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Research Article

Perspectives and recommendations of individuals with tetraplegia regarding wearable cameras for monitoring hand function at home: Insights from a community-based study

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Context: Wearable cameras have great potential for producing novel outcome measures of upper limb (UL) function and guiding care in individuals with cervical spinal cord injury (cSCI) living in the community. However, little is known about the perspectives of individuals with cSCI on the potential adoption of this technology.

Objective: To analyze feedback from individuals with cSCI regarding the use of wearable cameras to record daily activities at home, in order to define guidelines for improving the design of this technology and fostering its implementation to optimize UL rehabilitation.

Design: Mixed-methods study.

Participants: Thirteen adults with cSCI C3-C8 AIS A-D impairment.

Measures: Interview including survey and semi-structured questions.

Results: Participants felt that this technology can provide naturalistic information regarding hand use to clinicians and researchers, which in turn can lead to better assessments of UL function and optimized therapies. Participants described the technology as easy-to-use but often reported discomfort that prevented them from conducting long recordings of fully natural activities. Privacy concerns included the possibility to capture household members and personal information displayed on objects (e.g. smartphones).

Conclusion: We provide the first set of guidelines to help researchers and therapists understand which steps need to be taken to translate wearable cameras into outpatient care and community-based research for UL rehabilitation. These guidelines include miniaturized and easy-to-wear cameras, as well as multiple measures for preventing privacy concerns such as avoiding public spaces and providing control over the recordings (e.g. start and stop the recordings at any time, keep or delete a recording).

Keywords: Egocentric vision, Wearable cameras, Qualitative research, Tetraplegia, Home monitoring, Upper limb rehabilitation, Hand function, Spinal cord injury

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Introduction

Cervical spinal cord injury (cSCI) causes paralysis of the upper limbs, trunk and lower limbs, and varying degrees of autonomic dysfunction which significantly reduce an individual's quality of life and community participation.^{1,2} Regaining functional use of the upper limbs (ULs) is the top recovery priority for most individuals with cSCI,^{3,4} as this would allow them to be independent with their activities of daily living (ADLs) and instrumental ADLs (iADLs).⁵

Several challenges prevent the optimal recovery of UL function. Due to healthcare system pressures, patients are often discharged from inpatient rehabilitation to home prior to attaining optimal neurological and functional ability.⁶⁻⁸ As well, improvements in UL motor functions observed in the clinic have been shown not to necessarily translate into an increased functional use of ULs during ADLs.⁹ It would therefore be highly beneficial if UL condition could be monitored in the community to better understand how people with cSCI perform their day-to-day tasks in the home. This information could lead to the development of optimal rehabilitation strategies through personalized insights into the challenges encountered in the home and the strategies used to address them. Unfortunately, the distances between patient homes and rehabilitation centers,¹⁰ which are often distant from one another, constitute an additional barrier to tracking the UL recovery in the home environment. A possible solution is to capitalize on the increased interest in technologies for monitoring function in the home environment when distances are too great and/or access to outpatient services is limited.¹¹⁻¹³

Wearable devices have been used to describe activity or produce outcomes reflecting UL function during ADLs and iADLs in individuals with SCI and post-stroke.¹⁴⁻¹⁹ Several authors proposed the use of accelerometers or inertial measurement units which are comfortable and can be used for several hours in free-living conditions.^{14,16,19} Although advantageous for studying global kinematics of ULs, these devices fail to provide detailed information regarding hand and finger movements, as well as the context of functional use of the hands. Technologies such as sensorized gloves,¹⁸ which capture hand movements in greater detail, may instead be cumbersome and inconvenient for people whose hand function and sensation are impaired.

To fill the above gaps, wearable cameras (i.e. cameras mounted on the head) have been used to capture the functional use of the hands during ADLs and iADLs

in people with cSCI.²⁰⁻²³ A salient feature of the first-person vision paradigm (a.k.a. egocentric vision) is that the camera movements are driven by the user's attention, which results in video recordings focused on the hands and manipulated objects.^{20,24} Moreover, the possibility to obtain rich observational data of functional use of the hands is another advantage for implementing this technology in clinical decision making.²⁵

Recent work demonstrated the ability of computer vision to track the user's hands,²² detect functional hand-object interactions,^{23,26,27} and identify the presence of tenodesis grasp.²¹ These approaches constitute the basis for producing new strategies to monitor rehabilitation progress in people with cSCI living in the community and reporting novel outcome measures of UL function.²³

Although wearable video-based technology yielded promising results in the context of UL rehabilitation, we still have sparse information about its acceptability among individuals with cSCI, as well as feedback and concerns regarding its potential adoption during daily life. These aspects are of critical importance for integrating novel technologies into everyday life, especially in this case, where privacy concerns may arise from recording video at home.^{28,29} A previous study, in which video recordings were conducted in a home simulation laboratory following standardized protocols,³⁰ collected views of individuals with cSCI on the use of wearable cameras for monitoring UL function and reported concerns related to privacy and comfort. Regardless, the participants strongly believed that this technology could provide useful information for clinical and research applications. However, those video recordings were not subject to the challenges of the built environment, family members, or caregivers in the environment.³⁰

Given the potential contributions of wearable technology for optimizing UL rehabilitation in cSCI, there is a need to further explore its applicability in naturalistic settings. To date, information about the experiences of individuals with cSCI using wearable cameras at home has been limited to a pilot study of three individuals.³¹ Thus, our aim was to obtain feedback from individuals with cSCI who used wearable cameras in their homes to record unscripted activities, and to extrapolate key findings into a set of guidelines for improving how this technology can be designed and implemented to optimize UL rehabilitation. These guidelines are intended for clinicians working in outpatient SCI clinics and researchers developing wearable technologies for monitoring UL function remotely.

Table 1 Inclusion and exclusion criteria for this study.

Inclusion criteria	Age between 18 and 65 years Neurological level of injury between C3 and C8 AIS grade: A-D Traumatic or non-traumatic injury Unilateral UEMS between 10 and 23 for at least one limb Access to a caregiver that can help with donning and doffing of the camera system (only if participant requires help) Able to turn off the camera on their own, using the tablet provided Feasible to obtain informed consent from any other individuals who will unavoidably be captured in the videos
Exclusion criteria	Presence of other neuromusculoskeletal disease affecting upper limb movements Deformity of the upper limb joints Pain when moving the upper limbs

Materials and methods

Participants

Inclusion criteria are reported in Table 1. Eligible participants were contacted over the phone based on the research volunteer pool information provided by the centralized recruitment department at UHN – Toronto Rehabilitation Institute. Individuals interested in participating in this study were invited to the rehabilitation center for a first meeting where they were assessed using the Spinal Cord Independence Measure III (SCIM)³² and the Graded Redefined Assessment of Strength, Sensibility and Prehension (GRASSP).³³ The International Standards for Neurological Classification of SCI (ISNCSCI)³⁴ were extracted from clinical charts when available or self-reported. Thirteen individuals with cSCI were recruited. A summary of clinical and demographic information is reported in Table 2. The study was approved by the Research Ethics Boards at the UHN – Toronto Rehabilitation Institute. All participants signed informed consent according to the requirements of the Declaration of Helsinki. Any household members or caregivers who appeared in the videos also provided signed informed consent.

Study design

A detailed description of the acquisition protocol is described in Tsai *et al.*³⁵ Briefly, participants agreed to record their normal daily routine at home using a head-mounted camera (GoPro® Hero5 Black). Specifically, they were asked to record three videos of approximately 1.5 h each, over a two-week period, that would include them performing ADLs or iADLs that involved the use of hands. The content of the recordings was chosen collaboratively between the participants and researchers.³⁵ Participants were also trained to use a tablet (ASUS® ZenPad™ 8" 16GB) with pre-installed GoPro® application, which allowed them to start and stop the recordings at any time, make sure their hands were visible, and review and edit the recordings before returning the equipment. Examples of activities collected in this study included: feeding, brushing teeth, washing hands, doing the laundry, cleaning, and preparing meals.

Upon returning the equipment, participants were interviewed using a survey and semi-structured questions. The interview outline was designed to explore participants’ opinions about privacy considerations

Table 2 Demographic and clinical information of the participants (UEMS = Upper Extremity Motor Score; T/NT: Traumatic/Non-Traumatic).

Participant	Age (years)	Sex	AIS grade	Type of injury	Months since injury	Injury level	Bilateral UEMS
1	46	M	B	T	57	C5	14
2	61	M	D	T	60	C4*	48
3	54	M	D	T	53	C4*	42
4	44	M	D	T	25	C5*	48
5	63	M	D	NT	51	C4*	43
6	47	M	D	T	88	C8	46
7	63	M	D	T	18	C5	28
8	63	M	A	T	91	C4	30
9	61	M	C	T	13	C3	39
10	49	M	C	T	240	C5*	17
11	63	M	D	T	13	C5	48
12	54	M	C	T	31	C3	28
13	62	F	D	T	38	C4	37
Mean ± SD	56.2 ± 7.4	–	–	–	59.8 ± 59.9	–	36.1 ± 11.8

*Self-reported.

and concerns surrounding the use of wearable cameras in the home, the perceptions of usefulness of this approach, and usability aspects related to wearing an egocentric camera during ADLs and iADLs.

Interview guide and data collection

The interview outline is shown in the Appendix. The survey was composed of 17 statements to which participants responded by indicating the level of agreement on a five-point Likert scale (1-strongly disagree, 2-disagree, 3-neutral, 4-agree, and 5-strongly agree). The statements explored different aspects regarding the use of wearable cameras for monitoring UL function at home, for example: concerns about the use of recorded videos by clinicians and researchers (statements 1-4); comfort wearing a first-person camera at home or in public (statements 5-6); usefulness of letting researchers and clinicians access video data (statements 7-9); importance and difficulties of collecting and reviewing the videos (statements 10-13); interference with routine and household members (statements 14-15); and intended use of the technology if prescribed by doctors or therapists (statements 16-17).

The semi-structured questions were designed based on the Consolidated Framework for Implementation Research (CFIR).³⁶ This framework identifies factors that might influence the successful implementation of an intervention and allows us to interpret how the systematic uptake of research can be implemented into daily practice to improve quality and effectiveness of health services. Details elicited by the questions were in line with four main categories of the CFIR: outer settings – patient needs and resources (question 1); intervention characteristics (question 2); characteristics of individuals – knowledge and beliefs about the intervention (questions 3 and 4); and process (question 5). A sixth question was included to gather feedback not covered by the previous ones. Probes were used to explore the items into greater detail and to verify the interviewer's understanding of the collected information. Each interview lasted approximately 30 min and was conducted in person at the participant's home by the team member who trained the participants to use the technology (AB, whose background is in biomedical engineering). All interviews were audio-recorded and transcribed verbatim.

Data analysis

Mixed-methods analysis³⁷ was chosen to obtain a quantitative understanding of participants' perceptions of using the wearable camera and to depict their overall satisfaction with the experience. Qualitative interviews were used to better elucidate the survey responses as

well as to gain an in-depth understanding of the full experience. From this analysis we extrapolated key findings into a set of guidelines for improving how this technology can be designed and implemented to optimize UL rehabilitation.

Two members of the research team (AB, SLH) conducted a qualitative content analysis^{38,39} of the transcripts to identify the major themes of the interviews. First, the researchers independently read three transcripts to obtain an overview of the data and identify emerging and recurrent aspects pertaining the study.³⁹ Afterwards, these transcripts were thoroughly reviewed, sections of interest within the text were highlighted, and descriptive code was assigned to them. The two coders met to identify an initial coding framework, which was then used to independently code another three transcripts. Subsequent meetings and coding exercises produced a final version of the coding framework after three iterations. The final coding framework was re-applied to all the transcripts. Agreement between the two coders was consistently high and discrepancies were easily resolved. Themes were identified as a recurring category or connection made between the categories.³⁸ Investigator triangulation was used at each stage of the analysis process to ensure the trustworthiness of the data.³⁹

Results

Survey results

Summaries of the survey results are reported in Figs 1–6. Most of the participants (61.5–69.3%) expressed little concern about having data of their daily life used by clinicians and researchers for monitoring hand function, regardless of the type of information being accessed (i.e. raw videos or summary measures of hand function, Fig. 1). Moreover, participants would be more comfortable wearing a first-person camera at home than in public (Fig. 2).

All participants agreed that it would be useful to let researchers and clinicians access information regarding hand use at home. However, participants reported lower agreement when asked if they would find it useful to access this information (Fig. 3).

Regarding the importance and difficulties of collecting and reviewing videos, 69.3% of participants considered this technology easy-to-use (statement 10, Fig. 4). The percentage of disagreement and neutral responses was higher when participants were asked if it was easy or important to review the videos before sharing them with researchers (statements 11 and 13, Fig. 4). Instead, all participants agreed that it was important to start and stop the recordings at any time (statement 12, Fig. 4).

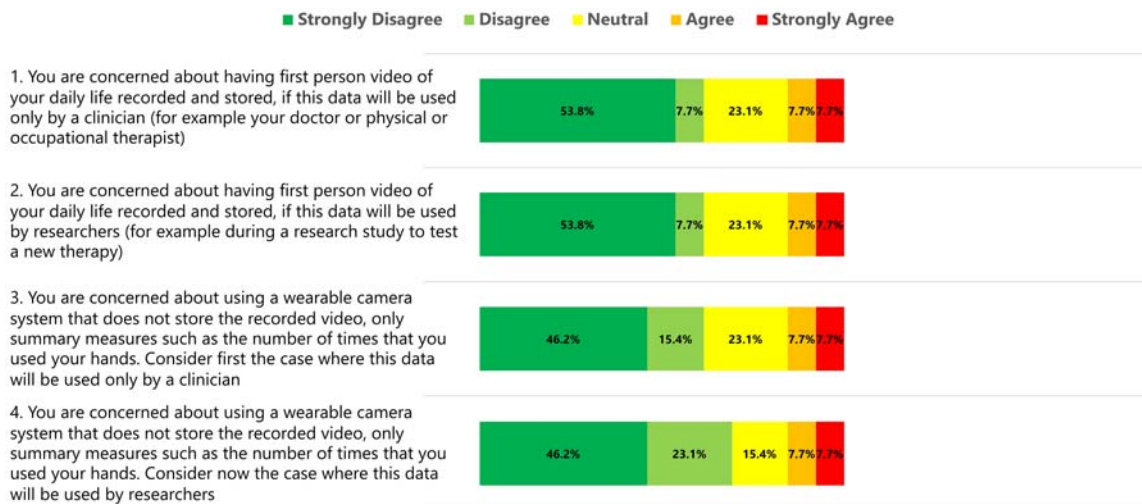


Figure 1 Distribution of responses to statements 1 to 4 (concerns about the use of recorded videos by clinicians and researchers).

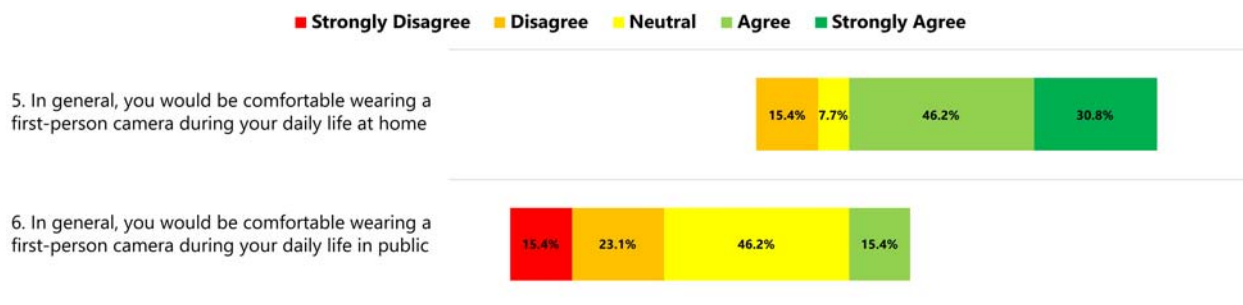


Figure 2 Distribution of responses to statements 5 and 6 (comfort wearing a first-person camera at home and in public).

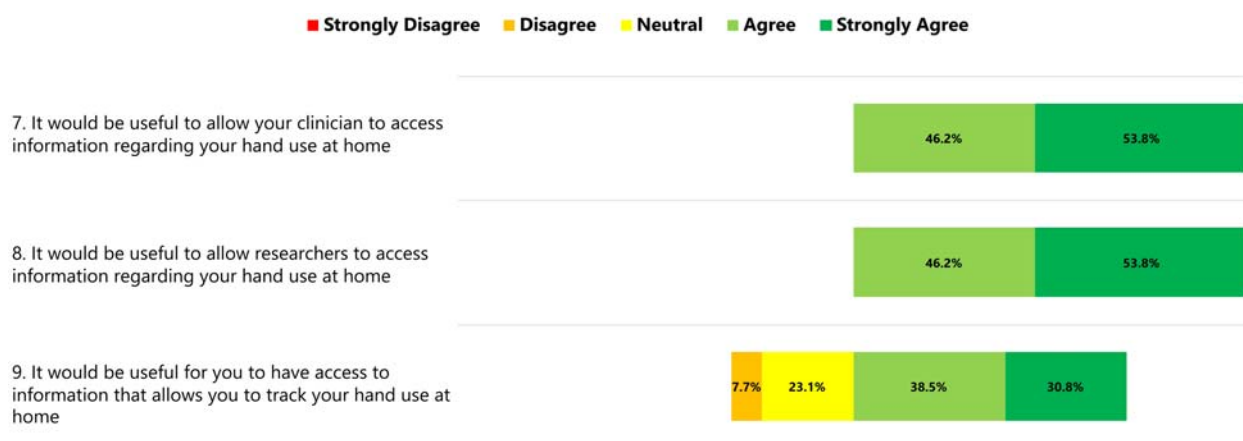


Figure 3 Distribution of responses to statements 7 to 9 (usefulness of letting researchers and clinicians access video data).

Conflicting responses were obtained when exploring the interference of technology with routine (statements 14, Fig. 5). In fact, 53.8% of participants felt that collecting videos interfered with their routine, whereas the rest of them either disagreed or gave neutral response. Most of participants (61.6%) expressed

concern for the presence of household members in the video (statements 15, Fig. 5).

Regarding the potential use of the technology if prescribed by a doctor or therapist, there was an overall agreement by the participants that they would use this technology if it were prescribed for recording

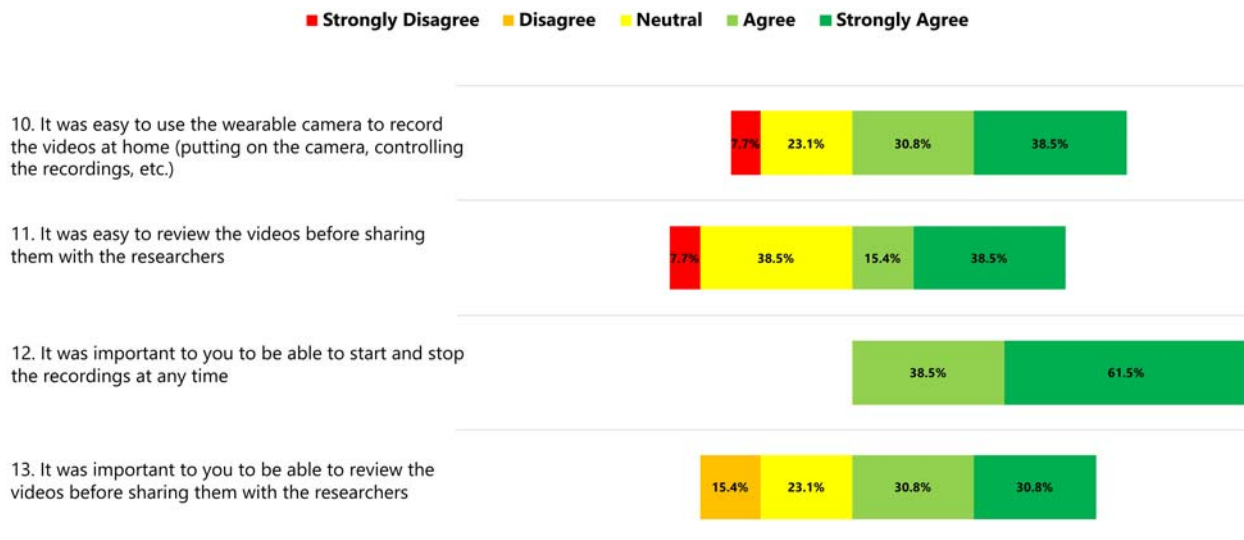


Figure 4 Distribution of responses to statements 10 to 13 (importance and difficulties of collecting and reviewing the videos).

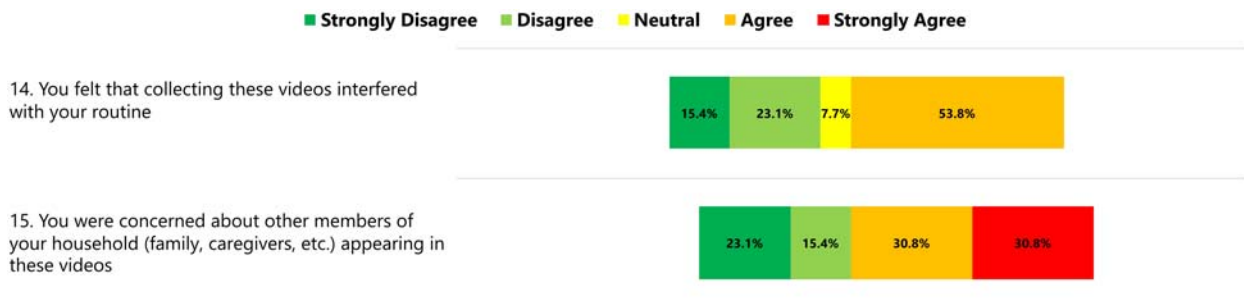


Figure 5 Distribution of responses to statements 14 and 15 (interference with ADLs and household members).

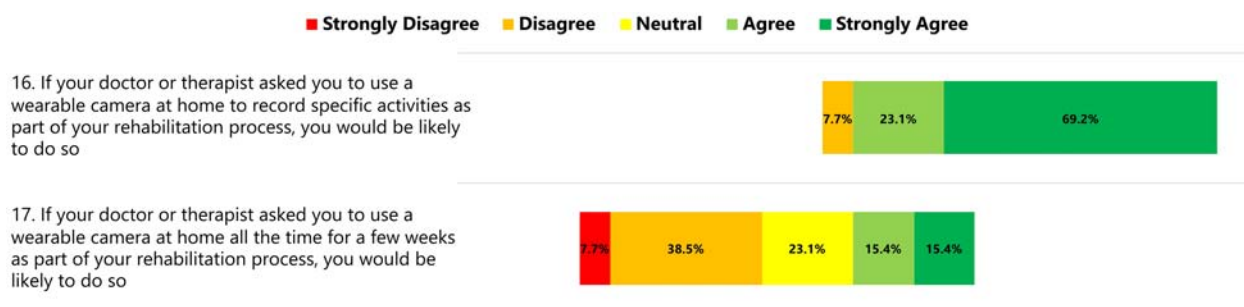


Figure 6 Distribution of responses to statements 16 and 17 (intended use of the technology if prescribed by a doctor or therapist).

specific activities at home. Conversely, participants showed less willingness to use it at home all the time for a few weeks as part of the rehabilitation process (Fig. 6).

Semi-structured interview results

The qualitative analysis of the interviews identified four themes related to the design and use of wearable cameras for capturing functional use of the hands at

home: (1) Comfort and technical aspects (with 3 sub-themes – likes, dislikes, suggestions for improvement); (2) Privacy; (3) Impact on routine; and (4) Added value of the technology. For each theme, selected illustrative quotes are reported in Tables 3–6.

Theme 1 – comfort and technical aspects

This area focused on the practical aspects related to the use of this technology, physical comfort in wearing the

Table 3 Illustrative quotes for Theme 1 – comfort and technical aspects.

- 1 “The camera is ok but, the only problem was how to wear it, because one of my hands is not really working. So, with both my hands working well I don’t think there’s any problems but, my right hand is not really working so I need somebody else to help me to wear it” (ID 9)
- 2 “To me the biggest thing was the camera is too heavy. It wasn’t the size of the camera but, it was the weight. As I said, when you moved your head and you could feel this weight that wants to keep going, you know?” (ID 11)
- 3 “After doing two sessions, then I feel like uncomfortable. It’s too much, like, it’s a little hard in the head. When will the one hour be over? This feeling and, uh, the heaviness of the camera and, um, uncomfortableness. It put pressure on my forehead” (ID 13)
- 4 “Ok. I would say one of the big ones it would be- just because it’s just recording hand functions. I found it really inhibitive the sound on the GoPro, because I was always more conscious of the sound than I was of the video” (ID 10)
- 5 “In terms of head mount it’s very effective in capturing that information but, I think, um, obviously with anything, the less intrusive and easier to wear or the less outwardly visible perhaps” (ID 4)
- 6 “If it was, um, more comfortable to wearable technology like glasses. Something that’s easy to put on and off. Something you could keep on for a long time that was, um, comfortable for long period of times and, um, you could switch on and off very easily” (ID 7)
- 7 “It would be nice if the batteries lasted longer too. Like, if it’s going to be an all-day set up kind of thing, it would be nice if the batteries either lasted longer or, were plugged into the chair or, something” (ID 10)

camera during data collection at home, and consideration on its design. One of the main aspects was the support needed for using the wearable camera. It emerged that participants with poor hand function often needed help from caregivers or household members to don and doff the camera (Table 3, quote 1).

Three sub-themes were identified: (1) Likes (i.e. what did participants like of the technology?); (2) Dislikes (i.e. what did participants not like of the technology?); and (3) Suggestions for improvement. When talking about the positive aspects of the technology, there was almost a complete agreement by participants that the technology was easy to use or that its use got easier over time.

Several participants found the camera uncomfortable for periods longer than 30 min, mostly because of its weight and overheating on the forehead. Other negative aspects were the limited battery life (approximately 1.5–2 h) and the awareness that sound was also being recorded (Table 3, quotes 2–4).

Suggestions for improvement focused on potential strategies to alleviate some of the above issues, such as having lighter and less intrusive cameras that would be easier to don and doff, and that could conduct longer recordings to capture more natural behaviors.

Table 4 Illustrative quotes for Theme 2 – privacy.

- 1 “I think you identified the proper measures. You made sure that you’re not doing personal hygiene or going to the washroom at any time. You identified to make sure anybody else caught in the videos, doing the videos, had the opportunity to sign their release or else you couldn’t use it and as for personal privacy, since you’re in control of what the camera was recording, so you had the opportunity to view and remove anything that you weren’t comfortable with and you shouldn’t have any concerns regarding personal privacy” (ID 2)
- 2 “Well, it’s a little bit of uneasiness because, you know, it’s something that I do that is personal but, since I am not in the picture, I don’t have much concern about it. So, to me it’s ok if, you know it’s just the environment and not myself in the video. Yeah, just concerned about other people, other than me, in the picture, I mean in the video, do not really want to be in it. Like, my wife, she doesn’t like to be in pictures or in videos” (ID 12)
- 3 “I was concerned about capturing someone’s image who did not want to be captured. For example: the postman, the next-door neighbor, um, tenants. So, I had to be careful. I was more cautious of where I was doing the video and I would check around me before I did the video. I didn’t want to capture anything that had any of my personal information. So, I made sure that my computer was off, addresses were covered, just that type of thing” (ID 7)
- 4 “I had to do more conscious to avoid my wife being involved. I also was conscious that things such as your conversations, because it records audio as well. So that might be something that would be a bit of a concern” (ID 11)
- 5 “Yeah, I mean to some extent. I was concerned about a few times, from time to time, about recording. Um, for example, you know, the screenshot of who I was texting in the phone or, if it was for business or, even for conversations that are in the video because I took some video while I was just working, doing what I’m usually doing, but, at the end of the day, you know, I don’t work for the CIA and what I do is pretty straightforward in terms of work so there’s really nothing that I am concerned about, you know, happening in the video” (ID 4)

Table 5 Illustrative quotes for Theme 3 – impact on routine.

- 1 “I didn’t want to leave a lot of dead time on the camera obviously for the research purposes so I kept very active with my hands. A lot of things I did I wouldn’t do back to back as I did on the camera but everything I did was routine that I do in the course of the day. I think I just did a lot of activities, as I said, to show what I do” (ID 3)
- 2 “I didn’t change much. I just made sure that because I wanted to make sure that I had longer videos, I just grouped more activities together that I would normally do anyway. I just group them to closer together. So, it really didn’t change my routine or, anything like that or, anything that I had planned” (ID 10)
- 3 “Well, there was kind of a little bit of planning before we started. Like, what kind of activities I’d be doing so that it shows mostly what I would do during the day and not specifically in the hour and a half of the recording. Sometimes I don’t do all that stuff at the same time. So, a little bit of planning” (ID 12)
- 4 “I didn’t do anything that I wouldn’t normally do. I maybe, sort of, try to make sure that I-Certain things that I would normally do, I probably tried to make sure I did them today, while I was wearing the camera, instead of like, maybe tomorrow or something like that. You know, it’s like, oh yeah I have to fill up an hour and a half” (ID 11)

Table 6 Illustrative quotes for Theme 4 – added value of technology.

- 1 “I think, if I could put a recording of my hand and show them: ‘here my issues this week’ or, ‘here’s what I do, can you further help me?’. There are tasks, for example, for me the simple task of opening a jar, and if a clinician could watch how I go about it perhaps they could help stretch, manipulate or suggest something further because oftentimes it’s difficult to explain. The day-to-day stuff that say at the clinic that day they put in front of you, which is great, but it’s not necessarily the same as you have at home. So, having the camera, this is my daily routine, my in-house function, yeah, for sure” (ID 3)
- 2 “Yeah. I think the biggest single thing is the daily living component. It’s the fact that it’s not as structured as being in a lab setting where somebody is instructed to do a certain activity. You know, because there’s going to be, um, the point of rehab and certainly you know assistance, is to be able to bring a real life, a real life activity, a real life scenario. So, I think there is going to be benefit. I will be able to see, firsthand essentially, um, activities might be more difficult than others, as opposed to just viewing somebody in a lab setting or a hospital setting” (ID 4)
- 3 “The benefit, the benefit of wearing the camera is that you see. It’s a visual, it gives them the chance to see instead of, now we’re talking. It’s still better to get a visual recording so that you can pinpoint the actual problem of the person who is wearing the camera. Like, say raising my hand, bending, doing chores, all that with the visual video. With the video you won’t have any problem distinguishing between the person who is sick, the way he is coping, and the way he is, uh, the progress the person is making” (ID 5)
- 4 “To incentivize or to give reinforcement showing improvement or showing areas to work on before looking at – oh you can twist it this way or that way, now you can or you can know that I can touch all the fingers or that you know have the strength that you didn’t have before or the fine motor skills to pick up that dime on the floor, see how much easier you pick it up” (ID 2)

Extending battery life and avoiding the recording of sounds were also noted (Table 3, quotes 5–7).

Theme 2 – privacy

This theme explored privacy-related issues that may arise from recording videos of daily routine at home. Participants identified several positive aspects that helped prevent privacy concerns and alleviated the worries of collecting video during daily routines at home, for example: the egocentric point of view of the camera, which did not show the user’s face; the possibility to start and stop the recording at any time; and detailed orientation and instructions from the research team (e.g. avoiding or stop recording during certain activities or in public places) (Table 4, quotes 1–2).

Despite these aspects, major privacy concerns emerged from the interviews. The possibility to record other people’s faces, especially if they did not consent to be part of the study, was concerning. Moreover, the possibility to capture objects that carry any sort of personal information (identity documents, phone

Table 7 Guidelines for integration of egocentric cameras into outpatient rehabilitation and research for monitoring UL function of individuals with cSCI.

Requirements	Implemented in the current study
Clear communication around the content to record	Yes (content was selected collaboratively, but participants still reported deviations from typical timing of ADLs or iADLs)
Implementation of smaller and less-intrusive camera*	No
The wearable camera must be easy to wear (e.g. glasses mount rather than elastic headband)	No
Disable audio recordings during data collection	No (audio was recorded but not used in any analyses)
Extend battery life*	No
Automatic pre-processing of videos before sharing them with clinicians and researchers to remove other people’s faces and personal information appearing in the video	No
Record videos at home and avoid any public spaces	Yes
Possibility to control (e.g. start and stop) the recordings via tablet, smartphone, or accessible button	Yes
Review the videos before sharing them with clinicians and researchers	Yes
Implement cues to remind individuals that camera is on (e.g. acoustic or visual cues), especially for smaller cameras	No

*Referred to the characteristics of a GoPro® Hero 5 Black, which was the model used in this study. Battery life was approximately 1.5–2 h at the selected recording configuration (1080p of pixel resolution and 30 frames per second).

numbers, etc.), and recording the audio were flagged as worrisome (Table 4, quotes 2–5).

Theme 3 – impact on routine

This theme focused on how the technology influenced the way activities were conducted at home during the data collection. Although one of the instructions given to participants before data collection was to conduct a normal routine without doing anything out of the ordinary,³⁵ it emerged that participants often planned their activities beforehand or conducted a higher than usual number of activities consecutively to fit the recording schedule (Table 5).

Theme 4 – added value of technology

There was wide consensus among participants on the fact that recording videos while conducting activities at home was the benefit of this technology.

Participants believed that hand use information captured within a natural context would allow clinicians and therapists to improve their understanding of hand function in real world conditions, conduct better assessments, and optimize interventions (Table 6, quotes 1–3). Moreover, the possibility to quantify hand use over time was seen by some participants as another benefit for individuals with cSCI, who could use this technology as an incentive for pursuing hand rehabilitation, by checking their improvements over time (Table 6, quote 4).

Discussion

This mixed-methods study has provided important insights on the acceptability and potential use of wearable cameras to observe UL function in persons with cSCI in their home environments.

Regarding the technology itself, most of the participants felt it was quite easy to use. A salient issue that arose, however, was that participants required assistance to wear the headband, especially those with reduced hand function. This aspect was anticipated by the research team, which provided training (when necessary) to family members and/or caregivers through a preliminary meeting or phone calls.³⁵ Tactile and thermal discomfort often arose after wearing the camera over time. Several participants suggested that smaller and easier-to-wear cameras would improve independence in using the device as well as its usability for longer recordings.

In line with previous studies,^{28–30} privacy arose as a major concern when collecting videos of ADLs and iADLs at home. However, concerns were not primarily related to their own personal privacy, as participants were willing to share videos of themselves for research and clinical purposes. They felt that the collected information could help clinicians conduct better assessments of UL function, thereby optimizing therapies. Participants also felt that the egocentric point of view of the camera and the possibility to control the recordings protected them from personal privacy issues. The major concerns, instead, were directed towards their surrounding environment, such as invading the privacy of household members, capturing objects with personal information (e.g. computer's and smartphone's screens), and recording audio of conversations. These issues can be partially alleviated if recordings are limited to within domestic environments (as suggested by responses to statements 5–6, Fig. 2) and audio is disabled during data collection. More sophisticated pre-processing would be required to alleviate concerns related to other people and personal information, for

example by automatically detecting and blurring faces and specific objects in the video via computer vision algorithms.^{40,41}

In addition to the presence of other people, discomfort in wearing the camera was the main factor that influenced the natural execution of ADLs and iADLs. Several participants felt that collecting videos interfered with their routine (responses to statement 14, Fig. 5). This fact was further accounted by the qualitative interviews where most participants expressed that camera's weight and overheating were constant reminders that a device was on their heads. Moreover, battery constraints pushed participants to plan and concentrate more activities within a restricted amount of time (Table 5). Nevertheless, participants confirmed that activities collected in the video reflected parts of their normal routine, and that planning might have caused only alterations in the timing of these activities rather than the type. We believe that less intrusive and easier to wear cameras, along with longer battery life, will facilitate the recording of natural activities in addition to solve problems related to discomfort.

Although planning might have been a drawback for recording natural behaviors, in some cases it might have helped alleviate some privacy concerns, as participants were aware of what they recorded. As a result, more than 30% of them felt there was no need to review the videos before sharing them with researchers, as indicated by the neutral and negative responses to statements 11 and 13 (Fig. 4). This point raises an interesting fact: smaller and less intrusive cameras might not be the panacea for all problems. While with smaller cameras it will certainly be easier to slip into more naturalistic behaviors, it will also be easier to forget them on while recording, increasing the chances of inadvertent privacy incidents. A trade-off must be found, for example equipping smaller cameras with cues that remind the user about ongoing recordings. However, given the preference of most participants to record shorter chunks, and avoid using the camera all the time as part of the rehabilitation (see prevalence of disagreement to statement 17, Fig. 6), we also believe that freedom in starting and stopping the recordings should be maintained for the user, after agreeing with therapists on which activities require more attention.

In terms of added value of this technology, wide consensus was found on the fact that this technology can provide more naturalistic information regarding hand use to clinicians or researchers, which in turn can lead to better assessments and optimized therapies. Some

participants also felt that this technology could provide direct advantage for patients, as the visualization of the patterns of hand function over time, especially in case of improvements during rehabilitation, can help them feel a sense of achievement to further incentivize rehabilitation participation.

Given the above findings, we have proposed a set of guidelines on how to integrate egocentric cameras into outpatient care and research for monitoring UL function in individuals with cSCI living in the community (see Table 7).

Limitations and future work

The main limitation of this study was the inclusion of only one female participant, which did not allow us to carry out any sex-based analysis. The reduced sample size, the limited age range (44–63 years old), and the prevalence of individuals with AIS grade D were additional limitations. With larger samples it will be interesting to investigate potential relationships between participant's responses, age, level of injury, and AIS grade.

Conclusion

We analyzed feedback from individuals with cSCI who used a wearable camera for recording ADLs and iADLs at home in the context of UL rehabilitation. The perceived potential of the approach was high, and the privacy considerations tractable, supporting earlier findings. Although egocentric vision has great potential for extracting novel outcome measures of UL function, several steps still need to be taken to translate the technology into outpatient care and community-based research. From this study, we provide the first set of guidelines to help researchers understand what these steps are. We are confident that with constant developments in hardware miniaturization and artificial intelligence, it will soon be easy to fulfill the suggested requirements to develop wearable video-based technology for remote monitoring of UL function in people with cSCI living in the community.

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Appendix

INTERVIEW GUIDE FOR PARTICIPANTS WITH SCI

Structured interview questions

How strongly do you agree or disagree with the following statements? [Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree]

1. You are concerned about having first person video of your daily life recorded and stored, if this data will be used only by a clinician (for example your doctor or physical or occupational therapist).
2. You are concerned about having first person video of your daily life recorded and stored, if this data will be used by researchers (for example during a research study to test a new therapy).
3. You are concerned about using a wearable camera system that does not store the recorded video, only summary measures such as the number of times that you used your hands. Consider first the case where this data will be used only by a clinician.
4. You are concerned about using a wearable camera system that does not store the recorded video, only summary measures such as the number of times that you used your hands. Consider now the case where this data will be used by researchers.
5. In general, you would be comfortable wearing a first person camera during your daily life at home.
6. In general, you would be comfortable wearing a first person camera during your daily life in public.
7. It would be useful to allow your clinician to access information regarding your hand use at home.
8. It would be useful to allow researchers to access information regarding your hand use at home.
9. It would be useful for you to have access to information that allows you to track your hand use at home.

10. It was easy to use the wearable camera to record the videos at home (putting on the camera, controlling the recordings, etc.).
 11. It was easy to review the videos before sharing them with the researchers.
 12. It was important to you to be able to start and stop the recordings at any time.
 13. It was important to you to be able to review the videos before sharing them with the researchers.
 14. You felt that collecting these videos interfered with your routine.
 15. You were concerned about other members of your household (family, caregivers, etc.) appearing in these videos.
 16. If your doctor or therapist asked you to use a wearable camera at home to record specific activities as part of your rehabilitation process, you would be likely to do so.
 17. If your doctor or therapist asked you to use a wearable camera at home all the time for a few weeks as part of your rehabilitation process, you would be likely to do so.
3. What were your thoughts about issues of personal privacy while using the wearable camera? PROMPTS: Did wearing the camera change the way you would do things? Were there certain activities that you would use the camera and others where you would not? How did others living with you react/respond to the camera? What concerns, if any, do you have about how the data would be shared and used?
 4. What aspects of using the wearable camera for capturing how you use your hands do you feel could be beneficial for helping clinicians and researchers to better understand what it means to have hand impairment? PROMPTS: Why or how do you think the information collected could be helpful to clinicians? How do you think researchers might be able to use the information? How do you think it might help others with hand impairments? How would you compare it to your experiences with traditional rehabilitation?

Semi-structured interview questions

1. Before starting the study, what were your expectations about wearing a camera and letting researchers and clinicians observe your daily activities? PROMPTS: What did you hope to gain from it, if anything? What concerns, if any, did you have?
2. After participating in this study, what was it like using the wearable camera in your home? PROMPTS: Were your expectations met or did they change? What did you think about the overall design of the system? How easy was it to use? What supports, if any, did you need to use the technology (i.e. putting it on, taking it off, etc.)? Did it get easier over time? What was convenient? What was inconvenient?
5. If there were not limits on money or the technology, what would be the ideal way to use wearable technology to help do assessments of your hand function in your natural environment (i.e. home, work, etc.)? PROMPTS: What kind of supports would you need, if any, to use it? What would the devices look like? How would you like them to be used? Where do you think they would be the most useful for helping clinicians better understand your needs?
6. Is there anything else about your experiences of participating in our wearable camera study that you would like to share but we didn't touch upon?