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Peers in life: ex-patients and relatives as reflecting teams

Carlos León

www.do-ge.ch

cleon@ccpp8g.org

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This paper reports a group of relatives and ex-patients interested in Open Dialogue that agree to start having some information meetings and evolve having a more regular familiarization and practice in polyphonic processes, listening, conversations and reflexions. Then, having a confidence / feeling of security, they spontaneously start to share personal issues and the meetings became more mutual help support sessions. Animated by some positive changes in their life, they asked for home visits involving me, the other voluntary participants and their relatives. These family visits, give us enough confidence to explore their reflexive participation in meetings with new families seeking information and help. In 19 workshops with the frequency of 1 meeting by month, the group of seventeen participants reduced to nine, have been in dialogical meetings for a total of 66.5 hours. From the first "giving information and responding therapeutically to personal needs", we have co-evolving building a mutual-help group based on dialogical processes and for six of them, establishing collaborations in the welcoming of new families seeking help. Four of six people are parents. During the process, there have been four evaluative discussions of the process. This experience is discussed according to certain basic assumptions of the Open Dialogue and the Peer support movement.

Introduction

We describe the process of a mixed group of psychiatric ex-users and parents/relatives that have been introduced to the practice of open dialogue and today participate as reflecting teams in open dialogue aid networks oriented for situations and families in mental distress. These persons and relatives have had the direct or indirect experience of been diagnosed and experienced traditional psychiatric system and treatments with medication and hospitalizations. It is in continuity with the collaborative, social trend in Open Dialogue where "all provision is organised around network meetings that bring together anyone who can help and support" (APOD).

Every voice counts

Participation of these people as resources is a new vision that supports diversity, inclusion and equity in the psychotherapeutic process. We agree with Jones and Brazzel (2006) talking generally about organisations and change when pointing out that the principle "every voice counts" - deserves to be heard, including people in conversations in the room - recognize that each individual has value and merit, has a unique contribution to make. It speaks directly to the subject of social justice and diversity intended to discover, understand, and foster change toward affirmation, inclusion, and open dialogue. It diminishes the hierarchy in systems and places equal value on every voice and individual. It is important in sustaining affirmative intervention and change, for supporting life-giving rather than life-diminishing experiences in organisations and processes of change.

Our work participate to a sustainable and continuous change in the culture of care that resonates which a growing consensus that the implementation of leveraging the power of lived experience is essential to providing a just and effective mental health system (Whitley 2019). We share the conviction that the future of psychiatry, mental health and emotional support must be more social and this trend must modify the institutional biological oriented psychiatry that had been dominant in our western industrial nations. That psychiatry becomes more social and community requires a thorough review of our interdisciplinary knowledge and mental health service policy. This belief is based on different sources 1. verification of failure with the dominant biomedical frame 2. the claim from users and the results obtained in family and systemic interventions, 3. the powerful influence evidence base coming from the integrative, social network, exploratory and reflective

Open Dialogue approach. Open dialogue is a way of organising services, a way of being and empowering people and a new respectful vision about human suffering.

Nothing about us without us

It is relatively recent that voices and presence of patients, families and users of psychiatry in the traditional healthcare system have been taken into account. A special moment in this story could be represented by the slogan “Nothing about us without us", originated in the disability rights community in the 90ths, and used for the "recovery movement of consumers/survivors/ex-patient in psychiatry” to obtain a right to participation in mental health care and transform the services to a more consumer-driven and recovery-oriented approach (Ostrow & Adams 2012).

However, from a more radical view in the early days, the recovery movement of persons with diagnosis of different forms of serious mental illness testifying meaningful involvement in every domain of life and felt oppressed by the power dynamic of institutional care, to a more and very discreet participatory involvement in systems starting in the 2000s, the topics of self-determination, choice, etc., continue still to be relevant today. The traditional system must embrace a recovery model but this seems to evolve within a semantic domain of re-adaptation to recovery and psychosocial rehabilitation. The coordination or integration between the academic and professional worlds of theory and the lived experience of people getting hurt. The mainstream system is always changing in a continuous manner but the structure of the system does not alter, the recovery view consisting in minor improvements and adjustments that do not change the system's core involving a new mission, leadership and organisational culture. The ethical imperative of how to help to prevent patronizing and exclusionary policies and actions requires an important organisational and epistemic change. For the "nothing about us without us" mantra being better enacted is needed a new radical vision where people with lived experience of mental illness must be meaningfully involved in every domain of mental health activity including service delivery, research, training, and governance (Whitley 2019). The comment of Ostrow & Adams (2012) remains current, that individuals with a diagnosis of a mental illness too often feel that they have been labelled and given a message by the treatment system and their providers of hopelessness about their lives, unending disability and inevitable deterioration; the goal of a meaningful life as an integrated member of the community still has not yet been achieved in a real way for many people. Over time, taking into account the subject subjective and existential in the first person, demanded by the recovery movement has become, within the framework of institutions, a rehabilitation paradigm understood as the "life and meaning of the person in the context of disability". Adherence to drug treatment and

education in symptomatology sickness for better knowledge of the disease remained frequently pillars, prerequisites for recovery. The message "that we can recover but that we have to live with the disease (!)" resulting a heavy paradox to bear (León, 2019)

Peers in recovery

Considering the advantage of the expertise accrued by people with lived experience of mental troubles is for the instant more possible by alternative models of care that are more independent. If self-supporting non-professional groups have its history, more specialized programs of Peers support in mental health spray around the world to support the potential possibilities for resistance and power of Peers in the transformation in mental health services. "PEER Support" designs groups and people making a good recovery from mental illness using their expertise by experience to help guide, support and instruct other people in the early steps of recovery.

Open Dialogue and recovery and Peers movement are aligned with the same quality and human rights values in mental health care (Von Peter et al. 2019). Then, here we can name the APOD program, registering qualified practitioners to practice Peer-supported in Open Dialogue network meetings, actively involved in promoting this as a model for mental healthcare across the NHS England, and internationally.

In Switzerland, this kind of collaborative programs between users and professionals started in 2010 on the German side by a private organisation, with some 180 Peers being trained until now. In the French area, the program started in 2013, with some 30 Peers being trained, also by a private initiative. Table 1 gives an idea of how low this participation remains in the French area (2.140.124 habitants in 2019).

Rate in %	Funding
20	Public
80	Public
20	Public
30	Private
20	Private
30	Private
20	Private
20	Private
50	Private

Table 1. Peers working in mental health in the French area of Switzerland.
From 50 people being trained, only 9 people are actively participating in some program. The common rate per person is between 20 and 30 % part-time. Financing is more private than public.

To note that the program to transform experience into expertise is currently focused on patients who can validate a recovery course. The peer practitioner program does not yet include families. Our

program looks new because the attention given to families and parents in a mixed team, its integration into psychotherapeutic processes and according to the vision of Open dialogue.

Relatives, parents and Peers in therapeutic networks

Our frame of reference is the open dialogue approach whose essence is the generation of shared meaning, shared experience and the resources multiplication in social networks around people concerned by psychological difficulties (Seikkula & Arnkil 2014). A central factor in Open Dialogue is his vision of human issues and his way of considering them.

We describe an experience that takes place at the level where some mental health actions could take place in the clearest partnership approach with users of services and their families. We report the process of a group of parents and people who have had the various experiences related to the traditional psychiatry system and as a consequence of a learning process is participating now in Open Dialogue therapeutic teams.

These people were informed about Open Dialogue in the framework of meetings operating in places belonging to mutual aid associations. In the Geneva area, self-support groups in mental health started to be created 30 years back. They were mostly supported by the psychiatric institution. The name of these organisations uses diagnostic categories by making heritage of the psychiatric model. There is the association of bipolar and depressive disorder, the OCD disorder group, the parents' group association, the hearing voices association...

- The first challenge in this process was to break down these categorical and practical distinctions and put together in the same learning space professionals, parents and people who have received a psychiatric diagnosis and treatment. That means going against an established tradition of separating issues by a group of belonging in a form both of creating distinctions/distances and affirming a labelled identity. Then creating open conversations different from arguing a point of view, going on discussions. etc. The concept of "Peers in life" being very useful widening the possibility of a human encounter beyond conceptual restrains identities.
- A second challenge was to manage a step by step processes following uncertainty progress in the co-construction of the experience, allowing to gradually emerge the needs and wishes of the group. As a result, an important emergent priority need was to work on life situations freeing the conceptual psychiatric enraging framework and place them in the perspective of

human phenomena as part of life and actualising them in the here and now! The training mixing in the beginning learning topics with therapeutic processes.

- An important aspect very present in most of our meetings was the resonance of situations evoking feelings of injustice and institutional mistreatment. Some members of the reflective team overreacting and going in conversations about big control theories in our society maybe as a way to elaborate the immediate experience of anger. The challenge is to what extent the reflections could be appearing free from projective aspects.

Participants and methods

This study has begun as an action which was in a second time accompanied by a flight of research, acting and leading with the participants the strengthening of the actors' capacity to act and at the same time carrying out ethical and epistemological reflections. Action research being the adequate approach for this process of mutual learning articulating theoretical knowledge, know-how and experiential knowledge.

We will describe a process that took place in four stages:

1. **Discovering Open Dialogue**. November 2017 - march 2018.
   (5 workshops 3.5 h each = 17h30 h)
   - The first is that of a group of people who have been informed by me about open dialogue and have shown interest in further developing knowledge about the approach.
2. **How to communicate better, starting practical exercises**. March 2018 - July 2018.
   (5 workshops 3.5 h each = 17h30 h)
   - The second phase is linked to the need of some participants to learn more on how to communicate to influence the change in the family member presenting the difficult situation. At this time, I was finishing the foundation training in the UK.
   - An initial assessment was carried out during this period.
3. **Self-support OD group and practical exercises**. September 2018 -to date.
   (9 workshops 3.5 h each = 31,5 h)
   - The third phase is to start à mix between general exercises and personal work on worrying situations and to receive adequate support from the group. I was acting as

responsible for the therapeutic aspects and the group started to participate as a reflexive group in concrete mutual situations. At this time I have started the trainers training in Helsinki;

- With this combination between me as a therapist and some members in the reflexive part we ask to move to the homes to perform open dialogue sessions with loved ones;
- two assessments were carried out during this period.

4. Participation as a reflexive team.

(7 situations, 45 meetings).

- The final phase is that of setting up meetings with people and families coming from outside who request intervention in Open dialogue, some members of the group present in their reflexive group function.

Phases 3 and 4 overlaps, workshops continue with the availability to participate in therapeutic outside meetings.

In all, 17 persons started the process. Initially, the group was made up of some professionals (4), patients (2 persons in medication withdrawal, 2 persons in psychiatric treatment), ex-patients (3 persons leading a quality of life) and relatives (5 four mothers and one daughter) 1 activist in quality rights.

At the end of 9 participants, 6 are currently part of the open dialogue aid networks oriented for situations and families in mental distress. They exercised in all 66.5 hours of dialogical practice. Table 2. synthesizes the structure of the process.

Table 2. In the first time, the meetings discussed the foundation and the principles of the OD. Professionals were curious to understand the approach, they roughly understood the approach and gradually withdrew. During the second phase, the 2 persons in psychiatric treatment and one in medication withdrawal participated but were in overload with the work requiring group exercises and introspection. Stage 3 is a very active work engaged in personal situations. In the last stage, 6 participants wished to participate actively in therapeutic meetings.

PARTICIPANTS	STAGE 1	STAGE 2	STAGE 3	STAGE 4
	November 2017 - March 2018	March 2018 - July 2018	September 2018 - to date	March 2019 - to date
	5 workshops = 17h30	5 workshops = 17h30	9 workshops = 31h30	7 situations = 45 meetings
		1st assessment 22.08.2018	2nd assessment 30.01.2019 3rd assessment 26.05.2019	4th assessment 6.01.2020
Professionals 4	√	X	X	X
Patients 4	√	√	X	X
Ex-patients 3	√	√	√	√ 2/1
Relatives 5	√	√	√	√ 3/2
Concerned activist 1	√	√	√	√

Observations about the process

Stage 1. Discovering open dialogue

As a result of some conferences and debates based on Daniel Meckler's documentary carried out in associative circles of people directly concerned with mental health, a group of 17 people feel the need to "know more and promote" this approach. They asked for a specific better understanding of Open Dialogue. For family members and patients having a long course with conventional psychiatric treatments, it is very attractive to hear about alternatives to traditional forms of intervention in mental health. Open Dialogue which gives a place to be heard, be part of the crises overtaking and discussions regarding the treatment look as a very valuable alternative, even more, when it is known the very good results with psychoses and mental health problems!

Stage 2. "Not preparing strategies behind the relative back"

13 participants were present in this stage. Gradually it became clearer for the other 9 participants their motivation to learn more on how to communicate to influence the change in the family member presenting the difficult situation.

The initial proposal "of obtaining information about Open Dialogue" in stage 1., changed to be more focused on personal concerns. An important need has been exploring more concrete personal situations. On the one hand, the need for the relative's participation in the meetings was discussed to avoid “talking behind the relative back". Once we have clarified the practical and ethical difficulty of working on the absent person, in the absence of the relatives, the purpose was to look at how all situation could affect them directly. This step was made in agreement to the holistic perspective that in any situation of crisis or installed chronicity, there is not only a person who suffers, that the relatives suffer equally and that it is valid and necessary to respond to this.

Of course, it is possible and inevitable that during these discussions the family member is talked about, but it is not about studying his behaviour, making causal assumptions about why and how, establishing strategies for the change of the absent person, or studying their situation to think about intervention plans! Participants were prevented to be attentive in not focusing on "why" the behaviours of the absent relative are producing. They were invited to differentiate between exploring " the why" and exploring contexts with circular questions, imagining the multiple functions a behaviour can have, expanding fixed representations in more open thoughts, etc., In another hand, they were invited not to think at the place of another person, not became very affirmative about the linear efforts to find the “truth”, the “cause”, that could explain and change actual symptomatic behaviours.

Polyphony. To realize the objective of exploring dialogism in their selves, it was necessary to introduce the knowledge of what a dialogue is, what differentiates it from a discussion or a dialectic's synthesis in Hegel conceptualisation. Here the distinction made by Morin () was important: "*dialogic is not in a reductive way as a simple overcoming of contradictions by synthesis but as the necessary and complementary presence of antagonistic processes or instances. The complementary association of antagonisms which allows us to connect ideas which in us reject each other, such as the idea of life and death which are the other side one of the other...".*

The learning in this period being how to be able to be in a quality dialogue without wanting to advise and influence or convenience another person!

Then the group were ready to start to experience the dialogue in their selves, sharing worries, being attentive to those interior and external voices. The emotions and concerns that came without prejudging and focusing on how to proceed to have influence, starting à dialogue opening new perspectives.

Stage 3. Self-support OD group and practical exercises.

Dialogues on dialogues. Following the experiential methodology that characterizes learning by doing, the team practised reflexions, exploring resonances and reflexions. This practice became a pleasant activity, is a challenge what to do with strong "unfairly resonances".

Two aspects deserve to be named:

- Listening situations of non-respect and lack of dignity in relationships with the treatment system activate very strong angry and sad reactions.
- Also, it was challenging avoiding tendencies to give advice and direct "counselling".

More open conversations were needed to give the allow talking about personal experiences in managing difficult situations. These aspects of sharing common experiences have had the function of uniting people around common feelings and values.

Solidarity and mutual help. Sharing similar experiences in a context of respect and security is one of the founding principles of mutual aid groups. This aspect was observed; the group begins to show mutual support. This mutual support was not looked for but appears naturally.

As the process progresses, the group quickly moves from a role-play practice to exposure of important personal dilemmas. Some reports of small "positive" changes in communication with the family member start to came describing better real situations with their relatives.

- *In this period, one of the participants start to came bringing the family member (mother) to our meetings. This person presenting several important difficulties. At the level of comprehension and expression, her mother tongue not being French, her expressions in Arabic were not understood. She had a disability, having certain deafness and a beguilement. In other, she had just a heavy abuse history and come out of 15 years of mistreatment by her husband who drugged her to take advantage of her financial situation, etc.*

The group opened a space of solidarity and understanding of this situation and there was a certain benefit for the person, and certainly, the group show a big opened to tolerance and understanding. Except that one day a crisis of anger took place and the two people's mother and daughter were in crises. This situation leaves clear the need to better differentiate two spaces, that of dialogical learning and practice and that of clear special attention to complex family situations.

Home intervention. At the same period, someone suggested visits be made at home with the family member's consent. This way what was done with the group developing an important activity in real life. Someone in the group created a "Whatsup" group, the messages start to be exchanged, the visit proposals were made in this way public with voluntary participation of those who want to come as a reflexive group. The therapeutically part of the process depending on my presence.
The evidence of this capability to offer real responses to real needs allows us to suppose that a certain competency has been established that can be used in other contexts such as real consultation.

Stage 4. Relatives and peers as collaborators in family consultations
Then we start another phase, the relatives acting as a reflexive group in real consultation of families that look for Open Dialogue as a solution to their concerns.

Generalization of experience**.** Currently, this path is being evaluated and the need to extend this experience is considered in a fundraiser.

Assessment results

Along the process, we have carried out four participatory evaluations in the form of dialogue. We present in clusters the most relevant comments made by the participants. The evaluation took the form of an open dialogue on various themes. We have defined four of these topics.

1. Difficulty expressed about listening and understanding

- *" Very difficult to exercise this no intrusive, confrontational no interventionist form" / "I realized my difficulty to listen, to distract myself, the emotion of the others did not interest me, only my concerns, I prejudged the way of expressing the other, his way of saying absurd" / "I was surprised myself not listening but look elsewhere" / " I have not tried outside" / I see a result but as I follows various therapies do not what comes from OD" / " I*

still have trouble listening" / " at the beginning I was lost. I did not understand after several sessions" / "Easy in theory but not in practice" / " It takes interior work to get listening"/

2. Open Dialogue as a different way of thinking, a global vision which gives meaning to behaviours and allows a better understanding of the other.

- *"The less emphasis the more there is a space for resonance" / "OD stimulates understanding" / " There can be different understandings" / " Od works on the confusion which prevents understanding and tends towards the monologue" / "OD opens a space of consciousness*
- *"Very beneficial ... the importance of saying words that we have heard and touched the most, the person feels heard and that calms the game" / "It opens up the possibility of going forward" / impression of never coming back to problems" / "I like this attitude of tolerance towards others" / " Everyone finds their own place" / "We can talk about our impressions" / It sounds very positive on my health- zen base" / "Do not define too much to work on objectives or symptoms enlarged the framework of the person"*
- *" It looks like it goes slowly outside but in fact it goes very fast!" / "I had never had an answer to my questions, I had assaults... we went to movies together, for 6 years we did not communicate! " / I had very quick results without giving advice or imposing obligations" / " Hard to believe is going on so well"*

3. Our home visits as different from home visits service of the institution

- *" Very important the home displacement for those with isolation locks" / "Is very different of how things are with the home visit service who works little with the words and are more drugs centred even if they say that they do not impose but propose but it is necessary to see the way how they propose!"/ " It is useful for caregivers; it decreases this impression of being different at work than at home. we are at work we relax to let go to each other at home..."/ " We don't force ourselves, we become useful caregivers" /*

4. Reflexions about reflexion

- *"There is this mirrored side to understand the thought of the other, to try to reflect it while respecting it by opening tracks... it seems abstract but I think it" / "I have to start from my reflection, to disregard getting out of everything I think, what I saw, which traumatized me, from a lot of things I received to help.../ " Focus on what the person say without thinking too much, without going to far.../ " Is the present moment that counts for the person to develop in the present moment" / "We stop the interview and listen to another polyphony made in a*

benevolent way" / "The elaborations of others do good ideas come without me having to please others as I will follow your idea or advice, without obligation to take it... is an opening itself"/ " Too many ideas is too much complexity, clutter the person in crisis that receives too much information without filter. So we can bring something new without repeating, without arguing" / "Few ideas and respect for silences is like breathing" / "I had less this feeling of self-defence, question-answer I must position myself!"/ "We work for the family and ourselves, it's great!" / "The work on oneself makes changes in the other!" / " create a space where you can say whatever is"/ "We can observe and be transparent. a part observes and we can live with this transparency"/ "You have to be careful what I say, maybe I use good or bad or not enough... evaluations... or you have to...and therefore, I have to stay in a space of progress to draw attention to the positive without being in positivism in utterance, stay in a recovery progress space"

Discussion

Our work has explored the possibility of participation of ex-patients and parents involved in psychotherapeutic networks. The inclusion of parents and caregivers who can put their expertise to the service by experience in therapeutic situations is an important novelty in Switzerland. Our work was gradually built in a dialectical process between the interest and the needs of people curious about Open Dialogue and my interests in the reinforcement of resources being able to make part of supports according to the dialogical approach in networks meetings.

The experience of the traditional psychiatric system had been frequently present as a form of trauma. During near all various sessions, the first part was charged with personal stories of abuse of authority, mistreatment, lack of finesse in relationships, iatrogenic results were present with a strong potential to create strong group resonances. These experiences have been presented as an important motivator to learn and replicate open Dialogue learning. The experience of psychic difficulty always put to evidence the system of care as long as feelings of dignity, fear, injustice are touched. These feelings are contrasting because the other side of the scene is the empathic force, deep intuition and transparent way of approaching aspects of the situations by the participants.

Beyond Heraclitus, the strength of self-organization

Well, that attributed to Heraclitus, the idea that one does not always swim in the same river, that the path and dynamic of the river is a property to which the swimmer or sailor must adapt, would seem

to be a metaphor linked to the fact that the "soul in a context" is the most incorporated thing that always flows in a world of constant change. Let me illustrate this image.

An aspect which appeared at the beginning as a question or challenge was in the ability of participants to distance themselves from this type of bad experiences and make them profitable in a context of personal development and mutual aid. As a proverb says, "experience is not what happens to us but what we do with it"! The challenge did not arise from my doubt of the group's ability to go through this process but above all the fact that the process described took shape gradually. It was not planned to proceed first to work on one aspect and then another. Accompanying the different manifestations emerging and constituting the dynamics of this group differentiate my function in this system. If in a first time my responsibility was to direct the "ship in which we sail", I found myself to be conducted by the group in its movement. I let myself be led by the dynamic movement of these souls in polyphonic movement and was both a great experience of discovery and inspiration.

As being myself part of this process, I followed and continue to follow the various spontaneous movements emerging in the group believing in another important dialogical principle that a system has this capacity to organize its vectors by their selves. Between auto organization and control in this process, I have been involved in the start point with an initial asymmetric role of "expert" in Open Dialogue, to be later also positioned as a collaborator in the accompaniment of their desires and actions to improve their situation. In return, their skills can be used for the benefit of other people. This is the emergent goal of this study, to look closely at these various tangled movements.

For the field of a social community approach in mental health evolve it may work at different levels. Stylianidis, (2014) describes the macro level of how the representations and values of our society about mental health are debated; the meso-level about how institutions (schools, health and social services, housing, employment and legal situations) are organised in the community in new perspectives and; the micro-level dominated essentially by what happens between people with core topics such as therapeutic as well as family and peer communication and support.

We see this experience as a pilot project and hope that it can continue to develop in the future with more institutional support.

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