

Why designing may help treat psychosis

Renedo Illarregi, Erika^a; Alexiou, Katerina^a; Zamenopoulos, Theodore^a

^a The Open University, Milton Keynes, UK.

The paper presents some initial theoretical insights on why designing may help people with experience of psychosis. The paper reviews how psychosis has been discussed in the literature from a phenomenological point of view, and how it links to designing by looking at the themes of agency and embodiment. These insights are then used to formulate the hypothesis that the experience of designing, and design iteration, may pose a continuous force (and have an indirect effect) towards the coupling, or pulling together, of dimensions of experience such as perception, cognition and action which in psychosis are sometimes experienced as particularly fragmented. The paper contributes to our understanding of design and introduces the idea of design as treatment for the development of design projects to support mental health.

Keywords: *psychosis; co-design; schizophrenia; mental health; self; agency; embodiment; phenomenology; experience*

1 Introduction

This paper is concerned with making connections between the experience of psychosis and the design process to explore whether designing can contribute to the treatment of psychosis.

Mental health problems represent the largest cause of disability in the UK, and there is a requirement of participatory research and development of new ways to improve the services' productivity (Mental Health Taskforce, 2017). The recovery movement, which broadly focuses on restoring functioning above and beyond symptom reduction and recognizes the ability of people with mental health problems to participate in society (Davidson, 2016), and the patient-oriented treatment plans that acknowledge experiential knowledge have opened up doors to imagine what could constitute treatment, and the exploration for new ways in which recovery is supported more generally.

While some studies exist that use design in mental health contexts, there is no research which explicitly looks at the effects of design thinking in mental health. There is no previous evidence to prove the benefits of designing for mental health problems, although authors experiences through professional practice seem to suggest positive changes. The paper focuses on describing a theoretical framework developed through the preparation of a co-design project with participants with psychosis at a mental health charity. The aim of the theory is to inform the set up of co-design projects and guide data collection, but it is expected that empirical evidence will in turn help re-evaluate and re-formulate the theory, and develop alternative perspectives.

A variety of arguments can be drafted to support the idea that co-design may be reimagined as a treatment, which does not necessarily focus just on the individual. One such argument is that as powerlessness, loss of credibility and identity, isolation and hopelessness create most suffering to service users (Kaite, Karanikola, Merkouris, & Papathanassoglou, 2015), co-design provides an empowering platform. By respecting participants as experts in their experience and key actors due to their contributions (Sanders, 2000), co-design may be reimagined as a treatment that transcends the individual and focuses on the wider community or context where psychiatric and psychological distress is happening.

Conceptualizing co-design itself as a kind of treatment is a radically different approach to the way co-design and co-creation have been approached and used within health services. Projects tend to focus on using co-design to inform the improvement of services or increase efficiency for instance, rather than using it as a treatment in itself. Some findings from a UK healthcare participatory project suggest participants did not think to be 'doing' the designing, and had doubts about the effectiveness of the intervention (Bowen et al., 2013).

Among the projects led by designers specifically within the mental health context, the focus has been on developing appropriate design methods or innovative processes, and describing the design outcomes (Glazzard et al., 2015; Kaasgaard & Lauritsen, 1997; Kettley, Sadkowska, & Lucas, 2016; Nakarada-Kordic, Hayes, Reay, Corbet, & Chan, 2017), leaving the effects of participation on mental health users -aside as general feedback- yet to be explored. Even looking at the wider area of design for health, studies focusing on the effects of co-design on participants themselves appear rare, with the exception of a couple of studies looking at the potential of design thinking to help those affected by long-term physical conditions such as spinal cord injury (Macdonald 2013; Langley et al. ,2013).

Nevertheless, the idea that participating in co-designing may have an impact in some way or another informed some studies which speculated why these changes could occur. With participants from the general population, Corcoran, Marshall, and Walsh (2017) suggest that cooperative place-making workshops supported changes to psychological and community wellbeing by enhancing both a sense of personal growth and a collective sense of place-related optimism. Hendriks, Dreessen, and Schoffelen (2016) describe how participatory design could 'enable' increase in perceived quality of life and secondary gains which (as (Albrecht & Devlieger, 1999) describe) occur when a person with a disability (in their case diabetes) finds an enriched meaning secondary to the condition brought on by the disability. Renedo-Illarregi (2018) conceptualizes uncertainty as a potential explanation for changes that could be expected in people with mental health problems who partake in design.

This paper focuses in the experience of psychosis in particular, and how the experience of designing may relate to it, building a hypothesis of why these may impact one another.

1.1 Why focus on experience

The lived experience of designing has been paramount in the study of design. According to Frauenberger, Good, & Keay-Bright (2010) the philosophical discipline of phenomenology provides the designer with a framework for studying user experience by affording an intrinsically contextual view of the way we interact with things around us. They argue that it also plays a critical role in participatory design when it is undertaken as an interpretive and generative process, mindful of end user experience rather than directed toward the specification of outcomes.

On the other hand, psychiatric research and treatment initiatives are moving away from traditional diagnostic categories and focus on transdiagnostic phenomena (Pienkos et al., 2019). Many psychotherapeutic or recovery-focused initiatives within mental health charities are now organized around phenomena and according to experience, and charities rarely use diagnosis in the way they design, organize and provide their services. This is reflected in initiatives such as the service offered by the mental health charity who are collaborating in this study, which provides psychotherapy for people who have experience of psychosis, regardless of the reasons for such experiences.

Increased awareness of the limitations of reductionist approaches that mostly rely on biologically oriented models, has led to alternative conceptualizations more interested in lived experience of psychosis (Hamm, Leonhardt, Ridenour, Lysaker, & Lysaker, 2018b). Indeed, as reviewed by Hamm et al (2018a), both the philosophical phenomenological model of psychosis and the recovery model, focus on the first-hand experience of psychosis, and although they differ on methodology and epistemology, they are both interested in the alterations of subjectivity that occur in psychosis, and both contribute to interventions that are responsive to these alterations.

Most recently, changes that relate to cognition, perception, selfhood and reality, temporality, interpersonal experience, and embodiment were reviewed across the psychiatry literature from a phenomenological point of view (Pienkos et al., 2019) providing a great opportunity to build a shared, interdisciplinary framework to understand the experience of designing alongside the experience of these changes occurring in psychosis.

With a primary interest on lived experience, in this paper we theorize changes that could occur (theoretically) when the experiences of designing and the experiences of psychosis interact.

1.2 The structure of the paper

The first part of the paper, centres around the question of how design may impact psychosis by discussing two main themes, **agency and embodiment**, which are of great relevance to psychiatry and design. The intention is not to provide an extensive literature review, but to provide an overall thematic analysis in order to illustrate insights that informed this project and the theoretical contribution which is presented at the end. The concluding section, presents a hypothesis of how designing could help treating psychosis by conceptually intertwining the themes discussed.

It is important to clarify, nevertheless, that the data collection for this project has just commenced, and this theoretical argument is one of few which may emerge once more data is collected. Following an abductive approach, the aim is to generate a variety of explanations that could account while we are collecting data, continuously checking for alternative theorizations.

2 Could designing treat psychosis?

In order to review the potential of designing to help with the limiting and debilitating aspects of psychosis, we first look at two common themes across the phenomenology of psychosis and design literatures, and organize brief summaries around two main themes, agency and embodiment, which are, paramount to both research agendas.

Arguably, the themes of agency and embodiment are also relevant to the subjective experiences of designing and psychosis.

In the literature in psychosis, we see these themes reflected upon from the point of view of what seems disrupted on the experience (diminished agency, disembodied self, disconnection with the world and others) but they are also seen as relevant for the proposed treatments or interventions to respond to the struggles often associated to psychosis.

2.1 Agency

A diminished sense of agency is a recurrent and common theme in research which deals with understanding the experience of psychosis. It appears central to studies that differ wildly both in epistemology and methodology. For instance Hamm et al (2018b) review the commonalities and differences across two research agendas, that is the phenomenology of psychosis and the recovery models. By philosophical phenomenology they refer to research concerned with structures of consciousness as experienced from the first-person point of view such as perceptual and cognitive aspects of how persons experience the self and its relation to the world around them (e.g. Parnas 2011). Recovery-oriented approaches on the other hand are those which focus on individual definitions of wellness and the processes which promote those (Leonhardt et al., 2017). They specifically focus on the ipseity disturbance conceptual model of schizophrenia, which is well known in phenomenological writings, and recovery writings that generalize from common and diverse experiences of movements towards well-being. Hamm et al (2018b) conclude that treatments following these paradigms need to address experiences of diminished agency and confused or fraught self-experience, primarily focusing on helping patients to name, reflect upon, and respond to their experience, as a basis for action – a very familiar process to designers.

On one hand, a diminished sense of agency may refer to the lesser ability to have an impact on the world around oneself. This feeling of disempowerment is something that most people can relate to and may experience at different points in their life. In many cases of psychosis, this particular sensation may indeed reflect the real situation quite accurately, as the power over the environment, others and even oneself can be extremely compromised by some events following breakdown such as being sectioned or treated compulsorily.

However, from the lived experience of the psychotic, a diminished sense of agency may not only refer to a lesser ability to impact on the environment or what is being done to them; in some cases, the lack of a sense of agency may extend to one's own inner world (e.g. thoughts, feelings, sense of will).

A diminished sense of agency thus extends to the sphere of one's inner world and experience. In these kinds of situations, the person is not only unable to act upon things and events 'out there', but he or she also experiences his or her inner existence as driven by foreign agency or subject to the agency of others.

These various cognitive phenomena have been framed as alterations of thought-agency and ownership (Humpston & Broome, 2015). Examples portrayed in (Pienkos et al., 2019) include 'thought insertion', which is the inward projection of "other" thoughts into one's mental space, and 'audible thoughts' referring to the vocalization of one's own thoughts into an external space. Furthermore, Mayer-Gross (as cited in Sterzer et al. 2016) proposed that thought insertion involves those thoughts to 'become sensory', no longer being experienced as thought but as objects inserted by foreign agency.

One of the most characteristic experiences of psychosis, hallucinations, are considered as self-disturbances to the extent they are perceived as occurring independently from self, and this separation between self and its automatic processing is also often experienced as due to foreign agency. (Pienkos et al., 2019)

Fuchs (2007) suggests that the inhibition of unintended thoughts or actions fails when the essential syntheses that relieve us of the task of actively connecting and building up the perceived objects, situations and habitual patterns of our life are disturbed. Associations or even bodily movements appear 'out of the blue' and instead of serving as a medium for the patient's intentional relation to the world, their thoughts, perceptions or movements may occur as single erratic blocks that stand in the way of their intentional effort. (Fuchs, 2007)

Agency is a fundamental pillar for the activity of designing. In design, the choice for action, is influenced by the perception of the consequences of the action. It is also been conceptualized as emergent from the interaction with design materials, see for instance (Tholander, Normark, & Rossitto, 2012), who describe this process in the context of intensive short-time prototyping.

Let us imagine and speculate what happens when a person with experiences of psychosis is presented with a design brief. The person is confronted paradoxically with 1) having to pay attention to the constraints of what is 'out there' therefore becoming aware that their actions will have a potential impact in the external world and 2) the multiplicity of responses that the brief entails, basically by endless choices. The person may make any decision but must also take into account the effects of the decisions and act accordingly. Being confronted with this situation, the psychotic needs to act upon external perception (e.g. brief) as well as personal narratives (e.g. there is many ways to respond appropriately to the same brief). Through this process, dimensions of experience such as perceptions, thoughts, feelings need to somehow coordinate.

2.2 Embodiment

As Hamm et al (2018b) summarize, if attending to subjective experience is addressed principally by promoting agency, treatment should attend to mental phenomena in the context of embodied experience.

The subject of embodiment is also one of the themes Pienkos et al (2019) use to organize their extensive review of the literature on hallucinations, suggesting it is central to the phenomenological study of psychosis.

A review of implications and applications of the subject of embodiment in schizophrenia is discussed in Tschacher et al (2017). They remark how embodiment has become an influential concept in psychology and cognitive neuroscience, and that the embodiment of the mind constitutes the basis of social interaction and communication. Sensorimotor dysfunctions are closely associated with affective and psychotic psychopathology, leading to altered timing in the processing of stimuli and to disordered appraisals of the environment.

Alterations of bodily self-representations have also been suggested to be a core component of schizophrenia, for example changes in size and shape, alterations in body ownership or out of body experiences. (Pienkos et al., 2019).

The idea of disembodied self is central to the existential interpretation of psychosis presented in *The divided self* (Laing, 1960). In Laing's thesis, the schizoid person, who may

or not develop psychosis, consists on an unembodied self, and a false self-system who deals with others and the world. He stresses that although most people regard the embodied position as healthy and the unembodied pathological, sometimes an individual should try to disentangle himself from his body, for instance to achieve discarnate spirituality.

On the other hand, the concept of embodiment also takes a central role in design research, often implicitly. As Peter et al (2013) describe, there is a strong view in the literature that any practical activity, and perhaps especially designing, embodies different types of thinking and that these types of thinking can interact with one another in achieving a particular goal. As (Loke & Robertson, 2011) summarize, the thinking is not in words or propositions, but in visual, tactile and somato-sensory forms.

Schön's work on reflection-in-action (e.g. Schön 1983), which guided an extensive research agenda referred to as the reflective paradigm or design as exploration (see Hay et al. 2017 for an extensive review), is highly related to the idea of embodiment, where thinking and doing are experienced as an integrated whole.

From a phenomenological perspective, Poulsen and Thøgersen (2011) argue that embodied engagement of the designers plays a fundamental role both in understanding the problem at hand and in opening up new ideas leading to a new design solution. According to their study, the verbal interaction constantly finds its meaning in reference to a tacit level of embodiment, which remains unspoken. The verbal interaction is also integrated into the designer's tacit use of items in the surroundings and design thinking relies on a more complex and multidimensional interaction, which is based on the pre-linguistic engaged perspective of the lived body.

Now let us again imagine a person with psychosis is presented with a design brief, and/or some tools to design, for instance paper prototyping. Suppose the person experiences the body as separated from self or alien, or even perceives his/her weight in an unusual manner. In responding to the brief, the psychotic is forced to use the body to react to the object of design through feedback (perception) and action. By following the design process, a psychotic person may iteratively reconnect to their self (mind and body) even if only in the specific context of responding to a brief.

3 Summary and discussion

Summarizing, we have described how a sense of agency and embodiment are critical dimensions both in the experience of psychosis and designing.

Our concluding thesis is that the activity of designing and design iteration may act upon this experiential landscape as a continuous force towards the gradual integration of the fragmented dimensions of experience found in psychosis.

This theoretical concept has been developed by immersing in literature in an attempt to empathize with the experience of psychosis and understand the profound ontological differences implied, whilst reflecting on first hand experiences of designing and visualizing how these positions may interact. The theory here described was first articulated in a visual, dynamic form, when trying to understand the experience of psychosis alongside that of designing, and explore the meanings portrayed by authors who looked at the lived

experience of psychosis and even described it in visual forms. The process involved the hacking of existing conceptual diagrams and the development of a new one, which is adopted here to assist in maintaining a conceptual thread and communicate the theory visually. Put it another way, the theory was 'prototyped' as in physical form.

The design object, or focus of attention, supposes a continuous demand on both perception and action and the body. For the design concept to move and iterate forward, and the designer to be able to make design decisions (which transcend personal preference and are embedded in the world) all these elements (agency, perception, action, body, object) need to coordinate with one another. As (Tholander et al., 2012) describe, neither technology nor people are the sole performing agents that drive activity forward – but rather the two in interplay.

The psychotic person may begin the task by compensating for this lack of integrated experience and agency with rational thinking (e.g. make conscious connections among things commonly experienced as integrated). But the designing continues and the object moves forward, demanding some coherence in the perceptions and actions that are most relevant to the present situation. Design activity may even encourage redirecting thoughts that are intrusive or dreamy back into the design focus by indirectly informing creative shifts or innovative ideas. By following the design process a psychotic person may slowly begin to pull these fragments of their experience together, which then provide the basis for the gradual emergence and realisation of agency.

In order to visually illustrate this theory and integrate it with earlier summaries, we look first how these fragmented dimensions of experience have been visualized in psychosis literature through two very different examples. Although referring to highly complex phenomena in reality, these diagrams are relatively simple ways to facilitate the comprehension of how radically different the world and oneself is experienced when dealing with psychosis. From the understanding of those diagrams, we build a final diagram which portrays our theory.

This first diagram (Figure 1) is found within the work RD Laing *The Divided self* (Laing, 1960). In this diagram, we understand how having a divided self may result in perception becoming unreal, and action futile, rather than meaningful. Simply put, when the self is embodied, action and perception are connected in a healthy cycle and the self has direct access to the other, which could be a thing, other people or the world for instance. When the self retracts to some inner dimension and a false self operates within the world, perception is no longer experienced directly, and action is no longer associated with one's own will. In this diagram, the disconnection or uncoupled action and perception results from a self being displaced. Experience is no longer integrated and embodied.

The main way to normalize this kind of situation according this diagram would be to try to help the inner self gravitate towards the centre to align again within the circle. If we try to visualize the act of designing within this conceptual diagram, we could imagine it as a rotating axis that crosses the centre of the cycle of perception and action represented (Figure 2).

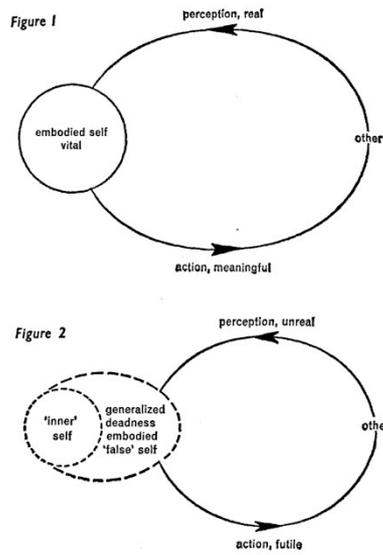


Figure 1. Pag 81 in (Laing, 1960)

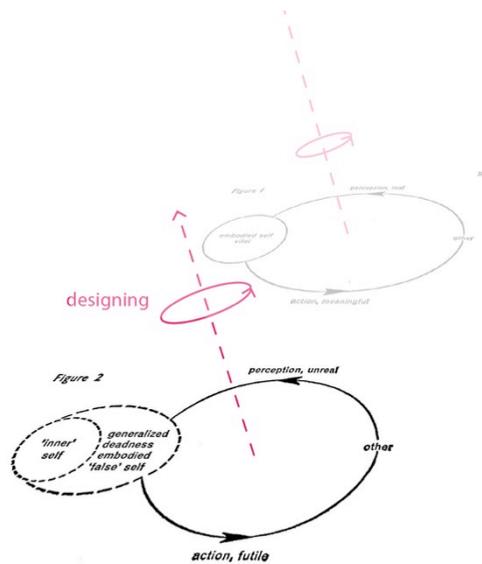


Figure 2. designing in relation to Laing's theory, (1960)

The next diagrams below, by Fuchs (2007), refer to a different phenomenon described earlier in this paper, that of intentionality, which is often disordered in Schizophrenic people who deal with psychosis. According to Fuchs (2007) the basic temporal structure of mental

life as an integration of past, present and future could be paralleled, phenomenologically, to Husserl's analysis of the structure of internal time consciousness, consisting of a retentive, presentational and protentional function. These functions operate in the most basic levels of consciousness and are capable of integrating the sequence of single moments into an 'intentional arc', enabling us to direct ourselves towards objects and goals in a meaningful way (Figure 3, (Fuchs, 2007))

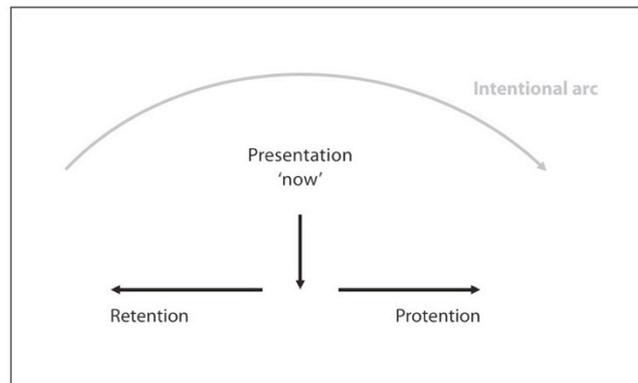


Figure 3. Structure of internal time consciousness, adapted by (Fuchs, 2007) from (Husserl, 1966)

The fragmentation of the intentional arc, leaves single elements of perception, action and thought processes unconnected, and they come to explicit awareness as alienated or opaque phenomena. As Fuchs (2007) describes, as a consequence the automatic constitution of reality is dismantled and has to be replaced by active or rational reconstruction, which overburdens the patient's adaptive intentional capacity.

In psychosis, a failure of the continuous intertwining of succeeding moments, and especially of the protentional function (represented in figure 4), leads to a loss of the tacit or operative intentionality that carries the acts of perceiving, thinking and acting.

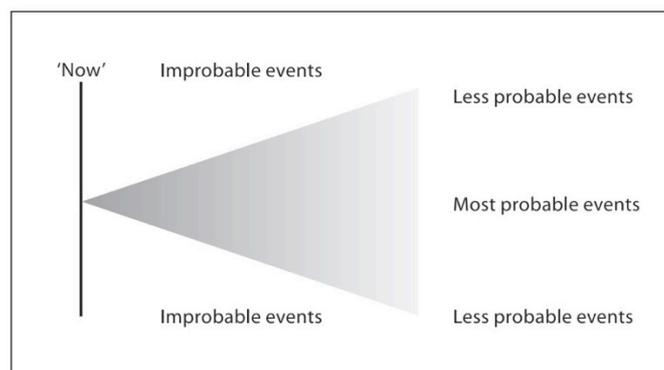


Figure 4. Protentional function (Fuchs, 2007)

In the following diagrams, the protentional function is represented in the cases of focused activity, alongside dilated and retracted protention which happens in creativity and dreaming or drug induced states for instance (Figure 5)

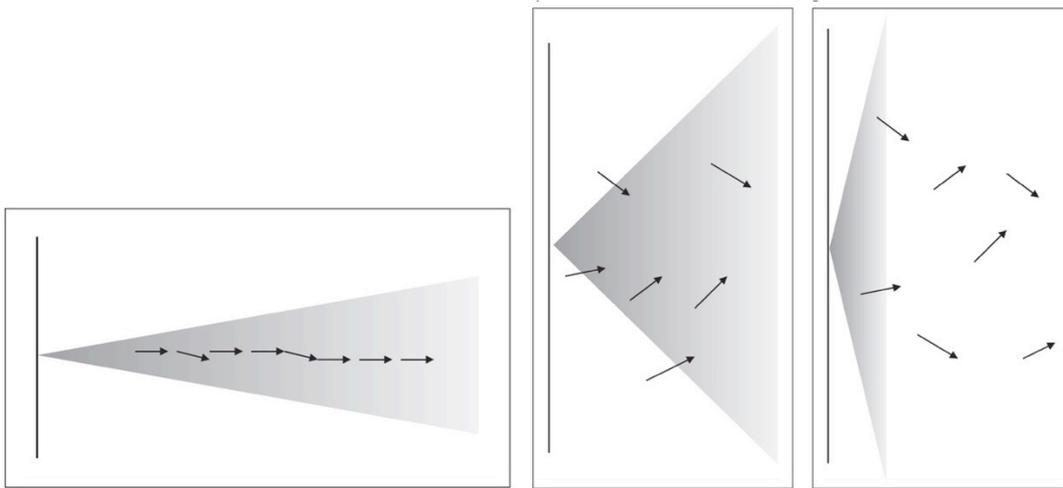


Figure 5. From left to right, focussed protention (e.g. in concentrated thinking or speaking), dilated protention (e.g. day-dreaming, free association and creativity) and retracted protention (e.g. in dreaming and drugged states). (Fuchs, 2007)

According to Fuchs, the schizophrenic patient still tries to think actively. Unlike the dreamer, he is not just the passive spectator of his mental experiences. His intentional activity starts, but then it is suddenly thwarted by intruding splinters of thoughts that appear 'out of the blue'. Thus we may say that his protentionality is not only weakened and retracted, but fragmented (Figure 6). (Fuchs, 2007)

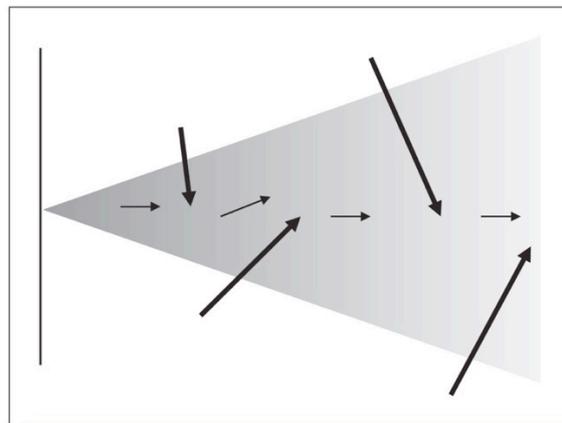


Figure 6. Fragmented protention in schizophrenia. (Fuchs, 2007)

Leading to our final contribution, we create a diagram that aims to integrate, phenomenologically, the two contributions of Laing and Fuchs. In this diagram, agency and intention emerge from this iterative cycle or perceiving, thinking and acting, as if by inertia forward in time, which is why it is represented in a vertical axis (Figure 7). When psychosis happens, however, fragments of perception, action and thought appear to awareness as alien, and thus a sense of agency and intentionality is unlikely to emerge and be sustained.

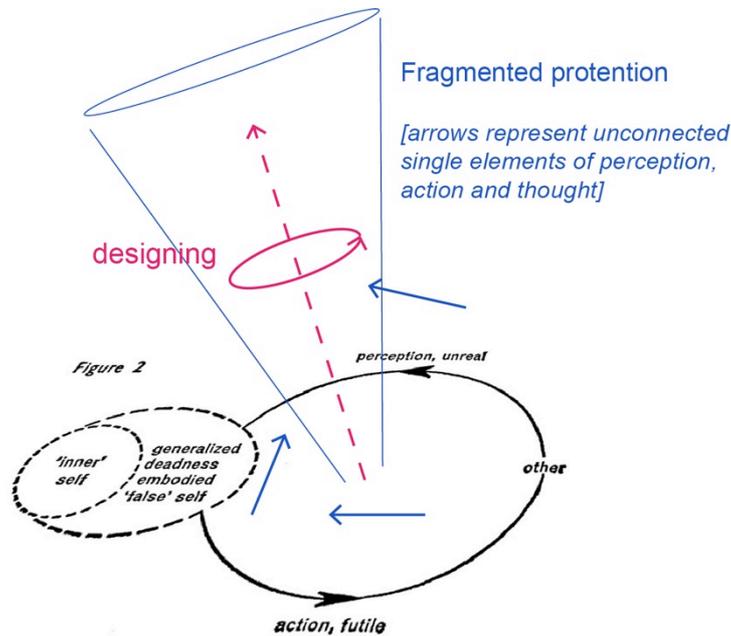


Figure 7. A diagram bringing together Fuchs and Laing's theoretical insights

In the final diagram which illustrates the proposed theory (Figure 8), we have represented the experiences of both the divided self and the unconnected elements of perceptions, thoughts and actions as lines and shapes within the lower layer. These lines and shapes represent dimensions of experiences of psychosis which have been discussed throughout the paper. Actions, thoughts and perceptions, may not be experienced as integrated, and there may be a diminished or lacking sense of self which is embodied and holds the experiences around some more or less stable citadel. There is a lack of sense of agency and intention which could be thought as emerging from, or necessary for, the continuous, coherent process of perceiving, thinking and acting upon the world.

We next invite the psychotic -who is often struggling with these experiences- to engage with designing. The design object, or focus of attention (Figure 8), represents the centre of our design efforts. It can be argued that the design focus of attention in itself holds within it some form of retention (where it came from or what informed it) and protention (what it will be for). Unlike art work, the design object moves forward by constantly pulling actions, thoughts and perceptions into some coherent frameworks which should be embedded in the context of use. Artistic exploration has a very different set of demands and in psychiatry has often had the function of helping express these fragmented and unusual aspects of experience. It is perhaps a brilliant medium to express the often-bizarre nature of one's experience, with tremendous therapeutic value. However, in contrast to design, artistic exploration does not always demand changing aspects of experience.

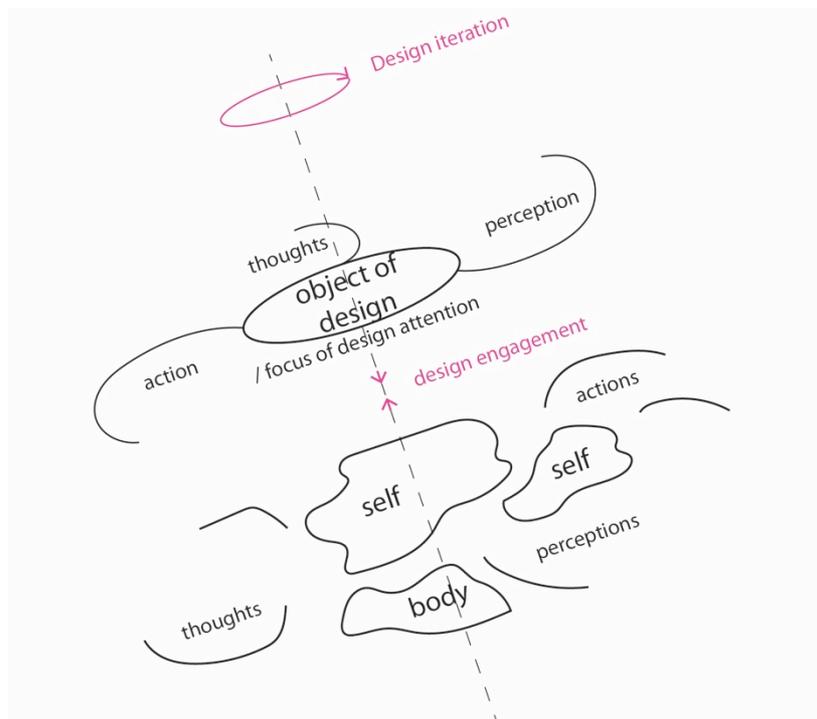


Figure 8. Diagram showing how designing may help treat psychosis by connecting fragmented aspects of experience.

Most actions performed in designing, and the decision making associated with it, demand the integration of perception and action quasi simultaneously. For instance, seeking feedback, testing out prototypes, sketching, making calculations, evaluating shapes or forms, all pull dimensions of experience such as acting and perceiving together. Within a design process, the next action (e.g. sketch) is determined by the previous perception (e.g. scale doesn't work for the user), via the body (e.g. using the body literally to sketch and even imagining our body interacting with the object to make a judgement of the scale).

The diagram shows the fragmented elements of experience, summarizing from earlier descriptions of how it is like to be psychotic, in the lower layer. The central axis, rotates through design iteration, and the object of design, functions as a force or focus of design attention, which continuously demands perception, action and thoughts to be put in relation to one another.

The repetitive, continuous activity of designing which moves forward through iteration, pushes the single elements that are experienced as alienated or fragmented to gravitate towards one another. A design focus may help the psychotic to couple and connect elements of action, perception and thought together in a meaningful way.

Designing and design iteration, may pose some revolving force towards the reintegration of the dimensions of experience, through which agency may, with time, remerge.

3.1 Next steps

The above theory was motivated by a co-design project which is currently taking place with patients attending a Psychosis service in a mental health charity. The aim of the project is to experiment with the use of design as a way to help with psychosis. Through this collaboration, participants are being encouraged to engage with and reflect upon designing, and the author is encouraged to reflect upon the experience of psychosis in relation.

In contrast with earlier work reviewed above, the lived experience of participants who go through the design process and the forming of this process from their point of view, is the main focus of this project.

In brief summary, the project recruited participants from an ongoing therapeutic service for people with psychosis, with the support of staff. It consists in one design facilitator, the author, attending the service space every week. The researcher facilitated a semi structured process, which was presented to participants to have three main stages: understanding design, finding and mapping situations and creating design(s). The challenge consisted in providing a space that would accommodate different ways to participate and acknowledge everyone's contribution as unique and valuable.

The theory presented here is based upon phenomenological descriptions of psychosis in relation to design and has been influenced only by the very first interactions with the participants that were recruited. As this project is still ongoing, it is too early to report any project results and mental health changes. The ongoing analysis of data may provide us more concrete evidence on the actual impact on people's lives, and may lead to different insights about the nature of designing and mental health problems.

The wider research agenda includes generating alternative explanations alongside further data collection and analysis. Following an abductive approach, the intention is to generate plausible explanations by constructing and testing different scenarios in practice (Zamenopoulos & Alexiou, 2018)

The research is expected to contribute to our understanding of design and how co-design projects within mental health, can motivate and influence the development of new treatments.

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About the Authors:

Erika Renedo Illarregi: In 2013, she co-founded a social enterprise to run co-design workshops with people with mental health problems, and began exploring ideas about their healing potential. She is currently studying a PhD that focuses on how and why designing may impact mental health.

Alexiou, Katerina: Katerina is a Senior Lecturer in Design. She has published articles in design cognition, collaboration, creativity and complexity. Her current research is focussed on co-design and co-production with civil society organisations and communities engaged in place-making and creative civic action.

Zamenopoulos, Theodore: Theodore is a Senior Lecturer in Design. He is a professional architect with expertise in design cognition, community-led design practices and complexity. He has been involved in numerous research projects around the themes of empowerment and civic engagement in design.

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