiently completing documentation requirements and freeing up more time with patients. P4 described how they “prep all of my notes... That way when I’m with the patient, my notes are already kind of ready. It just helps me be faster throughout the day and be more one on one with the patient.”, while P7 states: “I will jot myself little notes so that I remember what we’ve done in that time...but I almost never pull out a computer and type when the patient is right there because most of our patients need, if not hands on assistance, they need cuing and just kind of that skilled interaction.”

4.2.4 Proving Therapy Value. Proving the value of their skills and expertise to insurance companies emerged as a key theme in our interviews. When asked about what they were trying to capture with documentation, the majority of participants mentioned having to prove to insurance companies that they were helping the patient, that they were providing some sort of skilled need, and that they should be reimbursed for their services. P6 noted that “From a reimbursement and medical documentation standpoint, I think we really need to make sure that we’re highlighting the value and skill of our profession, that it’s not just something that anybody can walk in and do” while P7 stated that “I’m documenting for the insurance company to validate my skilled service so that [the patient] can stay and improve and so that they pay the bill”. In a telling quote, P9 described their motivation in supporting patient need for the continuance of therapy through their documentation strategy:

“You’re writing to the insurers pretty much, and you’re trying to let them know that the patient is improving and requires more therapy. That’s why they need to pay more. And I’ve learned to kind of work that in, that if the patient were to be discontinued from therapy, the patient is not near their prior level of function and would require more caregiver assistance or the patient is a high risk of hurting themselves... So I’ve kind of catered to that more just to make sure my focus is towards the insurer.”

5 FINDINGS AND DISCUSSION

The results from our survey and interviews highlight important issues and potential barriers for the successful design and implementation of telehealth rehabilitation systems. Key areas of consideration include the establishment of trust and the maintenance of the therapist-patient relationship, the importance of supporting therapist efficiency and productivity, the powerful role of the caregiver, and the need to provide accurate and detailed proof of care to satisfy institutional and regulatory requirements. The most challenging issue for assistive rehabilitation technologies in home based settings is the absence of the supervising therapist for most of the time/week. Therapists can typically visit patients at home twice a week for approximately 30 minutes per session. Designing assistive technologies that can automatically document patient activities in the home, provide support for patient and caregiver annotation of patient progress, and supply regular summaries of patient progress to the remote supervising therapist could enhance recovery without overly burdening the therapist.

5.1 Maintaining the therapist-patient relationship

The relationship between the therapist and the patient is deeply personal and vital in helping with prolonged patient recovery. The integration of the patient’s goals with the therapist’s recovery plan provides patients with agency in their own recovery process and this personalized approach promotes motivation and the likelihood
of adherence to therapy activities in unsupervised settings. The therapist helps the patient to interpret their own progress and can adapt the therapy protocol based on their assessment of the patient’s personality, likely motivation factors, and their current daily experience.

It is important that telehealth technologies foreground the patient’s goals and their progress towards them in a readily consumable way. Commercial health tracking tools provide consumers with helpful visualizations of their daily activities and reminders throughout the day to encourage activity. Carefully leveraging such approaches with patients with prior experience with such tools could support technology proficient patients in better “owning” their recovery process.

Establishing a productive rapport and a trusting relationship is important to the therapists, meaning that maintaining communication through encouraging feedback or reminders are important features to consider when proposing assistive systems. The therapists place tremendous value on the face-to-face time they spend with their patients and demonstrate ingenuity in preparing formal paperwork prior to visits or completing documentation after a therapy session in order to maximise face time with the patient. There are opportunities here to provide therapists with easily customizable system templates that can be pre-populated with data mined from the EMR based on previous patient sessions. In addition, the use of AI techniques to construct narrative prose from selected checklist features could also assist therapists in maintaining their primary focus on the patient during a billable session.

There are challenges here also in ensuring that the addition of technology support tools do not require time-consuming setups or adjustments during in person therapy sessions or provide inaccurate or confusing feedback when used unsupervised by the patient. Only one of the therapists in our study had (limited) experience with telehealth systems, indicating that training is required, which needs to be integrated into workplace activities, possibly in the form of continuing education credits. Technologies placed in the home also need to be robust and low-maintenance to ensure that the role of technology support does not further burden the therapist.

5.2 Involving the caregiver

Participants explained the role of caregivers as highly valued stakeholders, sharing relationships with both the patient and the therapist. The therapists rely on caregivers to provide information about a patient’s capabilities, to assist the patient with therapeutic and everyday activities in the home, and to encourage and motivate the patient in the absence of the therapist. Participants’ indication of their dependence upon caregivers and the importance of their role implies that assistive technologies that recognize, utilize, and value the role of the caregiver have potential.

Developing systems that include an input and management role for the caregiver as part of a broader partnership between them and the patient/therapist team could also lead to patient progress gains. While currently the caregiver typically relies on paper handouts to describe proscribed activities and instructions, systems that include educational material in the form of indexed and searchable videos could assist caregivers in remembering how best to support the patient. Systems that automatically document patient activity (e.g., wearable sensors) could also reduce the burden on the caregiver in terms of having to document patient activity through structured, standardized forms such as the Motor Activity Log (MAL). Providing digital interfaces where both the patient and the caregiver can annotate data collected or provide video diary functionality to describe daily observations about activity could be helpful both in personally marking patient progress and also informing the therapist about patient activities and their interpretation of them.

However, care needs to be taken here with regards to the level of transparency regarding the sharing of caregiver observations and the potential for causing tensions between the patient and the caregiver. In the examples of therapist/caregiver interactions described earlier in the paper, the communication between the two takes place without the direct knowledge of the patient. Ensuring that the patient/caregiver team is clear and onboard about what data will be collected and how it will be accessed and shared and by whom will be important in maintaining a trusting relationship between all parties.

5.3 Providing proof of care and patient progress

Therapists are clearly under considerable pressure in terms of the productivity expectations placed upon them by their employers and by health insurance companies. The documentation of their activities with their patients can take up valuable minutes in already time-crunched therapy sessions or lead them to use work breaktimes or even their own personal time to complete their documentation activities. There are clear opportunities here to alleviate some of the ethical struggles described by the therapists in our studies with regards to how they can best serve their patients, their institutions, and themselves through the use of their time. As noted above, using data mining techniques to pre-fill documentation templates prior to patient interactions could save time, while the use of common short word phrases and abbreviations for common therapy activities and observations could serve as “data blocks” used to generate prose narratives demonstrating proof of skilled care. Finally, the incorporation of data from home based systems and patient and caregiver annotations could also provide quantitative and qualitative proof of patient need and progress. This comprehensive record can support the therapist in convincing insurance companies about the ongoing needs of their patients and the fiscal requirement to support them, while also demonstrating the efficacy and value of their skilled expertise.

6 CONCLUSION AND FUTURE WORK

Findings from this study provide insights into the experiences of practicing therapists, revealing the complex and highly valued relationship between patients and therapists, the importance of the role of the caregiver as part of the recovery team, and the lived tensions and quandaries that therapists encounter in their daily practice. While our team will use these insights within the context of developing a semi-supervised home based system for physical therapy, we believe that the results are generalizable to diverse telemedicine and telemonitoring contexts, including diabetes, blood pressure, chronic obstructive pulmonary disease (COPD) and depression management.
7 ACKNOWLEDGEMENTS

This material is based upon work supported by the National Science Foundation under Grant No. (2014499).

REFERENCES


Juliet Clark and Aisling Kelliher