

Assistive Video Filters for People with Parkinson's Disease to Remove Tremors and Adjust Voice

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Abstract—COVID ushered in the widespread use of videoconferencing and it's here to stay. In virtual communication, we can alter everything from our appearance, voice and backgrounds. Most of these changes are fun gimmicks, but what if we could leverage these filtering technologies to a life-changing assistive technology? We propose the idea of developing assistive video filters for people with Parkinson's disease (PwP) that will remove involuntary tremors and smooth the stuttering in their voice. We surveyed 177 PwP and 107 people from the general public, and we personally interviewed 52 PwP as well as 3 health care professionals. We find overwhelming statistical evidence that these filters would fulfill a demonstrated communication need for PwP and that the general public also approves of a video filter that could assist with communication for PwP. To test the feasibility of our concept, we developed a filter prototype to remove physical tremors and tested it on two PwP. Although this paper focuses on PwP as a use case, we hope this work encourages others to ethically develop filtering technologies to help individuals with other movement disorders, eye-contact impairment and stuttering in computer-mediated conversations.

Index Terms—assistive technology, video filtering, Parkinson's disease, video conferencing, computer-mediated communication

I. INTRODUCTION

Parkinson's disease (PD)—the fastest growing neurological disability [1]—introduces involuntary tremors in the body and voice and currently has no definitive cure. PD can cause a decrease in quality of life by significantly reducing peoples' mobility, independence, and ability to communicate [2]. As the disease affects muscle control, people with Parkinson's (PwP) often experience tremors in their hands, limbs, face or neck as well as stiff, slow, and labored movement [3]. Speech can also be significantly impacted, and PwP may experience stuttering, slurred speech, and slowed, labored speech. In this paper, body and vocal tremors like stuttering are considered concurrently as they can both affect a person's capacity for communication, health and well-being.

For people with Parkinson's, their tremors can affect how they are perceived.

"People see the tremor and they lose confidence...People see the tremor and they think that

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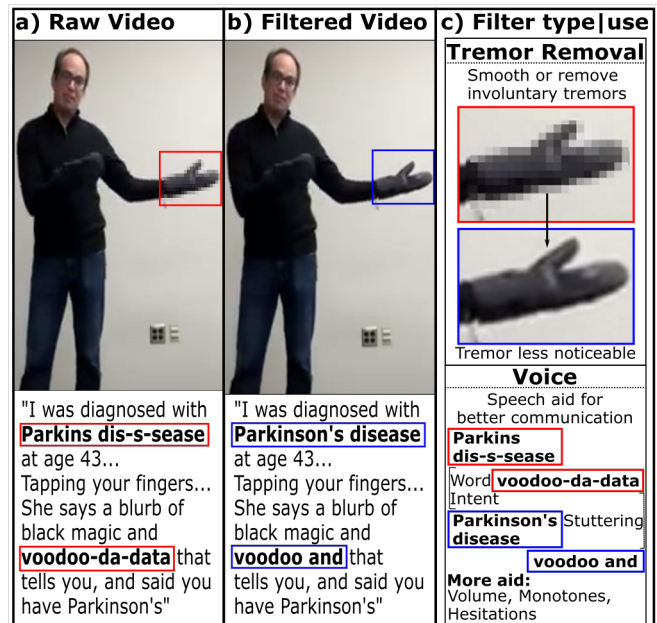


Fig. 1. **Concept Figure.** This paper proposes assistive video filters for People with Parkinson's (PwP) Disease and discusses their implications; (a) Raw video - red boxes denote areas targeted by the filters (b) Filtered video - blue boxes denote the filtered areas. (c) Filter types and usage - Tremor Removal filter and Voice Filter.

this person is not as with-it as somebody else...They think I'm in withdrawal from alcohol, I'm a meth addict, or I have Parkinson's, and with someone who's 40, they don't think Parkinson's."

PwP can be perceived as less credible because, to a lay person, tremors look like shaking or sound like a slurred speech [4]. This lack of understanding can cause pressure on professional and social situations. PwP are aware of the stigma associated with their tremors, which can increase their stress level, in turn affecting their physical health, leading to increased tremors and fatigue [5].

Some stigma stems from a lack of knowledge of Parkinson's disease (PD) [6]. Changing the culture surrounding tremors is a long-term goal, but in this paper, we propose a potential new technology that could help PwP communicate in the near future [7]. As virtual communication becomes more common,

especially from the COVID-19 pandemic, filters are making their way into professional communications [8]. For example, the Zoom “touch up my appearance” filter has become more widely used. Given the prevalence of filter technology, it may be possible to extend it from a fun gimmick to a life-improving application for PwP [9], [10].

When we communicate digitally, constraints on how we present ourselves no longer exist and one could change their appearance entirely [11], [12]. We envision an immediate future where PwP could remove their involuntary tremors and stutters using a filter in computer-mediated conversations. Figure 1 provides a concept diagram of what these filters may accomplish. However, as researchers, we must evaluate whether these changes are necessary and ethical. In this paper, we investigate whether certain filters have a place in our society and whether PwP want this technology to be developed, focusing specifically on filters as potential assistive technology.

We surveyed 177 PwP and 107 people from the general public, as well as personally interviewed 52 PwP to understand the ethical landscape behind developing assistive filters for PwP. Overall, we sought to evaluate whether PwP would want to utilize a video filter of this nature. To provide evidence that tremor removal filters could be created in the near future, we developed a high-fidelity prototype to remove the physical symptoms of tremors through pose-translation based on the existing codebase of the paper “Everybody Dance Now” [13]. We tested the prototype on 2 PwP, one male and one female.

In this study, we found:

- Overwhelming evidence that both the PwP and the general public find utility in developing a video filter that could smooth physical and vocal tremors of PwP.
- The general public reported that the involuntary tremors of the PwP were distracting and caught their attention often.
- PwP fear that others perceive them as less competent because of their tremors.
- Pose-translation is a viable method to remove physical, involuntary tremors of PwP.
- Based on our PwP interviews, these filters could help relieve their mental burdens, convey information more effectively and stay in the workforce longer.

Overall, based on the results of our need-finding investigation, we recommend developing PD filters and prioritizing the development of a voice filter.

II. BACKGROUND

In this section, we investigate stigma, communication barriers for people with chronic illnesses, effects on mental health, and the ethics of using assistive technology to combat these communication barriers. We then examine prior works on applying filters in social media, video-conferencing, and virtual-reality settings (on PwP). Our research suggests that assistive filters can be used to improve the mental health of PwP by helping them communicate better.

A. Stigma and Communication Barriers

Stigma plays a significant role in the lives of people with chronic illnesses and disabilities. Similarly, anticipated stigma from family, friends, coworkers, and healthcare workers results in a lower quality of life due to higher stress levels, lower social support, and lower patient satisfaction [14]. Identity threat – the perception that one is at risk of being treated negatively at work because of chronic illness – is “related to both feelings of psychological strain and (lower levels of) perceived work ability” [15]. The increased stress caused by stigma not only affects the person’s psychology, but their physical health, as “stress is often cited as a contributing factor to autoimmune disease progression and symptom flare-ups” [15]. Coping with this stigma includes deciding whether to disclose their condition and potentially face additional stigma, or try to hide the condition, which could also lead to stress [16]. Stigma can substantially affect how people with chronic illnesses and disabilities communicate because it ostracizes people who are stigmatized and discourages disclosure. Combating stigma is a communication barrier all PwP must face. We hope that these assistive video filters will be able to remove the physical signs of the disease. Without anything to explain, PwP can avoid unwanted stigma should they choose not to disclose.

B. Depression and Parkinson’s

Around 40% of individuals with Parkinson’s are diagnosed with persistent depression [17]. Besides biological factors like prior history of mental illness and PD-induced changes in the brain, psychological factors like social isolation and negative thoughts can contribute significantly to the onset of depression [18]. For example, the interviewees in this study indicated that one of their greatest losses as a result of PD is the degradation of communication (due to tremors in voice and body). These filters would help PwP regain that tragic loss, at least in video call environments. In addition, a technology that reduces the physical signs of tremors in video footage could alleviate anxiety in recorded presentations, helping PwP communicate better to their audience, and this feedback loop could improve their mental health.

C. Ethics of Assistive Technology

When investigating the use of assistive technology in older adults, a study found that assistive technology leads to “increased choice, safety, independence and sense of control, improved quality of life, maintenance of ability to remain at home, the reduced burden placed on caregivers, improved support for people with long-term health conditions, [and] reduced accidents and falls in the home” [19]. While some study participants accepted and used assistive technology, others preferred “retaining an undisturbed home and uninterrupted life”, an opinion that “may be linked to individuals feeling stigmatised by the presence of [assistive technology]” [19]. While assistive technology may lessen the impact of a disability or chronic illness enough to allow a person to work, other factors “such as gender, race/ethnicity, age, socioeconomic status, insurance coverage, education, and previous work experience

can influence how disability is experienced by the individual” [20]. Another ethical consideration of assistive technology is ensuring that information such as the role of the technology, how to obtain it, the cost of it, and who is responsible for that cost is transparently communicated to all users [19].

Ethical and privacy concerns must be carefully addressed when creating and using assistive technology. Privacy and security are not attainable unless the system provides “functionality corresponding to user needs, usability to ensure that the needs can be fulfilled, and reliability to ensure that the system is available” [21]. Additionally, the system must adhere to quality assurance protocols and be free from any security weaknesses. If care settings use assistive technology, they need to have “informed policies and procedures using an ethical framework that is defined by their national legislation on the protection of the rights of citizens” with chronic illnesses [21]. The design of assistive technology can have an impact on how the user is perceived [22]. Specific devices mark their users as having a disability, in part because functional access took priority over how the user would be perceived as a result of the technology [22], [23]. It can be important for assistive technology devices to have a discrete look and feel. However, it is preferable for accessibility to be built into existing and mainstream technologies. This not only increases the number of people who can access the help they need, but it will also increase social acceptability. When a separate technology is necessary, assistive technology should be designed for social acceptance in order for people to feel comfortable using the technology. This new design approach could go “beyond functionality and usability to prioritize the social contexts in which assistive technologies are used, thereby avoiding the creation of designs that mark or stigmatize” [22]. Given that these filters are applied to videos and videoconferencing is widespread, the technology is well suited to uphold high ethical standards. There will be no identifying device to mark the PwP for using the assistive technology ensuring their privacy.

D. Filtering Technology

Although filters in social media (like Snapchat) started with simple color manipulation, they have since developed ways to alter one’s face and voice. A user can look like a baby, appear more masculine, or even turn into a bird with only their eyes and mouth visible. Besides social media sites, the widely used video-conferencing service Zoom has developed a more functional “touch up my appearance” filter in addition to the just-for-fun ones.

To the best of our knowledge, there is no prior research that applied filters directly on videos of PwP. However, a group of researchers created a tremor smoothing virtual reality (VR) environment using an Oculus Rift headset [24]. PwP can engage in everyday tasks wearing the device. The researchers found anecdotal evidence that the decreased appearance of tremors (in the VR environment) led to a decrease in tremors when performing activities like signing forms [24], [25].

While most of the research on PD focuses on diagnosis and treatment, there is a need to develop tools that PwP can harness to improve their daily lives [26]. Although the development of a tremor-smoothing filter would not be a critical advancement in disease detection or treatment, it would, according to reports from PwP, improve their quality of life.

III. METHODS

Our methods consist of targeted surveys, interviews and prototype development. We have included instructions for accessing our data and prototype code in the appendix. We used HIPPA compliant servers when necessary to preserve the privacy of the participants. We surveyed 177 PwP (interviewing 52), surveyed 107 members of the general public, and interviewed one mental health professional and two neurologists. Our interviews were done remotely and video recorded over zoom. We analyzed these videos by conducting inductive thematic analysis [27] on the data collected from the 52 interviews with PwP. Three researchers collaboratively analyzed the data, discussed and resolved the disagreements, and summarized the themes. We also developed a high-fidelity prototype that removes physical tremors for PwP.

A. Surveying People with Parkinson’s Disease

Many PwP are older adults who don’t use filters regularly. Therefore, we prepared a demo video where we applied a simple gender filter and voice-altering filter available on Snapchat. In designing the questions, we were interested in understanding how the participants felt about choosing to apply the filter to videos of themselves versus how they would feel if viewers applied the filter to their videos.

B. Surveying the General Public

We used Amazon Mechanical Turk (AMT) as a crowdsourcing platform to gather the opinions of the general public. We showed Turkers a video clip of a woman with Parkinson’s Disease giving a TED Talk who has a visible tremor in her hands¹. We checked their understanding of the video by having them give a summary. We probed them about how distracting the tremors were, whether this affected their understanding, and how they felt about PwP using a video filter to remove the tremor in videos of themselves. We also asked if they would apply a tremor removal filter to the video of the person with PD to aid their own understanding and if they would perceive PwP as more competent if the tremor was removed.

C. Statistical Analysis

We analyzed the survey data overall and evaluated if there were differences in opinion based on age, race, gender, and education level. For all demographic groups, we split results into two groups (i.e. white/non-white) because splitting our sample size further would mean that each subgroup would be too small to yield meaningful results. Each survey question is on a Likert scale from 1 to 5. To determine whether or not there is a convergence of opinion amongst the respondent

¹<https://www.youtube.com/watch?v=Hs-vPqfs00Q&feature=youtu.be>

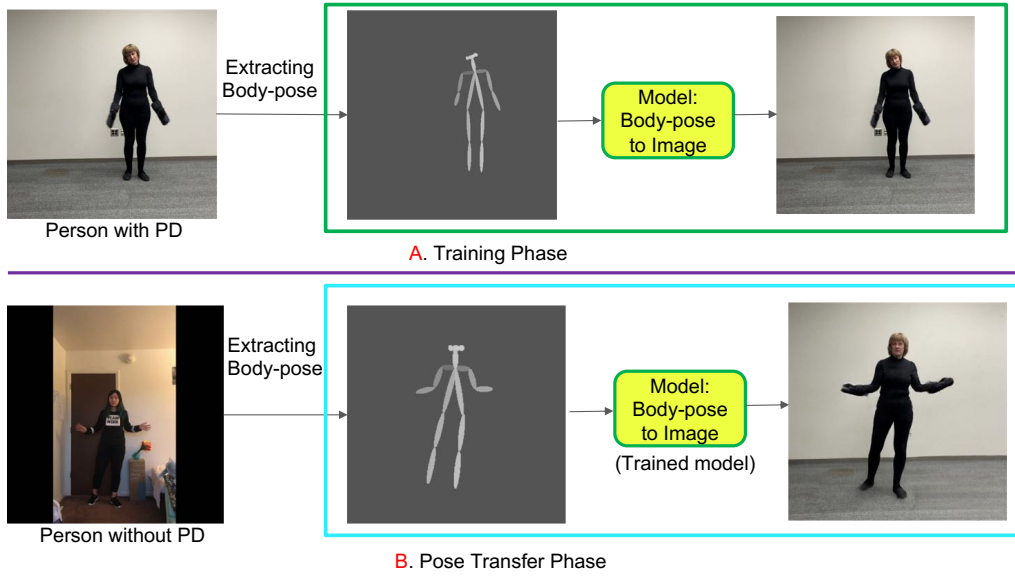


Fig. 2. A. Denotes the training phase where the model learns a personalized mapping of pose to image pixels based off 10 minutes of video. B. Denotes a video of a person without PD moving around. The pose values from B. are fed to the model learned in A. and the corresponding image pixels are sequenced replicating the motion of B.

group (e.g. PwP or general public), we discretize the responses to two values: agree and disagree. E.g., an answer to a survey question with values 4 or 5 is mapped to agree while a 1 or 2 is mapped to disagree. For the two-proportion z-test, we discard the responses for people who gave a choice of 3 (neutral) because we cannot effectively group neutral responses with the agree or disagree populations. However, we did capture the nuances of these neutral responses in the Mann-Whitney U tests. To determine if there was a convergence of opinion, we employ a proportions z-test and assume there is no difference in opinion (e.g. the number of respondents who agree is equal to the number of respondents who disagree), and reject if the p-value is significant. If it turns out that the p-value is not significant, then we divide the respondent group into subgroups based on the above demographic conditions to see if there exists a difference of opinion amongst the subgroups. We evaluate whether the difference in responses from these subgroups is statistically different using a Mann-Whitney U test.

D. High Fidelity Prototype

We developed a prototype for tremor removal to test the feasibility of our video filter concept. Figure 2 outlines how we built this prototype. We translated the pose of a person without Parkinson’s disease onto a PwP to remove the appearance of the tremor. This works because, in our case, a sequence of pose values is the motion of a person without the disease and does not have a tremor.

IV. RESULTS

A. PwP Surveys

1) *PwP Survey General Findings:* When analyzing the survey responses from the 177 PwP, we found that 71% would

like to have the option to remove their tremors in videos ($p < 0.01$) and 71% would like for viewers to have the option to remove their tremors in videos ($p < 0.01$). 66% of PwP also reported that they feel that their tremors cause others to perceive them as less competent ($p < 0.01$). However, only 52% of PwP think that their tremors affect their level of confidence. Table I shows these results.

TABLE I
RESPONSES FROM PwP ON THE TREMOR REMOVAL FILTER SURVEY. PARTICIPANTS RESPONDED ON A 5-POINT LIKERT SCALE. RESPONSES WERE CONVERTED INTO TWO CATEGORIES – AGREE AND DISAGREE. NEUTRAL RESPONSES WERE DISCARDED. A POPULATION Z-SCORE TEST WAS PERFORMED AND THE SIGNIFICANT RESPONSES ARE MARKED BY * WHEN $p < 0.05$ AND ** WHEN $p < 0.01$.

Questions	Agree
I would like to have the option to remove tremors from videos of myself.	**71% (76 out of 107)
I would like for viewers to have the option to remove tremors from a video of myself.	**71.2% (79 out of 111)
I feel like my tremors cause others to perceive me as less competent.	**66.7% (90 out of 135)
My tremors affect my level of confidence.	52.6% (71 out of 135)

2) *Comparison Among Subgroups:* We found that PwP that use video calling/posting in higher frequency wish to have the option to remove tremors from videos ($\mu = 3.62$) more than PwP who use video platforms less frequently ($\mu = 3.13$) ($p < 0.01$). The high-frequency users would also like to give the viewer the option to remove the tremors ($\mu = 3.57$) at a higher rate than low-frequency users ($\mu = 3.15$) ($p < 0.01$). Table II shows these results. We did not find any other statistically significant differences based on our subgroups.

TABLE II
COMPARING STRENGTH OF OPINION OF PwP FOR SUBGROUPS
DISTINGUISHED BY VIDEO CALL FREQUENCY. THE VALUES IN THE TABLE
ARE THE AVERAGES FROM THE (1-5) LIKERT SCALE. ONLY THE
SIGNIFICANT RESPONSES ARE SHOWN DENOTED BY * WHEN $p < 0.05$
AND ** WHEN $p < 0.01$.

Questions	Video Call Frequency High — Low
I would like to have the option to remove tremors from videos of myself	**3.6 — 3.1
I would like for viewers to have the option to remove tremors from a video of myself.	**3.6 — 3.1

B. PwP Interviews

We interviewed 52 PwP and after resolving the disagreements between coders' interpretations, several finalized themes emerged from the analysis. These themes are relieving mental burdens, effectively conveying information, societal messaging concerns, ensuring optional consent, and ensuring optional transparency.

1) *Relieving Mental Burdens*: 23 PwP (44.2%) mentioned that PD symptoms have brought them a series of mental burdens with increased self-consciousness being the most common. One PwP emphasized:

"PD has impacted my life tremendously. Even if now I can do pretty much anything again, I am more self-conscious, withdrawn. I always think people look at me differently."

Another PwP pointed out that her vocal tremors make her anxious as she has to consciously think about her volume and pronunciation. Another mental burden is outright frustration. The progressive development and unpredictability of the physical and vocal tremors make reliably managing PD symptoms very challenging. This frustration makes concentrating on what to say difficult.

We find some evidence that PD filters have the potential to relieve these mental burdens. Our interviews show that 16 (30.8%) PwP think that applying PD filters would enable them to concentrate better, and feel more confident and comfortable while talking. This alleviation of stress could even have positive effects on PwP's physical symptoms according to the experience of one PwP:

"My symptoms absolutely increase when I am more nervous or self-conscious. So using the filter could actually have a physical impact."

2) *Effectively Conveying Information*: Almost all PwP that we interviewed, 48 out of 52 (92.3%), expressed a desire to apply the filters in situations when effectively conveying information is essential. One PwP mentioned:

"I never want to hide my tremor from someone who doesn't know I have them, but I don't want them to be focusing on my tremor or my voice, not to hear what I'm saying."

Using the video filters would absolutely enhance communication as the physical and vocal tremors are either smoothed out or removed entirely.

3) *Societal Messaging Concerns*: Eight (15.4%) individuals expressed concern that building these proposed filters might imply that PD symptoms are shameful and need to be covered up cosmetically. This would be sending the wrong message to society. However, one PwP proposed an interesting idea which could be used for educational purposes and help to correct the stigma surrounding PD:

"Use it as an educational tool. Create tremors on people and make them more aware of what it is like to have PD."

4) *Ensuring Optional Consent*: We identified a broad spectrum of PwP preferences on the amount of control they would like to have over the PD filtering consent process. 14 (26.9%) PwP have no concerns about when and how others apply such filters on their videos, as long as the goal is to make the communication more effective. However, 31 (59.6%) PwP want more control over how the filters are applied and would like to be asked for consent when someone else uses the filter. Some reasons mentioned by the interviewees include being concerned about others misusing the filters by impersonating their voice or videos and mocking them. Five individuals (9.6%) would neither apply filters on others nor let anyone apply the filters on themselves.

5) *Ensuring Optional Transparency*: One of the chief ethical concerns gleaned from the 52 PwP interviews was the fundamental risk of dishonesty. 21 (40.4%) PwP noted the trade off of the PD filters being an assistive technology to aid communication versus portraying yourself falsely by altering a person's real video & voice.

6) *Sub-themes*: Under "effectively conveying information", we identified the sub-theme that 15 (28.8%) PwP would want to use it in professional settings to leave a better first impression. For "societal messaging concerns", one sub-theme we found is that four (7.7%) PwP may find the filters unhelpful because they are cosmetic and potentially offensive in certain context.

C. General Public Surveys

1) *Overall Findings*: As shown in Table III, 95.1% of respondents understood the content of the video they were shown ($p < 0.01$) and 97% perceived the speaker as competent ($p < 0.01$). However, 81% of respondents said they were looking at the tremors frequently ($p < 0.01$) and 66% found the tremors distracting ($p < 0.05$). 83.1% of respondents supported giving PwP the option to remove their tremors from videos of themselves ($p < 0.01$). The responses displayed in the agree tables were collected on a 5-point Likert scale, tailored to the question for comprehension purposes, and then condensed into agree-disagree for analysis. Table III shows these results.

2) *Comparison Among Subgroups*: There were no statistically significant differences in responses based on gender, race, or age. However, there were significant differences between education levels. We investigated the differences in opinion between different levels of education because previous findings have indicated that people with a college degree tend to be

TABLE III

RESPONSES FROM THE GENERAL PUBLIC ON THE TREMOR REMOVAL FILTER SURVEY. PARTICIPANTS RESPONDED ON A 5-POINT LIKERT SCALE. RESPONSES WERE CONVERTED IN TWO CATEGORIES – AGREE AND DISAGREE. NEUTRAL RESPONSES WERE DISCARDED. A POPULATION Z-SCORE TEST WAS PERFORMED AND THE SIGNIFICANT RESPONSES ARE MARKED BY * WHEN $p < 0.05$ AND ** WHEN $p < 0.01$

Questions	Agree
How often were you looking at the tremors?	**81.8% (63 out of 77)
I found the tremors to be distracting.	*66.2% (45 out of 68)
I understood the content of the video.	**95.1% (97 out of 102)
The speaker should have the option to remove the tremors from the video.	**83.1% (74 out of 89)
I perceive the speaker as competent.	**97% (98 out of 101)
Removing the tremors from the video would help me understand the content better.	50.5% (46 out of 91)
I would like to have the option to remove the tremors from the video.	49.5% (45 out of 91)
The speaker would appear more competent if the tremors were removed from the video.	46.1% (42 out of 91)

more open-minded [28]. People without a college degree found the tremors more distracting ($p < 0.05$), but also perceived the speaker in the video as more competent ($p < 0.05$) than people with a college degree. People with a college degree think that removing the tremors would help them understand the content ($p < 0.01$), and they would like to have the option to remove the tremors more than people without a college degree ($p < 0.05$). Additionally, people with a college degree think that the speaker would appear more competent if the tremors were removed ($p < 0.01$). Overall, it seems that people with a college degree were more in favor of altering the video to remove tremors.

TABLE IV

COMPARING STRENGTH OF OPINION OF SUBGROUPS FOR THE GENERAL PUBLIC DISTINGUISHED BY EDUCATION LEVEL. THE VALUES IN THE TABLE ARE THE AVERAGES FROM THE (1-5) LIKERT SCALE. ONLY THE SIGNIFICANT RESPONSES ARE SHOWN DENOTED BY * WHEN $p < 0.05$ AND ** WHEN $p < 0.01$.

Questions	Education College — No College
I found the tremors to be distracting.	*3.2 — 3.5
Removing the tremor from the video would help me understand the content better.	**3.2 — 2.5
I would like to have the option to remove the tremors from the video.	*3.1 — 2.8
I perceive the speaker as competent.	*4.3 — 4.7
The speaker would appear more competent if the tremors were removed from the video.	**3.3 — 2.1

D. Health Professional Interview

The social worker believes that viewers removing tremors from videos of her patients would have a positive effect on her patient’s mental health, noting that it could especially help people stay in the workforce. She remarks that

“I can see it particularly for people who are trying to remain in the workforce. They would welcome it because they’re trying everything they can to stay for as long as they can because often when they leave their jobs, it’s another big hit to them.”

She also notes that it would help viewers to see her patients without tremors.

E. Neurologists Interviews

Overall, both neurologists interviewed were interested in the PD filters for communication, rather than designing the filters for telemedicine diagnosis. Specifically, they both saw great use in the voice filter,

“How bad their speech helps us assess them, but once that assessment is done and we’re actually trying to communicate, having a voice filter would be helpful.”

They also acknowledged that it could be very useful for many of their patients, especially those still in the workforce mirroring the insights from the social worker. In addressing stigma, one neurologist said

“The best use of this type of filter may be for patients to use personally as some feel social stigma from the presence of tremor.”

F. Prototype

We tested our prototype on two individual’s – one male and one female – and conclude that pose translation can be used for the tremor removal task of videos of PwP. The male participant shared his view on the output of the filter:

“I think the prototype is extremely well done and would be very useful to people with tremor, dystonia, bradykinesia or other awkward movements. I have Parkinson’s Disease and would absolutely use a filter like this, so that the subject of my communication is the focus not the presentation (just as I use a touch up filter now for Zoom calls). I would use it in video-conference calls and for social media as well. I think it has great potential.”

The female participant shared her opinion as well:

“I feel like you were giving the person with PD movement that she doesn’t really have. On the positive, the motions and manners of the person with Parkinson’s are exceptionally well captured by the person without PD. If you took the PD person as the before and the other person as after, then I think you’ve got it captured.”

Although we would have liked to show the filtered videos to viewers apart from the two test individuals, we could not because of the sensitive health information involved and lack of consent from the PwP participants.

V. DISCUSSION

A. Recommendations for Developing the Filter

1) *Development of Tremor Removal Filter:* Although it could be argued that such a tremor removal filter is not necessary or useful due to the questions that were not statistically significant in table III, the majority of data presented in this paper demonstrates a strong desire for such a filter. Given that the general public pays attention to the tremors of a person with PD, often finds the tremors distracting, and believes the PwP should have the option to remove the tremors highlights public support of filter development. Also, we found that PwP

feel that their tremors cause others to perceive them as less competent and would like to have the option of removing their tremors. Lastly, an overwhelming majority of PwP personal interviews (48 of 52; 92.3%) think that the filters could aid in communication and 26.9% specifically saw a use for it in professional settings.

Altogether, we strongly believe that people with health conditions should be able to access the tools they need to advance their careers and social life [29]. While the perception of PwP being less competent is misinformed, it does exist. While these tremor removal filters only offer a temporary solution to the stigma that PwP face in video environments, they could also offer some needed relief.

2) *Priority of Voice Filter*: 14 (26.9%) of the interviewees indicated a stronger desire for a voice filter over a tremor removal filter. Undoubtedly, a voice filter would revive a critical loss of Parkinson's: the ability to communicate effectively. It could be used in professional settings, support groups, meetings with families or friends, or even, poignantly, in recorded last messages to loved ones, as was pointed out by two participants.

Another major benefit of a voice filter is its applicability beyond PwP. Although those we interviewed see a direct utility for PwP, there are many communities that could benefit from a filter that raises their volume and smooths stuttering [30]. For example, people with other movement disorders, speech disorders, or anyone who felt the filter could improve their communication would be well served by this technology.

3) *Security Concerns*: During the interviews, many users mentioned that they do not want to be shown doing or saying anything that they did not truly do or say. They were concerned that the filters might operate like deep fake technology, and that their likeness could be used negatively. Thus, the filters would need to be developed with a secure encryption scheme to ensure that a person's body-mapping cannot be obtained and manipulated. Or, another method of filtering technology should be pursued rather than one that requires the collection of such sensitive information.

4) *Disclosure and Decision Rights*: In the survey, although a statistically significant proportion of PwP reported that they want the viewer to have the option to apply the filter to their videos, 31 (59.6%) PwP in the interviews said that they would like to be in control of whether the filter is used on them. Therefore, the developers of this technology should add an optional consent component where the PwP gives their permission for the filter to be applied on their video/audio. This consent process could be enacted by having a request sent by the person who wishes to apply the filter on the PwP or other persons. The PwP could then choose to accept their request or not to ensure consent. In addition, every user of a video conferencing platform could have an option in their settings where they could disable this procedure if obtaining consent is not important to them. A PwP using the video filters on themselves to enhance their communication need not disclose this filter usage if they desire to keep that information private. However, nothing is stopping that individual from

informing their audience if ensuring transparency is important to them as brought up by some of our PwP interviews.

B. Limitations

The high-fidelity prototype that we developed uses pose-translation to map the movement of a participant without PD onto the body of a PwP. This is different from strictly removing the tremor from the PwP's video. To simplify the process of rapid development of the prototype, we also use mittens and tight black clothing to reduce the complexity of the modeling.

We used AMT as a representation of the general public and note that it is not a truly random sample because Turkers overrepresent demographics such as those familiar with technology. We also did not interview anyone from this general public sample and thus, were not able to gather in-depth qualitative data about their opinions on the filter technology.

C. Future Work

As voice filters were very positively received by PwP during the interviews, our next step would be to develop a voice filter prototype to assist with low volume, stutters, and prolonged hesitations for PwP. Developing the voice filter will require approximating the threshold for a long pause, detecting the correct sets of words from the PwP's speech, and uttering those words in a voice very similar to the PwP.

VI. CONCLUSION

In this exploratory study, we see strong evidence that we should pursue the development of assistive video filters for PwP and begin building/refining them appropriately. This paper makes clear that the PwP expressed a demonstrated communication need for assistive video and voice filters. The need these filters address will have a positive effect on mental and social well-being for PwP as they regain their ability to communicate in videos, experience less stigma induced anxiety, remain in the workforce longer, and engage in more meaningful social interactions. Overall, this means that these technologies should be developed with iterative ethical evaluations and continual peer review. While the work presented here focused on PD as a use case, it opens up further research on ethical integration of filtering technologies to help individuals experiencing difficulty with eye contact, Tourette's syndrome, and other speech disorders. Perhaps one day, these Computer-mediated communications could help make our conversations more equitable by allowing people to communicate judgement-free using these filters, should they decide to do so.

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REFERENCES

- [1] E. Dorsey, T. Sherer, M. S. Okun, and B. R. Bloem, "The emerging evidence of the parkinson pandemic," *Journal of Parkinson's disease*, vol. 8, no. s1, pp. S3–S8, 2018.
- [2] G. P. D. S. G. S. Committee, "Factors impacting on quality of life in parkinson's disease: results from an international survey," *Movement Disorders*, vol. 17, no. 1, pp. 60–67, 2002.
- [3] J. Opara, W. Broła, M. Leonardi, and B. Błaszczyk, "Quality of life in parkinsons disease," *Journal of medicine and life*, vol. 5, no. 4, p. 375, 2012.
- [4] L. A. Christman and D. H. Branson, "Influence of physical disability and dress of female job applicants on interviewers," *Clothing and Textiles Research Journal*, vol. 8, no. 3, pp. 51–57, 1990.
- [5] M. R. Luborsky, "The cultural adversity of physical disability: Erosion of full adult personhood," *Journal of Aging Studies*, vol. 8, no. 3, pp. 239–253, 1994.
- [6] J. Schuhl, A. Chatard, and É. Lambert, "Reducing stigmatisation of employees with disability: example of a brief intervention in a company," *Le travail humain*, vol. 83, no. 2, pp. 91–114, 2020.
- [7] R. Imrie, "Rethinking the relationships between disability, rehabilitation, and society," *Disability and rehabilitation*, vol. 19, no. 7, pp. 263–271, 1997.
- [8] S. Martikainen, V. Wikström, M. Falcon, and K. Saarikivi, "Collaboration face-to-face and in virtual reality-empathy, social closeness, and task load," in *Conference Companion Publication of the 2019 on Computer Supported Cooperative Work and Social Computing*, 2019, pp. 299–303.
- [9] D. Lupton and W. Seymour, "Technology, selfhood and physical disability," *Social science & medicine*, vol. 50, no. 12, pp. 1851–1862, 2000.
- [10] C. H. Shirazipour, M. B. Evans, N. Caddick, B. Smith, A. B. Aiken, K. A. M. Ginis, and A. E. Latimer-Cheung, "Quality participation experiences in the physical activity domain: Perspectives of veterans with a physical disability," *Psychology of Sport and Exercise*, vol. 29, pp. 40–50, 2017.
- [11] M. A. DeVito, J. Birnholtz, and J. T. Hancock, "Platforms, people, and perception: Using affordances to understand self-presentation on social media," in *Proceedings of the 2017 ACM conference on computer supported cooperative work and social computing*, 2017, pp. 740–754.
- [12] R. Rezapour, P. Ferronato, and J. Diesner, "How do moral values differ in tweets on social movements?" in *Conference Companion Publication of the 2019 on Computer Supported Cooperative Work and Social Computing*, 2019, pp. 347–351.
- [13] C. Chan, S. Ginosar, T. Zhou, and A. A. Efros, "Everybody dance now," in *Proceedings of the IEEE International Conference on Computer Vision*, 2019, pp. 5933–5942.
- [14] V. A. Earnshaw, D. M. Quinn, and C. L. Park, "Anticipated stigma and quality of life among people living with chronic illnesses," *Chronic illness*, vol. 8, no. 2, pp. 79–88, 2012.
- [15] A. K. McGonagle and J. L. Barnes-Farrell, "Chronic illness in the workplace: Stigma, identity threat and strain," *Stress and Health*, vol. 30, no. 4, pp. 310–321, 2014.
- [16] G. Joachim and S. Acorn, "Stigma of visible and invisible chronic conditions," *Journal of advanced nursing*, vol. 32, no. 1, pp. 243–248, 2000.
- [17] J. L. Cummings, "Depression and parkinson's disease: a review," *The American journal of psychiatry*, 1992.
- [18] P. Foundation, "Depression," <https://www.parkinson.org/Understanding-Parkinsons/Symptoms/Non-Movement-Symptoms/Depression>, accessed: January 13, 2021.
- [19] R. Beech and D. Roberts, "Assistive technology and older people," *London: SCIE*, 2008.
- [20] A. M. Jette, "The promise of assistive technology to enhance work participation," 2017.
- [21] S. Martin, J. E. Bengtsson, and R.-M. Dröes, "Assistive technologies and issues relating to privacy, ethics and security," in *Supporting people with dementia using pervasive health technologies*. Springer, 2010, pp. 63–76.
- [22] K. Shinohara and J. O. Wobbrock, "In the shadow of misperception: assistive technology use and social interactions," in *Proceedings of the SIGCHI conference on human factors in computing systems*, 2011, pp. 705–714.
- [23] P. Parette and M. Scherer, "Assistive technology use and stigma," *Education and Training in Developmental Disabilities*, pp. 217–226, 2004.
- [24] J. Cornacchioli, A. Galambos, S. Rentouli, R. Canciello, R. Marongiu, D. Cabrera *et al.*, "Virtual reality tremor reduction in parkinson's disease," *Preprints*, 2020.
- [25] G. Sutton and K. Sykes, "The effect of withdrawal of visual presentation of errors upon the frequency spectrum of tremor in a manual task," *The Journal of Physiology*, vol. 190, no. 2, pp. 281–293, 1967.
- [26] A. J. Espay, P. Bonato, F. B. Nahab, W. Maetzler, J. M. Dean, J. Klucken, B. M. Eskofier, A. Merola, F. Horak, A. E. Lang *et al.*, "Technology in parkinson's disease: challenges and opportunities," *Movement Disorders*, vol. 31, no. 9, pp. 1272–1282, 2016.
- [27] V. Braun and V. Clarke, "Using thematic analysis in psychology," *Qualitative research in psychology*, vol. 3, no. 2, pp. 77–101, 2006.
- [28] N. Denson and N. Bowman, "University diversity and preparation for a global society: The role of diversity in shaping intergroup attitudes and civic outcomes," *Studies in Higher Education*, vol. 38, no. 4, pp. 555–570, 2013.
- [29] J. Johnson, R. W. Black, Y. Chen, and G. R. Hayes, "Older adults with dementia in an online forum: A preliminary analysis," in *Conference Companion Publication of the 2019 on Computer Supported Cooperative Work and Social Computing*, 2019, pp. 231–235.
- [30] T. Irino, S. Higashiyama, and H. Yoshigi, "Speech clarity improvement by vocal self-training using a hearing impairment simulator and its correlation with an auditory modulation index."

APPENDIX

To access the survey questions used for people with Parkinson's disease (PwP), the general public, mental health professionals and neurologists specializing in movement disorders, as well as the transcripts from the PwP qualitative interviews, and code for the prototype, please email khaut@u.rochester.edu for the link. Thank you.