'I have a feeling I can't speak to anybody': A thematic analysis of communication perspectives in people with Huntington's disease

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ABSTRACT

Objectives

This study explored the perspectives of people affected by Huntington's disease (HD) on their own communicative abilities.

Methods

Qualitative semi-structured interviews were carried out with eight people with early HD. The data were analysed through thematic analysis.

Results

Four themes were constructed from the data, characterised by the following core topics: How HD directs and mediates communication; Regaining control to improve communication; Emotional outflows into communication and the struggle for separation; Sheltering as a way to boost confidence in communication.

Discussion

Separating patients' identity as individuals from that of a person with a disease can help increase communicative control. Consistent with the general theory and model of self-regulation, patients should be allowed a wider range of choices to regain control over communication. Achieving better emotion regulation is of paramount importance for communication, and factors such as medication regimes, relationships and existing coping strategies should be strengthened. Consistent with previous research, feelings of safety and the idea of a safe place ('sheltering') represent an effective coping mechanism. Practical implications include the refinement of communication and relationships among clinicians, caregivers, and patients with HD by considering a wider range of medical, psychological and socio-environmental factors.

Keywords: Huntington's disease, communication, emotion regulation, thematic analysis, patients' perspectives

Introduction

Huntington's disease (HD) is a hereditary chronic neurodegenerative disorder, which affects 10–12 people per 100,000 in the western world.[1] Typical symptoms include involuntary movements (chorea), cognitive deterioration, psychological difficulties, and psychiatric disorders.[2] Since the transmission mechanism is autosomal-dominant, affected individuals have a 50% probability of transmitting it to their children (usual age of onset is 40–50 years). The mean life expectancy after the diagnosis is typically 20 years.[3] Genetic testing is available for individuals at risk, allowing them to know if they carry the disease gene before the onset of symptoms. All individuals with the gene without symptoms ('presymptomatic' people) will develop the disease.

Many cognitive impairments have been reported in people with HD, including problems with all aspects of communication. Communication is understood in this context as a multifaceted discipline that investigates how people create meanings through messages transmitted across various channels, media and contexts,[4] and includes elements of language, speech, as well as emotion and social abilities. Regarding more specific aspects of communication, speech

production is often impaired and starts to deteriorate before comprehension,[5] and the spontaneous initiation of conversations is reduced.[6] Research on nonverbal communication, such as body language and emotional processing, is less frequent in HD, with the exception of emotion recognition.[7] In this respect, studies have indicated that all these components can be affected by the disease.[8] In addition, HD can also negatively affect the ability to comprehend and reflect on the mental states of oneself and others (i.e. theory of mind[9]), which plays a fundamental role in communicative competence, especially through the attribution of intentions.[10]

Nevertheless, the current literature on communication in HD appears to be mainly characterised by quantitative studies focused on the observation of medical and cognitive impairments,[11] with a tendency to prioritise the perspectives of clinicians.[12–14] The investigation of the perspectives of people with HD on their own communication abilities is generally much rarer and only recently has an interest started to emerge in communication as a phenomenon that embraces social skills and interactions, and not just the traditional underpinnings of language and speech.[15] Indeed, even when patients' perspectives on the general impact of the disease have been investigated, data analysis falls more in the quantitative category, with greater focus given to the frequency of reoccurrence of themes rather than a qualitative exploration of patients' narratives themselves.[16] On the other hand, to our knowledge only two studies have so far used a qualitative approach to investigate communication in HD.

Hartelius et al.[17] adopted individual interviews and focus groups to triangulate the information between people with HD, family members and caregivers, finding that a number of social and environmental factors play a relevant role in complicating communication. These included the speed of conversations or having fewer people to talk with, while a positive impact was reported for sensations of safety, having the opportunity to speak for a longer time, and the perception of support and adjustment from the person with whom they were speaking. However, the thematic analysis was characterised by a very descriptive approach, and the interviews did not include any questions on nonverbal aspects of communication. In the second study conducted, Power et al.[18] carried out a single case analysis with a man with advanced-stage HD and also found that supporting social and environmental factors can have a positive impact on communication. However, their approach (content analysis) offered a useful but predominantly descriptive report and did not allow for a more in-depth interpretation of meanings, as well as omitting nonverbal elements of communication such as emotional processing.

Therefore, considering the current gap in the literature, the research question addressed by this study was the exploration of how people affected by HD make sense of their communication experience with others.

Methods

Methodological approach

A qualitative design was adopted, based on semi-structured interviews analysed through thematic analysis (TA). We selected TA for its recognised usefulness within the field of psychology and communication disorders,[19] and its ability to allow for the usage of both deductive (i.e. theory-driven) and inductive (i.e. data-driven) analyses of the themes identified within the interviews.[20]

Sampling

People affected by Huntington's disease were invited via post across the North West of England by the Huntington's Disease Association (HDA). Of the people who expressed their interest, eight participants with symptomatic HD were considered eligible. The inclusion criteria included being aged 18 or more, being able to be interviewed in English and being symptomatic at an early or moderate stage of disease. This limit was due to the difficulties in attending personal interviews that arise in the later stages of HD. As the study focused on the impact of the disease on patients' communicative experiences, we did not include any pre-symptomatic individuals. See Table 1 for the demographic details of the participants.

Table 1. Participants demographic data.

Participant	Gender	Age (yrs)	Diagnosis (yrs)	HD Stage
1	F	53	5	Moderate
2	F	53	7	Early
3	M	53	9	Moderate
4	M	41	5	Moderate
5	F	50	5	Early
6	F	62	5	Early
7	M	57	8	Early
8	F	49	6	Moderate

Procedure

Individual semi-structured interviews were carried out face to face with the participants at a time and place convenient to them (usually their home). We selected this approach to allow the in-depth exploration of relevant themes as well as to ensure that all participants felt comfortable and had all the assistance they might need.[21] The length of the interviews ranged from 40 to 60 min ($M = 45$). A caregiver (e.g. participant's partner) was often present during the interviews, but was asked not to contribute in any way and any comments they made did not form part of the data collection. We structured the interviews according to a framework consisting of four general topics: Verbal Communication, Nonverbal Communication, Mediators of Communication, Contexts of Communication. The topics were based on some of the most common categorisations of communication dimensions[22] and to be as broad and yet comprehensive as possible.

Data analysis

All the interviews were transcribed verbatim and analysed using thematic analysis (TA). The six steps outlined by Braun and Clarke[19] were used as a guide to analysis.

Results

Identified codes and themes

Following familiarisation with the whole dataset, 73 codes were generated. These were then collated to six initial candidate themes. Upon further revision, the final code list was reduced to a total of 36. Out of these, four final themes were identified that were distinctive in their own right, as well as coherent with the broader scheme of the analysis and relevant to the research question. See Table 2 for the final theme list and breakdown into the respective codes.

Table 2. Final list of identified themes and breakdown of relative codes.

Theme	Codes	
'You ever wanna say thing to people, but you can't': How HD directs and mediates communication	Articulation is harderChronic fatigue makes communication harderFear of saying or doing something wrongInterrupting or jumping into a conversationMemory has changedNot into communication anymore	Not understanding what is going onNot willing to go outPublic places are uncomfortableSpeaking is harderThe HD faceWriting is harder
Becoming a director again: Regaining control to improve communication	Being open about HD helps communicationCommunication with familiar people is easierCommunication with more than one person is harderCommunication with strangers is harderGetting used to new people helps communicationListening rather than speaking	New or unexpected things are harderNew technologies can be helpfulNot using the phone anymoreTexting helps communicationPhysical contact and proximity are harderRetiring from work is helpful

Theme	Codes		
'One moment I'm fine, the next moment I'm not': Emotional outflows into communication and the struggle for separation	Acceptance helps with emotionsEmotions have changedFeeling discriminatedFeeling ignored-Feeling lonelyFeeling misunderstood	Having a close family is helpfulHaving relatives or friends around is helpful-Medications help with emotions	
'I go back into my little world': Sheltering as a way to boost confidence in communication	Home is a safe placeMy little bubble	My little world	

'You ever wanna say things to people, but you can't': How HD directs and mediates communication

All the participants agreed that HD plays an important role in their communication with others. In fact, they made sense of their communicative difficulties by seeing HD as the main cause and this expressed itself both directly and indirectly. Directly, the participants saw HD as an external agent that actively blocks their communication:

> I think it is a funny illness, but affects you in different ways. […] you ever wanna say things to people, but you can't. Because it feels there's something wrong, with your illness. […] You want to say things, but you can't! (Participant 3)

The effects of HD can present in many different ways, starting from speech and language. Problems with articulating words, controlling voice speed, or respecting conversational roles were frequently reported and disrupted verbal communication at its core:

> I probably speak fast. And also not loud enough. Sometimes I have to speak twice. I probably do articulate a bit harder. […] I don't use many long words now, where I used to. I used to bullshit to heaven, but now I don't. (Participant 7)

The cause of these difficulties was entirely attributed to HD, which the participants perceived as the external reason they felt and behaved the way they did. In this perspective, HD acts as director of the participants' communication, taking control over their active role in everyday interactions by drastically decreasing their communicative repertoire. As some of them pointed out:

> You don't speak to people… the illness makes you feel that way, even though you're trying to speak to people. (Participant 3)

However, the influence of HD on communication is not confined to its most apparent manifestations, such as articulation impairments. Indeed, many related difficulties such as feelings of constant fatigue, memory problems and attentional drops can indirectly affect the participants' communicative experience. Although not strictly related to the verbal side of communication, these problems ultimately play an important role in participants' everyday life by undermining their ability to interact with people or read situations:

> I like speaking with my son, I just keep… running out of things to say, because I keep forgetting. […] For example we go to my sister's for Christmas, and I was trying get involved but I just feel so stupid because I can't think, my memory is very random […] and it just adds more and more pressures because I start getting agitated with myself. […] It must be to do with HD… […] I don't know what's going on half of the time. (Participant 4)

> The other thing that happens sometimes is that I can't think of a word to say next. (Participant 8)

Therefore, HD not only directly influences participants' communication through its characteristic symptoms, but also subtly mediates it via less apparent yet related conditions that pull the strings of nonverbal interactions and greatly increase the effort involved in simple discourses. Just as for their verbal issues, however, the participants made sense of these mediational effects as an external source of discomfort due entirely to HD. Not surprisingly, the combination of these influences eventually led the participants to develop a reluctant attitude towards communication. This particularly manifested through being quiet or avoiding situations in which communication is required:

> I just can't be bothered, I just bugger off. I got a little scooter, so I just nip off to the quarry. […] I don't really bother that much talking. If it's not the neighbour then I wouldn't bother. Yeah, it's just a bit of an effort. […] I just say hello to acknowledge people. (Participant 1)

Again, it is worth noting how these behaviours were seen by the participants as due to the disease, to the extent of listing them among its stages and symptoms:

> I don't really mean [to speak to people], because one stage of HD you don't intermingle with people, leave them on your own, if you will. I don't know if you know… (Participant 4)

Indeed, one of the participants mentioned being identified with HD by her parents, by having 'the Huntington's face':

> They say… 'you know, you look as you have Huntington's'. I've got the face. The Huntington's face. It's just the expressions that my mum used to do with Huntington's. And they say I look the same. (Participant 6)

Clearly, being identified this way can lead to significant difficulties in communication. From this perspective, the participants' tendency to conceive HD as an external director and mediator may represent one of the causes of the 'fighting' metaphors often used to describe their struggle with symptoms and their consequent attempts to regain control over communication and prevent it from being incorporated into their own identity.

Becoming a director again: Regaining control to improve communication

Of all the effects of HD on participants' communication, the lack of control appeared to be perceived as one of the most substantial and, as mentioned, it manifested in several direct and indirect ways. However, it also seemed to drive the participants' will to develop strategies to reacquire control over communication and become once again the real director of their daily interactions. For instance, all the participants claimed to find using the telephone much harder since the onset of the disease, due to the difficulties people had in understanding them. As a consequence, they started avoiding phone conversations, asking their carers or partners to intercede for them. However, this went beyond a mere avoidant behaviour, since it was often taken by the participants as an opportunity to shift the communication to more comfortable settings and modalities, like meeting in person or replying by email:

> The phone is probably the most difficult one. […] I talk to people, but it's just the phone sometimes. I prefer to leave it. […] If somebody phones me, and I have to get back in touch with them, I just use text or an email. That type of thing. (Participant 7)

Texting was a popular choice for most of the participants, as it did not impose the same constraints as other communication methods in terms of time and effort. As Participant 4 noted:

> Texting! That's one thing that I can do! If I text people, they understand what I'm talking about! (Participant 4)

From this perspective, delegating phone conversations and switching to texting represent a good strategy to shift part of the burden of communication. This was even clearer when some of the participants claimed to prefer listening over talking. Well aware that communication consists of both sending and receiving, they appeared to have developed a preference for the latter:

> I can still listen, you know what I mean. I prefer listening to speaking. I can understand what people are talking about, I can listen. If I'm going to a group or something, I sit and listen, and then… when I feel comfortable with people around me, then I can open up and I think that has to do with HD… (Participant 4)

This is probably due to how listening allows engagement in conversations without the amount of energy required by speaking. As Participant 5 noted:

> I know when to chill out and I know when to use the energy. Like this is using more energy than I would normally. But tomorrow daytime I can relax and I've got a birthday party tomorrow night and I know I'm gonna use more energy for that, because I'll be seeing a lot of people and I'll be talking to a lot of people. (Participant 5)

In addition, the management of these aspects of communication seems to benefit from an attitude of general openness towards HD and its effects. Indeed, many participants mentioned telling people about their condition, in order to prevent any distressing situations:

> I'm more open. I know I can explain things to people. […] I do say to people 'look, if I sit with you, I know I might bump into you'. If I'm going out somewhere I'll sit at the end of the table. […] People understand. If I'm open about it, people understand. (Participant 2)

Openness, however, comes at the cost of potential misunderstandings, as reactions and interpretations may differ significantly among people:

> The worst thing people do, is tell people. As soon as you tell them, That's it. Bloody terrible. I've never done, I'd never tell anybody again, I've never advise anybody to tell anyone. 'Cause once you've told them, then you're not going to get employed or you're going to have a rough ride from then on. (Participant 7)

Thus, trying to be open to regain communicative control can backfire, by turning communication into a source of emotional discomfort.

'One moment I'm fine, the next moment I'm not': Emotional outflows into communication and the struggle for separation

One of the most challenging effects of HD was how it made emotions become unstable, and for many this was a new experience:

> One moment I'm fine, the next moment I'm not. Different things upset me… I was at work, and there was this nurse, she was bossing me about, and I said 'you're being horrible to me' […] and I got angry with her – never been like that before […] I was thinking 'what's wrong with me?' And she said to me 'what's wrong with you?', I said 'I don't know', I said 'I'm going to go and get tested. I may have Huntington's'. (Participant 6)

Moreover, the emotional aspects varied significantly. For instance, Participant 5 mentioned getting progressively detached from her emotions:

> I used to watch telly and I used to cry at the drop of a hat, and I used to have a box of tissues next to me and be soppy at anything, and then now I'm not. That box of tissues can stay there for months *laughs*. […] I'm not as sympathetic as I used to. […] I can still get angry, but not as much. I'm becoming more and more apathetic. Definitely. (Participant 5)

On the other hand, Participant 6 seemed to experience the opposite situation:

> I think I am sort of angry a lot more that I used to be, but I don't mean to be. […] I knew there was something wrong with me, snappy and shouting at people, and I thought that's not like me, because I don't shout. I do now. It's my Huntington's, I can't help it. (Participant 6)

However, the actual effect perceived by affected individuals can be rather homogeneous, since the participants made sense of it as a general external influence beyond their control. As for speech and language, emotional issues were perceived as a symptom of the disease, rather than part of the psychological adjustment to the illness. As Participant 2 noted:

> I think it was just the fact that… a symptom of the disease. As for depression. (Participant 2)

Difficulties with emotions can become even more problematic when, as previously mentioned, distressing emotional situations may arise while trying to be open about HD and regain control over communication. Although openness and control can promote illness acceptance (which is considered of primary importance in psychological adjustment to chronic illness[23,24]), those emotional experiences took a major toll on the participants, ultimately leading them to perceive their emotional and communicative life as a source of unsteadiness that frustrated any attempts at accepting their condition:

> With this illness, even though I accept it, it's very hard to accept things. I cannot drive anymore, and that's what I loved. I loved to drive all the time. All the sport's gone… (Participant 4)

> I'm good at crying… I think I've got a little more sad. I started to be sort of thrown off without sense. I think when you have to be strong every day, sometimes it is hard… (Participant 8)

One of the ways to manage their communication and ultimately promote illness acceptance was for the participants to learn better how to regulate their own emotions. However, with the participants, emotion regulation seemed to happen at the cost of engaging with extremely difficult and fundamentally disturbing thoughts, which led them to deal with challenging emotional outflows into their communicative experience. As Participant 4 mentioned:

> The thing with HD, I've noticed, if I am aggravated or someone else is aggravated or agitated, it takes some 5 or 10 minutes to me to calm down, but with HD it has a knock-on effect so it's like taking 3 times as long for me just to calm down because I go up on it, got more and more to think about and it drives me crazy. (Participant 4)

The process of achieving a better level of separation between communication and emotions clearly plays a pivotal role from this perspective. Yet, this can prove to be a very long and painful path, characterised by pervasive feelings of anxiety and instability that can turn communication into both a benefit and a liability, a 'double-edged sword':

> I know it's important to talk to people, but when everybody comes around to see me, I just feel a bit nervous about talking. And I think it must be the illness, Huntington's, making me feel like that way. But I don't mind people talking about my illness to people, so it's a double-edged sword. (Participant 3)

However, whereas such a separation is achieved, emotion regulation has a clear beneficial effect. In the case of the participants, it promoted healthy grieving, helped them to better accept their condition, and ultimately improved their communication:

> I think I got better, 'cause I've grieved for what I've lost. So I accepted that. 'Cause a couple of years ago, I'd go into a shop and say 'I've got Huntington's' and I'd cry my eyes out. I've come to terms with it. (Participant 1)

Although long and challenging, the process of regulating emotions was seen to be promoted by a number of medical and psychosocial factors. For instance, all the participants agreed on the paramount importance of medication:

> I was just tired and couldn't be asked to do things, you know. But now, once I started to take Citalopram I felt so much better in myself, it really lifted me up. (Participant 2)

In certain cases, being prescribed the appropriate medications could even benefit communication directly:

> I've got my medications now I'm fine. […] I wouldn't even be able to speak if I didn't take them. (Participant 6)

A similar beneficial effect was also mentioned for social and environmental factors. In particular, having a close family and friends around allowed the participants to feel more comfortable about communication, as well as safer when coping with daily situations by being able to ask for help when needed:

> I do feel more comfortable here, you know. Like if you have people around, I'm fine. […] I'm alright with going to different places. Well, I do try to, I like to try different restaurants and stuff like that, which I've already done. That hasn't gone yet. And we do have people round for meals and stuff like that. (Participant 7)

It is also important to notice how the positive relationship between emotion regulation and communication is bidirectional: just as regulating emotions can improve communication, so communicating better can promote emotion regulation; similarly, better relationships can improve both emotion regulation and communication – and vice versa. Thus, the successful expression and reinforcement of these factors allowed for a virtuous circle to come into being, which considerably improved the participants' quality of life.

'I go back into my little world': Sheltering as a way to boost confidence in communication

Another beneficial factor that emerged from some interviews was the idea of having a personal safe place where the participants could take shelter. Initially, this idea appeared to be mainly identified with a feeling of preference and protection for their own home:

> I think, if I'm here, just sitting here, it feels comforting. I feel better at home. (Participant 8)

> I don't know, I just… I feel my Huntington's. […] I just need to get in the house, get in my comfy house. (Participant 6)

However, as a couple of participants further elaborated, the idea reached a deeper level of meaning which transcended the geographical space and embraced a more abstract concept of safety. For example, Participant 4 talked of his 'little world':

> I go back into my little world, you know what I mean […] I just shut down, I don't know how I'm doing it *laughs*. (Participant 4)

Similarly, Participant 5 mentioned her 'little bubble':

> I know that sounds so ignorant, but I can just sort of getting into my little bubble and just completely close down if I need to, you know. (Participant 5)

This mental safety net appeared to have developed to help the participants deal with their everyday emotional and communicative life: when fatigue kicked in, emotions became overwhelming, or the circumstances got too demanding they could return to their shelter – of which their house in some cases only seemed to constitute a physical representation:

> I just seem to be able to switch off because I don't know what we are talking about. […] It's quite hard to explain… I just shut up… I just shut down and ignore people and then I look back here [at home]. (Participant 4)

From this perspective, the idea of sheltering appeared to provide the participants with an effective coping mechanism to boost their self-confidence. By knowing that they had a safe shelter, they could feel safer while dealing with everyday life's demands. Indeed, as a consequence of the process of taking shelter, of 'feeling like in their own home', they could also feel comfortable enough to open up again and communicate:

> I do try to talk to people. Sometimes when I just feel… like in my own home. Yeah, my own home. So I invite people to come around here, to chat with people. (Participant 6)

Therefore, along with the aforementioned beneficial effects of medications and close relationships, sheltering seemed to play an important role in maintaining or restoring participants' communicative abilities.

Discussion

Summary of main findings

The four themes identified by our study showed substantial areas of relevance to current models and theories of communication and psychological adjustment to chronic illness. The first theme concerned how HD acts as both director and mediator of the participants' communication, affecting their linguistic abilities by making them feel blocked and not able to speak as they used to, or pulling the strings of a number of collateral conditions that deeply affected their communicative experience, such as chronic fatigue and memory problems. According to the self-regulation model (SRM[25]), patients' representations and beliefs regarding their chronic illness have a substantial effect on the successful development of coping strategies and ultimately their psychological well-being. The SRM has been specifically adopted with HD,[26,27] finding that the perceptions of the disease are often characterised by strong illness identity due to its overwhelming perceived effect on all domains of their life. From this perspective, by conceiving HD as an external, separate agent the participants seemed to lay the foundations to fight for a fundamental domain of their own life by taking back some control over communication, which in turn can promote an identity less characterised by their illness.

The importance of control was emphasised in the second theme: Retaking control over the features of communication appeared to represent an effective coping strategy aimed at improving the participants' communicative skills. Whether it was the possibility to avoid phone conversations, the decision to prioritise listening over speaking, the management of scarce energy resources, or being open about HD, regaining aspects of control affected the participants positively by giving them a chance to break free from the pervasive nature of HD, better accept their condition and become the director of their communication once again. This view fits with the general theory of self-regulation,[28] which sees self-regulatory skills as a limited resource that can be exhausted – a phenomenon that has been named self-regulatory fatigue or ego

depletion[29] and that plays a pivotal role in quality of life and coping in chronic illness.[30,31] Thus, regulating energy and fatigue by having a choice can represent an effective strategy to deal with the demanding nature of communication.

The third theme focused on how HD threatened the participants' emotional life and stability. Presentations of this included inconsistent feelings of anger and sadness, apathy, and considerably longer emotional 'cool-down' times, which are not uncommon in HD.[1] These ultimately led the participants to perceive their emotions and communication as a source of unsteadiness. One possible solution was represented by improving emotion regulation, which is a concept that refers to the process of influencing which emotions one experiences, as well as when and how such experiences occur,[32] and whose importance in mental health and well-being has been widely recognised over the last decade.[33–35] However, for the participants emotion regulation required engaging with difficult and disturbing thoughts, leading to challenging emotional outflows into their communicative attempts, which caused pervasive feelings of anxiety that could turn communication itself into '*a double-edged sword*.' Nonetheless, where a better level of separation between emotions and communication was achieved (and also thanks to the medication and supportive social relationships), emotion regulation allowed for a substantial improvement in their willingness to communicate.

Last, the fourth theme explored a coping strategy adopted by many participants: the idea of having a personal safe place where they could take shelter. This was initially identified with their home, but later exceeded the physical dimension and extended to a more abstract idea of safety, a '*little bubble*' where they could switch off. The idea of sheltering provided the participants with a feeling of safety that helped them deal with stressful situations, and eventually shaped an effective mechanism to boost their self-confidence in regulating emotions and regaining control over communication. This finding seems consistent with the positive effect of feelings of safety reported by Hartelius et al.[17]

Limitations and future directions

A number of limitations should be considered with our results, such as the inclusion of people at the early to moderate stages only. In this study, the SRM was adopted as a general theoretical framework to interpret the findings, since it has produced meaningful conclusions in previous studies with people affected by HD.[26,27] However, other theoretical models could also be useful – such as Sharpe and Curran's hierarchical model on world and self-views[36] – and future studies could take advantage from their adoption. It should also be remembered that communication is only one aspect of a number of challenges, which these participants were managing. Seeing this in the context of their more general illness experience is also important theoretically. Future research should also aim to find ways to investigate the personal experiences of people at later stages of disease, using more adapted communication methods such as LiteWriters™.

Conclusion and implications for clinical practice

Our study has helped shed new light on multiple factors that have the potential of informing clinical communicative strategies between clinicians, caregivers, and patients with HD. First, our results suggest that patients could be encouraged to develop an identity which is less focused on the belief that the biomedical manifestations of HD are responsible for all the difficulties that they experience. Stigmatising language (e.g. 'the Huntington's face') should be avoided. Secondly, patients should be allowed to regain actively some control over various features of communication, by, for example, having a choice on avoiding phone conversions, or managing their own energy in a way which is not then pathologised.

Finally, more effort should be put into helping patients reach a better level of emotion regulation. This could be achieved through the combination of a wide number of factors, including the review of medication regimes, the promotion of close relationships, the refinement of current coping strategies (such as sheltering), and their inclusion in new therapeutic interventions.

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