INTERSUBJECTIVITY AND SOCIAL PERCEPTION IN EPILEPSY

abstract

This paper defends the idea that alterations in social perception of people with epilepsy may be crucial in the development of co-morbidities, involving a circular and mutual relationship between the person and her/his social environment, between the self and the world. We aim at exploring the role of these processes in psychopathological phenomena in people with epilepsy. Through a phenomenological and enactive account of intersubjectivity and the model of circular causality, enriched with interviews conducted with people with epilepsy, we develop the hypothesis that the originary domain of a person’s experience with epilepsy expands and modifies the fundamental interrogation of the sense of self. Furthermore, we observe how disturbances in the dynamical coupling and coordination among agents may contribute to psychopathological phenomena, and to changes in intersubjectivity and social perception.

keywords

intersubjectivity, embodiment, phenomenology, seizures, anxiety, depression

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“I often fall down into nothingness. I must push my foot stealthily lest I should fall off the edge of the world into nothingness. I have to bang my head against some hard door to call myself back to the body”

Virginia Woolf, The Waves

“It is like being in an ocean in the midst of this storm, all you automatically do is make moves to survive, you just think, ‘survive, I’ve gotta survive’, you don’t see land, and then you see land, and then you’re like, ‘OK, I’ll just float on this wave, I’ll just go with this wave because it’s gonna take me back’.”

Description of a seizure by a person with epilepsy

1. Intersubjectivity and social perception

The issue of intersubjectivity is central both in the field of philosophy and in mental health sciences. In this essay we will use a phenomenological and enactive account of intersubjectivity to explain disturbances in social perception in people with epilepsy, and to show how the development of psychological co-morbidities may arise from an alteration of the relationship of the self with the world.

For a long time, intersubjectivity has been understood in a representationalist sense, grounded on the assumption that people act according to a representation (a model or a theory). According to this view, the access to feelings, thoughts or mental states of others is possible through the inference of external bodily behaviours. This position seemed to be supported by early studies on mirror neurons, for example, which endorsed a third-person paradigm of social cognition as a passive observation of others’ behaviour. According to these findings, the brain appeared to be modelled upon an inner process, mainly characterised by inferential or simulative models. This tendency to rely on brain to explain social cognition and social perception reduces intersubjectivity to an inferential or projective process encapsulated in the brain, overlooking interactions between the individual and their environment. On this basis, disorders of intersubjectivity have been attributed to a dysfunction of Theory of Mind modules in the brain (Baron-Cohen, 1995; Bora et al., 2009). More recent findings, however, have shown that mirror neurons contribute to social perception on a relatively low level, and that they acquire their properties through sensorimotor learning and interaction with the environment (see for review Heyes & Catmur, 2021).

These more recent findings are potentially reconcilable with a phenomenological and enactive account of intersubjectivity, which claims that intersubjectivity is a result of a complex series of interactional processes, including bodily resonance, affect attunement,
coordination of gestures, facial and vocal expression and others (Fuchs & De Jaegher, 2009). This interpretation of intersubjectivity is anchored in Husserl’s meditation (Husserl, 1973a, 1973b, 1973c). For him intersubjectivity shows the exchange of thoughts and feelings, both conscious and unconscious, between two subjects. Subjectivity gains its full relation to itself and to the world in intersubjectivity, and this latter only exists and develops in the mutual interrelationship between subjects that are related to the world, conceived as a common and public field of experience, a shared world. The possibility of sociality as such presupposes a certain intersubjectivity, and this may happen only through the body. For Husserl the body is the link to one’s insertion or being-in-the-world: the body is conceived as Nullpunkt (zero point) from which the perceived world is organised (Husserl, 1989). Everything is oriented in relation to the lived body (Leib), which is central in the localisation of kinaesthetic and tactile sensations. According to Husserl, the self-understanding is accessible only via another subject’s perception of my body, and through an appropriation of this perspective I can adopt a reifying and abstractive view of my own body (Zahavi, 2003, pp. 104-105). The body, thus, is not only the link which allows to meet the other, but it is also what allows so-called open intersubjectivity: the body as the condition of possibility of each encounter.

Drawing on by Husserl’s conception of the body, we refer to embodiment as an ongoing act, continuously shaped by our experiences, by the relationships and interactions with others, and the environment. Enactive intersubjectivity is based on a complex and rich constellation of assumptions, among which, i.e. that “social understanding is as much an interactional as an individual affair, that intersubjectivity relies heavily on embodiment in a rich sense of the word, that intentions are expressed in action and can be perceptible to others and are transformative and transformed in the process of interacting” (Fuchs & De Jaegher, 2009, p. 470). The bodily experiences of interacting are the foundation of understanding both each other and of understanding the world together, and the embodiment consents precisely our immediate apprehension of others (Merleau-Ponty, 1962; Fuchs & Schlimme, 2009; Jensen & Moran, 2013; Taipale, 2014). In other words, the immediate, enactive form of subjectivity and intersubjectivity are closely intertwined (Fuchs & De Jaegher, 2010; Gallagher, 2013; Hutto, 2013).

If we combine the phenomenological and enactive approach described above, intersubjectivity may be characterised by the embodied, interactive coordination of sense-making which proceeds through a mutual incorporation of processes in which the lived bodies involved form a common intercorporeality. From enactivist perspective, living beings do not act passively, as mere receptacles of information from the outside that is translated into internal representations; rather, individuals actively participate in the creation of meanings. This means that the brain does not receive an external world without the body participating in it: on the contrary, the external realm is the result of an interaction between the sense-making activity of an agent and the responses from its environment. This requires dynamical coupling and coordination among the agents. The frame within which this happens is that of a “mutual circulation between cognitive science and phenomenology in which subjectivity and experience play the vital role that they also have in the everyday doings of living, sentient, sense-making beings” (De Jaegher et al., 2017, p. 494).

Understood as a circular process of relations between individual and environment, intersubjectivity may be considered as an ongoing process in which the person constantly influences the others by her actions, and vice versa. In the words of Merleau-Ponty, “the communication or comprehension of gestures comes about through the reciprocity of my intentions and the gestures of others, of my gestures and the intentions discernible in the conduct of other people. It is as if the other person’s intentions inhabited my body and mine his” (Merleau-Ponty, 1962, p. 215). In this framework, the model of circular causality is central (Fuchs, 2017, 2018, 2020) and sheds light on how the individual and the environment work in
reciprocal and mutual relations. The circular causality modal works at two levels: on a vertical level, explaining relations within the organism; and on a horizontal level, explaining the interrelation between the subject and the environment. The brain as an organ of a living being in its environment, becomes a social organ of mediation, transformation, and modulation, embedded in the individual relationships with others and the surrounding world.

What happens when intersubjectivity is disrupted by psychopathological alterations? Contemporary psychiatric paradigms are mainly grounded on a brain-centred view: from this perspective, psychopathological phenomena are mainly and often regarded as brain dysfunctions. On the contrary, a phenomenological view conceives these phenomena as disturbances at different levels of intersubjectivity (Fuchs, 2015). The limited capacity of the person to interact and respond to the social environment may be at the origin of certain psychopathological experiences and may affect the ability to reach a shared understanding of the world. Phenomenological approaches to intersubjectivity and its disturbances start from the consideration of the pre-reflective embodied relationship that the self has with the world. As such, intersubjectivity is regarded as 'intercorporeality' (Merleau-Ponty, 1962).

In what follows, we further explore this theoretical framework of intersubjectivity, in which the body is central in people with epilepsy; we suggest that comorbidities, such as anxiety and depression, may arise from disturbances in the dynamical coupling and coordination between individuals, impacting both the pre-existing neurological condition and changes in social perceptions.

2. Epilepsy and intersubjectivity

Epilepsy is a common, highly stigmatised chronic neurological condition characterised an enduring predisposition to seizures and by the neurobiological, cognitive, psychological and social comorbidities and consequences of the condition (Fisher et al., 2014, Keezer et al., 2015). Worldwide, at least 50 million people have active epilepsy (GBD, 2016 Epilepsy Collaborators, 2019) (i.e. continuing seizures or on treatment). Epileptic seizures are caused by the sudden disruption of normal brain functioning due to excessive abnormal activity or hypersynchronous neuronal activity (Fisher et al., 2014). Epilepsy is classified according to the underlying cause, for example “structural” (if associated with e.g. a brain tumour or scar tissue in the brain), “genetic”, “metabolic” (if associated with e.g. mitochondrial disease), “infectious”, or “immune” (Scheffer et al., 2017). The category “unknown” includes as of yet unidentified genetic, metabolic and structural causes (Scheffer et al., 2017). Most people associate epileptic seizures with “grand mal” or “tonic-clonic” seizures, in which the individual loses consciousness, falls to the ground, and delete their body shakes uncontrollably for several minutes, but seizures are very variable and can be much more subtle. Importantly, the occurrence of seizures is unpredictable for most people. This means that even if seizures are infrequent (e.g. once a year), they still have a profound impact on daily life as there is always the possibility that a seizure may happen. In most countries, for example, people with epilepsy are allowed to hold a drivers’ license or certain jobs only if they were seizure free for at least one year. Psychological comorbidities such as anxiety and depression occur in 20% respectively 23% of people with epilepsy (Scott et al., 2017). One study in people with

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1 Generalized seizures engage networks on both sides of the brain (Scheffer et al., 2017). They can be subtle, such as in absence seizures, or very clear such as in generalized tonic-clonic seizures. "Focal" seizures originate at a certain location in one hemisphere. This type of seizure usually leads to brief (seconds to several minutes) alterations in awareness, perception, consciousness and/or behaviour, that are manifest to the individual and/or others (Scheffer et al., 2017)
Pharmacoresistant epilepsy reported depression in >50%, which was linked to a significant reduction of quality of life (Boylan et al., 2004). To date the occurrence of these comorbidities is incompletely understood: hypotheses on biological factors such as low-grade brain inflammation or neurotransmitters have thus far not been fully confirmed. One study found a bidirectional relationship between depression and seizure frequency (Thapar et al., 2005). Others found that depression, but not anxiety, predicts seizure frequency over time (Thapar et al., 2009, Dehn et al., 2017). A study from 2021 showed that mental health, but not seizure frequency, was linked to quality of life (Johnstone et al., 2021). Another study showed that mental health and quality of life are linked to knowledge about the disease, attitude towards it, and perceived stigma (Yeni et al., 2018).

We here develop the hypothesis that the sudden seizures with changes in bodily function (including perception, awareness and action) may lead to an alteration of intersubjectivity, which may induce self-stigmatization, social stigma and psychopathological phenomena. Psychopathology in people with epilepsy may occur both before and after the diagnosis: in the first case, they may worsen because of epilepsy, in the second they originate in the subjective and intersubjective space that is altered by the seizures or the possibility of seizures. Anxiety and depression act as a vehicle of disturbance in the dynamical coupling and coordination between individuals, undermining the possibility of the agents to react and take action. This is particularly evident in psychopathological phenomena in general, but may be more significant in pre-existing neurological conditions. In the case of epilepsy, anxiety and depression determine changes in social perceptions, both from the side of the person with epilepsy, and from the side of the social context which may not sufficiently understand the neurological condition to act adequately during a seizure, or take the condition into account when building interpersonal relationships. Disturbances in intersubjectivity and social perception are at the core of the development of many comorbidities, but they may be particularly crucial in the occurrence of comorbidities in epilepsy, and involve a circular and mutual relationship between the person and their social environment, the self and the world. The question “Who am I?”, fundamental for each philosophical investigation and essential in the domain of mental health, becomes more urgent when it is accompanied by the question “Why does this happen to me?”. We explore these hypotheses using interviews with adults with pharmacoresistant epilepsy who participated in a randomized controlled trial assessing the effects of a group mindfulness and therapeutic education intervention on quality of life at the University hospital of Grenoble, France. Before and after the intervention study participants were invited to participate in semi-structured interviews, which consisted of open questions on different aspects of the subjective and intersubjective experience of epilepsy and the effect of the interventions. Interviews, lasting on average an hour, were conducted by phone, recorded and transcribed verbatim. This material consists of a total of ~10 hours of interviews recorded from eight individuals. The interview guidelines were developed to specifically investigate the effects of the interventions from the perspective of the interviewees. Sections of the interviews conducted before the randomization and intervention, however, included descriptions of the experience of self, others and environment. Since the interviews were not
conducted with these research questions in mind and only sections of the interviews were used, we chose not to do a full analysis.

Through repeatedly re-reading the sections of the transcripts in which interviewees talked about the experience of self, others and environment, and an iterative process of peer-debriefing in which we discussed these sections, we observed three emerging themes, which may be important in the origin and maintenance of psychopathological conditions in epilepsy: (1) different levels of awareness of seizures and disruptions in verbal communication; (2) fear of sudden loss of bodily control and alteration of the sense of belonging to the world; (3) social anxiety and stigmatization process. The three themes were present in the transcripts of all three interviewees. Below we describe each of these themes in more details, supported by illustrative quotes from the interviewees. We chose the quotes based on their clarity and on how illustrative they were of the theme.4

Seizures are experiences that often go beyond day-to-day vocabulary. For many, seizures are not remembered as such. People know that something happened, yet what exactly remains a mystery to them: “I can’t tell you what happens, my family tells me or tries to film it, [...] I find myself either on the floor, or people look at me strangely, so I know that something happened but I have no idea what”. The person realizes that something happened because others look at her strangely. The space of intersubjectivity is altered both because of the agent and the environment. From the outside, the seizure is experienced as an interruption of normal actions of the body, common space is no longer occupied by the body in a certain expected positions and movements, and this leads to the disruptions of atmospheres. From the inside, the seizure is a sudden, unexpected gap in a continuous experience.5

Other people are conscious during seizures, but still then the experience is hard to grasp, as one participant illustrates:

It’s a flash with the impression of reliving a dream [...] and then suddenly there is an electric shock; the electric shock is in different areas of my body. Generally, it starts from the head and spreads to different parts, from the arms to the chest. [...] Actually, it doesn’t last very long, it must be two-three minutes. It happens so fast that I don’t know how to say how I experience it [...] it’s a bit frightening, because [...] it reminds me of bad memories in relation to dreams, which is a bit odd, afterwards I don’t even remember which dream, it’s a bit strange.

This person’s comparison with dreams reveals three important elements:
(1) The nature of seizures as ungraspable.
(2) Seizures and dreams share a sudden alteration of atmospheric qualities, regarded as a pre-theoretic and pathic spaces that contribute to determine intersubjectivity.
(3) Seizure and dreams displace the subject from its attentive participation in the experience: he knows that something is happening to him but he does not have control over it. Different levels of awareness of seizure phenomena impact verbal communication in reporting such

3. Disruptions in verbal communication, bodily control and social anxiety

3.1. Different levels of awareness of seizures and disruptions in verbal communication
experiences: the ungraspable nature of these experiences is displayed by a lack of language. The recourse to metaphors help people in communicating not only the experience per se, but also how they felt with reference to what happened and how they feel with reference to what can happen again.

The loss of awareness of time and place seems to be a common feature in the reports of participants: seizures interrupt the flow of time, the continuity of actions and they fragment the perception of physical space in tiny frames. Recollecting them and putting them in sequence afterwards seems beneficial, when it is possible by talking to others about what happened. Some describe seizures like a wave which crashes into the body, revealing a radical emptiness which swallows the person; a wave that has the potential to drown the person and roll over every emotion, thought, and gesture.

Fear of seizures is common and often linked to the loss of bodily control that occurs during seizures, especially when the person is conscious during this loss of control. One person reported:

I am always afraid that I will have a seizure, a seizure in which you lose consciousness, in which the body shakes - at the very least when the body shakes when you lose consciousness, that’s fine with me, but not losing consciousness and your body shaking without being able to manage I don’t like that, I don’t like that at all.

This loss of control can be so extreme that it triggers existential anxiety, as another participant stated:

The first seizure I had without losing consciousness, I said to myself “I’m going to die”, because I didn’t know what was happening to me, it was the first time, so you drool, it’s not the drool you normally have, it’s frothy drool that you can’t hold in, your mouth is all twisted, I was saying to myself ‘damn I’m going to die alone here on my sofa.’

Fear of seizures is strongly related to an alteration of the sense of agency: for people with epilepsy, at any given moment and without an apparent reason, the body may be completely out of control, showing the shift from the lived body (Leib) to the object body (Körper). Phenomenological accounts of embodiment (Moran, 2013; Legrand, 2010) show how the intertwining between lived body and object body is always present in many of our bodily experiences. There is a tension between these two aspects which silently weaves through our daily life. When this is unbalanced, we observe how the body, primarily conceived as our main anchor to the world, shows its unstable foundation. As a consequence of this interruption of balanced tension, intersubjectivity is compromised: for some patients, the body may be regarded as a continuous threat to their experiences, as well as in the construction of relationships (personal and professional) and in the search of existential meaning for seizure phenomena.

The loss of bodily control displays the relationship between the body and the existential feelings, a kind of pre-theoretical structures of the experience of being-in-the-world. It is precisely when our ability to master the body is not possible anymore that the world may appear “unfamiliar, unreal, distant or close. It can be something that one feels apart from or at one with. One can feel in control of one’s overall situation or overwhelmed by it. One can feel like a participant in the world or like a detached, estranged observer staring at objects that do not feel quite “there” (Ratcliffe, 2008, p. 37). Existential feelings are basic structures for the constitution of social space, since “they constitute a sense of relatedness between self.
and world” (Ratcliffe, 2009, p. 180). The loss of bodily control interrupts the belonging to the world: when one’s bodily disposition to the world is compromised, then also the orientation of the experiences – as well as thoughts, feelings, desires – is not embedded in a certain horizon of possibilities.

3.3. Social anxiety and stigmatization process

People with epilepsy often report how they feel anxious for loved ones, as witnesses of seizures: “Precisely we don’t control [the seizures], and also seeing the people around us, the fear that they had for us and then and for them it’s the same, it’s not the kind of thing that we see regularly right”. One of the main concerns is not only about how the seizures affect themselves, but also how the seizures may affect others. Especially the first seizures are described as shocking events that impact the entire family. These are often medical emergencies in which the seizure may cause injuries and an ambulance is called. Several participants describe that their children witnessed the seizures and react in different ways; some refuse to speak about it, others become extremely careful and worried – leading almost to a role reversal. Within their families, people talk about the seizures to demystify them and reduce the anxiety for themselves and family members. Some people give their family members and close friends precise instructions on how to deal with seizures.

Social anxiety, experienced both in the context of close personal relationships and of social environment, impacts the self-understanding of people with epilepsy. Here it is possible to see two levels of anxiety: a personal one, related to the person’s own experience of epilepsy; and a social one, related to the fear that others may have of the seizures. These two levels are in a mutual relationship: we hypothesise that a good ability to express one’s own feelings and emotions, a family environment open to dialogue, a certain awareness of what epilepsy is and how one can be of help during the seizures, may reduce the mutual process of increasing anxiety: loved ones become less concerned and less worried, which means that the person with epilepsy, in turn, worries less about them.

This is connected to the issue of interiorization, stigmatization and self-stigmatization: while speaking to family, close friends or loved ones about epilepsy and seizures can reduce anxiety, speaking to more distant acquaintances or work colleagues is more difficult. Often, people with epilepsy do not disclose their condition. They have different reasons for this:

it’s a disability that can’t be seen, so that’s why at work, people don’t understand […]. I think that when it touches the brain, I have the impression that it’s frightening for others; but for us too, but we live with it so we can grasp it, saying well I have all my mental faculties but I’m not sure that the others know that we have all our mental faculties […]. As it affects the brain, there’s immediately this … between madness and … well, you know what I mean… It’s the brain; the brain allows you to think, so if it’s affected, you’re not completely clean.

This excerpt reveals two key points:
(1) epilepsy is an invisible condition, most of the time: it is only through the possibility that the seizures occur that it manifests itself. This is known only by the person, but to no-one from the outside.
(2) The common yet false belief of the link between madness and epilepsy: epilepsy is a neuropsychiatric condition. Negative stereotypes about this condition are so deep-seated in

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6 Epilepsy is a condition that has been viewed differently throughout time. The term “Epilepsy” is derived from the Greek verb epileambanein (επιλαμβανειν), meaning to be seized, taken hold of, or attacked. The ancient Greeks ascribed
society that many people with epilepsy accept them, and hold the same or similar beliefs as
the society that devalues them. They have therefore often not felt empowered to change
the situation, which in turn has enabled the stigmatization to remain pervasive and effective
(Epilepsia, 2003).

As a social construction, stigma is always linked to certain values placed on social identities
(Goffman, 1963). The relationship between public stigma, as the perception held by others that
someone is socially undesirable, and self-stigma is harbinger of many elements: stigmatized
people experience a decrease in self-esteem which often leads to depression. A pervasive
sense of shame and embarrassment is often accompanied by a sense of guilt, which increases
existential anxiety. Depression, social anxiety and a sense of shame limit social interactions,
destabilize the construction of intersubjective space and affect the quality of life of people
with epilepsy and their families. The circular process at the core of the interaction between
the agent and the social environment seems to reduce the possibility of sociality and, as
consequence, to disturb the interactive coordination of sense-making of the lived body,
blocking the open intersubjectivity (Zahavi, 2001). The process of self-stigmatization offers
some clues on what it means to be a self especially in relation to resilience against, and recovery
from, stigmatization (Eriksson, 2019), involving many issues among which the psychological
impact of stigma in the understanding of the self, the commitment to an existential project,
the quest of finding meaning in life, and the possibility to share a collective intentionality
(Zahavi, 2021). Among the many theories of the self, following the Husserlian legacy, we
refer to selfhood in relation to the experiential self (Zahavi, 2009, 2014). What ultimately
determines the mineness of experience is the way experiences are experienced: how they are
originally given to me: “It is exactly the primary presence or first-personal givenness of a
group of experiences which constitutes their myness, i.e., make them belong to a particular
subject” (Zahavi, 2000, p. 64). How I distinguish my experiences from yours is grounded on the
fact that experiences are necessarily mine, and as such depending on the original givenness.
The mode of givenness of each experience is very different for each person, and for those
who live with a neurological condition such as epilepsy this is even more radical, even if the
self is supposed to remain the same because of the transcendence of the ego (Husserl, 1973a,
p. 246). Under this regard, a phenomenological investigation of experiences of people living
with epilepsy is capable of showing the peculiarity of the givenness of such experiences, and
enrich the understanding of the minimal self and its relationship with the world, also in light
of overcoming stigma and destroying boundaries.

This paper suggests that the perspective of people with epilepsy on their condition is central
in understanding the dynamical coupling and coordination between themselves and their
environment. Our exploration highlights how the originary domain of a person’s experience
with epilepsy expands the fundamental interrogation of the sense of self, conveyed through
the body. In a paroxysmal condition like epilepsy, the disease is not there continuously, yet at
all times the body has the potential to be subject to a seizure. These sudden and often violent
changes in bodily experience may alter the sense of agency of people with epilepsy and their
sense of belonging to a shared world. The interplay between embodiment, atmospheres,

4. Conclusions

epilepsy to divine interference, although Hippocrates recognized it as a brain disorder (Epilepsia, 2003). Still in some
cultures, epilepsy is seen as a type of possession (Obeid et al., 2012). Despite much progress in understanding epilepsy
and improved therapeutic options, the condition remains stigmatized, also in western societies (Epilepsia, 2003). Few
people in western societies believe in possessions or in divine causes of disease, yet the dominant positivistic and
organicistic brain-centered view sometimes reduces beings to brains (Schwaab, 2010) and consequently, if something
is wrong with the brain, something is wrong with the person.
emotions and psychological comorbidities is a hallmark of this condition. The dynamic interpretation of the interrelation of self and world is revealed here as the origin of the change in social perception, in which self-stigmatization and social stigma result in (the worsening of) anxiety and depression.

This paper aims to contribute to a better understanding of psychopathological phenomena in people with epilepsy and to unveil the existential vulnerability linked to this condition. We nourish the hope that also in the domain of epileptology and neurology the value of the phenomenological method may be discovered and understood, and that first-person accounts may be used to better understand the ungraspable nature of seizure phenomena and psychopathological consequences of the condition. We hope that this will lay the foundations for further studies and proposals for novel therapeutic interventions for people with epilepsy, contributing to the reduction of stigma and prejudices surrounding this chronic condition.

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