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Relational, ethically sound co-production in mental health care research: epistemic injustice and the need for an ethics of care

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ABSTRACT

Co-production and service user involvement are increasingly encouraged in mental health care research. However, power hierarchies in knowledge can affect the co-production of knowledge by stakeholders. Therefore, the purpose of this article is to deepen our understanding of the relational dynamics at stake in co-researching teams and larger groups of stakeholders involved in research. We reflect on a process of co-production in psychiatric emergency care and show the ethical responsibilities of researchers in dealing with the power dynamics. A collaborative reflection on the process of co-production shows that the voices of service users, who participated as co-researchers, were silenced, thereby reinforcing epistemic injustice. Ethics of care offered guidance for ethical reflection and ways to manage relational dynamics. Instead of 'fight and flight', the 'tend and befriend' option was fruitful for relational ethically sound co-production, leading to teams and stakeholders jointly reflecting on knowledge co-production. Relational reflexive work brings people together for solidarity, support, and advice.

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Epistemic injustice; co-production; service user-involvement; ethics of care; participatory health research

Introduction

The co-production of knowledge by diverse stakeholders, including experts, researchers, and service users, is becoming of increasing interest in mental health care (Drew et al., 2011; Ferraz, 2018). The authors work in participatory research in health and social well-being (Abma et al., 2019; Wright & Kongats, 2019), Participatory Health Research (PHR) for short. PHR is an umbrella term that unites various traditions that endeavour to share power among all actors involved, including service users. This critical approach gives particular attention to power hierarchies in research that are inherent to the medical and health care field (Groot & Abma, 2019). One key tenet of PHR is that leaving out the perspectives of those whose life and work is at stake will lead to a decreased understanding of our social world, and dishonour the capacities of those whose voices are not heard.

Respect for knowledge diversity is a core ethical and epistemological value in participatory research. It entails respect for a variety of knowledge sources such as propositional (academic ideas and theories), practical (skills and competencies), and experiential (through empathy and resonance) (Reason & Rowan, 1981). Service users derive their experiential knowledge from face-to-face encounters with persons, places, or things (Reason & Rowan, 1981), and have the 'bodily' lived experience of, for example, an involuntary admission in psychiatric care (Weerman & Abma, 2018). Although co-production of knowledge as well as peer education are merging in psychiatric care, experiential knowledge from service users is still not yet considered a mainstream and valid source of knowledge in psychiatric research.

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In Dutch psychiatric research, a large group of researchers work on the assumption that only experts with scientific (propositional) knowledge have methods and techniques to produce objective truths, perpetuating the perception that ‘against our everyday knowledge, only scientific understanding may give us, however tentatively, the true picture of the world’ (Glas & de Ridder, 2018, p. 72).

Service users still experience a low recognition of the value experiential knowledge. This type of knowledge brings a different picture of the world than scientific knowledge. The integration of different types of knowledge is therefore experienced as complicated. Consequently, in acute psychiatric care participatory research, that facilitates dialogue and learning featuring both (former) service users as co-researchers and professionals, is relatively rare.

Worldwide, there are groups of service users practicing service user-led research (Baart & Abma, 2011; Fox, 2017; Staddon, 2015; Thornicroft & Tansella, 2005; Trivedi & Wykes, 2002; Turner & Gillard, 2012) and research from the base of Mad Studies (Beresford & Russo, 2016). In both approaches service users are in control of the study, minimizing relational dynamics issues. In a PHR based approach, there is a commitment to share power in the research process among all participants, be it service-users, academics with and without experiential knowledge, and other stakeholders such as professionals who work in the field of emergency psychiatric care (psychiatrists, nurses, ambulance staff, police men).

In this article, we present a collaborative reflection on the process of co-production shaped by our PHR study in Dutch psychiatric health care in 2016–2017 – the ‘Good-Care-in-Crisis’ study. We reflect on the relational dynamics between six co-research members and other stakeholders involved in the process, offering support for the inclusion of experiential knowledge in research, and providing guidance for team members of co-production processes.

This article contributes to the understanding of the relational dynamics in collaborative research (Nordentoft & Olesen, 2018; Phillips et al., 2018; Thomas-Hughes, 2018), as well as the emerging literature on relational ethics of participatory action research (Banks & Brydon-Miller, 2019; Hersted et al., 2019) and community engagement (Reynolds & Sariola, 2018), particularly in the field of mental health and psychiatry (Faulkner, 2004; Rose, 2009; Russo, 2012; Schneider, 2010; Telford & Faulkner, 2004). Ethics of Care (Tronto, 1993, 2013) offers valuable guidance to research teams who work in the co-production and participatory research field, by defending a caring attentiveness to epistemic injustice (Fricker, 2009; Simons & Greene, 2014) where a human subject is wronged in their capacity as a knower (Fricker, 2009). It also calls for an approach to ‘tend to befriend’ rather than ‘fight and flight.’ Finally, it asserts that it is in relationships that people express their needs, communicate, and receive care and recognition. Explicit attention to relationships in the research process widens the scope of values by encouraging deliberation and dialogue about what good care and caring means (Abma et al., 2020).

Material and methods

Author team

The first author is an academic researcher and coordinator of the Centre of Client Experiences in the Netherlands. The second author is a representative of the service user perspective, has a background in social work, and has lived experiences as a service user in psychiatric emergency care. The third author is a professor in Participation & Diversity. All authors were actively involved in the Good-Care-in-Crisis study and share an interest in relational ethics and co-production of knowledge.

Methods of reflection in this article

Data were generated in a participatory fashion in two phases: during the study (2016–17), and afterwards in a relational reflexive period (2018–2019). An overview of the data and data-gathering periods can be seen in [Table 1](#). All data yielded insights into the feelings, thoughts, and considerations of the team members during the study. The co-research team of the ‘Good-Care-in-Crisis’-study

Table 1. Data of the study and period of data collection.

Process of reflection during and after the 'Good-Care-in-Crisis'-study	
Period	Data
During process (2016–2017)	<ul style="list-style-type: none"> • Diary notes of individual research team members • Emails between research team members • Notes of phone calls in which reflections about challenges were discussed (taken by the first author) • Notes of conversations about the study between care professionals and the authors • Achieved emails of conversations about the study with the directors of the mental health care institutions with the authors • Transcribed audios of a group session about critical incidents in the research team
• After process (2018)	<ul style="list-style-type: none"> • Transcribed audios of interviews (60–90 minutes) within the research team members by the first author (n = 5) • Dialogue sessions with the authors about the process (n = 3)

consisted of six people, including the present authors. Some members combined a background in academic research with lived experiences in psychiatric emergency care as service-users, and as formal or informal carers. For anonymity reasons, we do not elaborate on this more in detail. The data was analysed systematically, in line with the approach of thematic analyses (Braun & Clarke, 2006).

Context: 'Good Care in Crisis' study overview

'Good Care in Crisis' was a PHR study which aimed to improve the psychiatric emergency care service delivery. The experiences of stakeholders and their commonalities were gathered in dialogue sessions. In Table 2 we provide an overview of the methods of data gathering and the methodology of the study, including the nature of co-production in all phases. The 'Good-Care-in-Crisis' study was commissioned and funded by two psychiatric care organisations and its findings were published on a Dutch report (Vink et al., 2017) and on a scientific article (Groot et al., 2019).

By opting for co-production in the 'Good-Care-in-Crisis'-study, we wanted to acknowledge the capacities of service users, defending the emancipatory idea that they have the right to have a voice, so often silenced, in the evaluation of the service responsible for their care in a crisis. Their participation enriched the conclusions and generated more ideas for improvement.

Based on the ideal typologies in collaborative research relations (Phillips et al., 2018), the authors co-created collaboratively by researchers and co-researchers in the field the objectives of the project and all content. This means that all actors, especially service users, participate on an equal footing and are equally committed. This is in line with the approach of the Centre for Client Experiences, where the study was initiated. However, we didn't discuss this approach explicitly with our team,

Table 2. Co-production in all phases of 'Good-Care-in-Crisis'-study.

Process of responsive evaluation in the 'Good-Care-in-Crisis'-study		
Phase	Activities	Co-production
I: Creating social conditions	Informal conversations with key figures	All conversations in pairs (a co-researchers with lived experiences and an academic title)
II: Exploration	Data gathering (interviews with service users and professionals) and a focus group with care givers	All together (co-research team), we ... <ul style="list-style-type: none"> • ... created a recruitment-plan of service users • ... conducted the interviews and focus group • ... analyzed the data • ... discussed the findings for report
III: Validation	Focus groups with service users and professionals about the findings in homogenous groups	
IV: Writing report	Writing the findings in a report	Co-researchers with an academic affiliation were in the lead in reporting and writing academic articles
V: Dialogue and mutual understanding	Dialogue session with heterogeneous groups	All together (co-research team), we organized and facilitated the session

commissioners and other stakeholders, but only in the proposal phase and within a small group. In retrospect, some team members possibly expected a more traditional co-production approach where the researchers define the project's aims and content and invite field actors to take part in a fixed, pre-set framework.

Ethics

In 2018, we asked all the team members who participated in the study to join a collaborative reflection. The aim was to gain an in-depth understanding of the process of co-production to produce an academic article. Two of the three other members were open to interviews about their experience, but did not want to join the writing process. The third member did not want to participate, but consented for their experiences to be used in the article. We were all extra attentive and careful about the relational dynamics in this study by caring for each other following the lessons from a previous study on ethics of care in collaborative work (Groot et al., 2018).

The story

Centre of Client Experiences received an invitation to conduct a participatory evaluation from the perspective of service users which became the 'Good-Care-in-Crisis' study. Previously, the mental health care organisations had only done evaluations from the perspective of the care professionals. A solid, diverse team was brought together and collaborated in the development of the design, strategic decisions, and in the process of data gathering and analysis. On a reflexive group session held to discuss the beginning of the research, one team member with experiential knowledge stated:

Overall, I think it was a collaborative study. We tried to work together on every step of the research. From the start ... the safe setting was crucial; we reflected on our inclusive way of working collaboratively, and decided together that we wanted to work in this way throughout the research process. (January 2017)

Despite the positive experiences using co-production, we encountered several challenging relational dynamics and power issues which happened at three critical moments: reporting; discussing the findings; reception, rewriting, and reconnecting. Each phase is described from the perspective of each of the three authors, followed by a reflection.

Critical moments: reporting

Silencing the service users voice due to tight deadlines

The deadline for the submission of the full report was approaching. We had planned a dialogue session with stakeholders in the psychiatric care service delivery (including emergency psychiatric care professionals, police officers, and experts by experience). We were to send a copy of the full report to all invitees beforehand. At that point, however, the team had only produced the results collaboratively, but not the conclusion, discussion, and summary. One of the team members with an academic affiliation and experience as a parent of a service user produced a draft, about which a team member with lived experiences commented on a phone call:

I saw that a few sentences were written by someone who could not empathise with the position of the service user. ... I felt dispossessed and unable to change these sentences. Who owns the final version? Who decides what words are chosen? Who has the power to decide the content of this most often read and most important part of the report [the conclusion]? It feels like X [the author of the draft] has all the power. (May 2016)

Upon reflecting on this incident, we noted that co-authoring a report is a precarious relational process, and epistemic diversity needs to be respected. Asking for a deadline extension can be difficult when research is funded externally but, in retrospect, that would have been the right thing to do in order to have time to include all 'knowledges' and perspectives. For the team members with lived experiences, it was crucial to use language that gave equal footing to service users and

professionals in the conclusion and summary, because the report would guide the strategic vision of the mental health care organisations. Academic researchers might find difficult to share power and control over a report and feel responsible for meeting the deadline. A team member with lived experiences stated in a one-to-one conversation:

What is at stake for whom? The agreed upon budget and timeframes in the proposal were important in the decision made by X [the author of the draft]. In the end, as a potential service user of the emergency department, I could have to face the actions that are taken based on the conclusions in the report in a care situation, but there is not much at stake for X. (April 2018)

We found that researchers in hierarchical academic contexts who produce and uphold inequalities may seek to assert dominant 'logics,' and preserve the knowledge of the already privileged.

Exclusion of service users who are limited in their writing skills

One of the team members has dyslexia and can only give feedback verbally. The research proposal, approved by the commissioners, included a written report as a deliverable. The team member experienced this situation as an exclusion mechanism:

I could not make myself clear, not even to X. ... My arguments were not understood or didn't come through when I talked, and I could not write [my thoughts] down like the others. ... Others gained influence by writing. Parts of my knowledge have been lost because I have to speak, rather than write. ... Not everything has been heard or understood. (November 2017)

Reflecting on this incident, we concluded that, in the academic world, the focus is on written texts which is not an inclusive practice. The team mainly used text, despite conducting creative analysis sessions and including items from that analysis in the final report, such as song lyrics, collages, drawings and paintings. Some members of the team feared that using alternative media such as video, voice, or music would qualify the research as 'unscientific,' and stakeholders would undervalue the results.

Critical moments: discussing the findings

Not believing or valuing the experiential knowledge of service users

A session with all stakeholders to discuss the findings and stimulate dialogue was held but many of the participants felt offended by the findings of the study. Afterwards, we discussed the defensive behaviour of the emergency care professionals who seemed to deny the veracity of the experiences of the service users. A team member with lived experiences stated:

We did not make up the story in the report! But, they gave me that feeling [that we had]. We followed all the 'academic guidelines' of audio recordings and informed consent, and were affiliated with a highbrow medical university, under the responsibility of a well-known professor! And still, we were treated as if it is not important to listen to us. (June 2016)

The team members with lived experiences felt that their knowledge and the voices of service users were played down or not taken seriously:

I felt that I was seen as a service user, not as a 'whole person,' and definitely not as an expert-by-experience ... nor as a co-researcher. It was terrifying because that is my current identity, role, and expertise. As a service user and advocate of psychiatric patients, you need to prove yourself again and again, and show that you have distance from the subject of the study. You have to show that it is not only 'your own story,' but also the story of a variety of service users. (June 2016)

The academic researchers sensed that the qualitative and participatory nature of the research was dismissed due to a positivistic scientific tradition and managerial context, which values evidence-based medicine and where the focus is on objectivity and distance. It can be difficult for stakeholders such as medical specialists and care workers to recognise that stories and qualitative interpretations are valid sources of knowledge. In future research, we should be prepared for the pushback that our

approach might generate. For people with lived experiences, it can be painful to be confronted with oppositional views as well.

Lost connections and reproduction of strategic behaviour

While analysing the positions of the mental health care professionals after the dialogue sessions, one team member pointed out the parallelism between professionals and service users experiences in the emergency psychiatric department. The mental health care professionals defended themselves by pointing out that they felt unsafe and were scared of potential outbursts of anger from service users, and that previous experiences had engendered a lack of trust. The confrontation and power asymmetry complicated a dialogue that required 'openness' and a 'receptivity to otherness' to foster mutual learning (Gadamer, in Abma et al., 2017). The professionals felt trapped between the dominance of the system and the values of productivity and safety.

The disconnection between mental health professionals and service users in the dialogue session and the subsequent team discussions revealed a willingness to understand the perspectives of the professionals, essential for restoring these connections. A passage from an email discussion on the day after the session revealed this empathy for the professionals:

It was intense. Taking a quick look back at the session, I can say that we might have underestimated the fact that we also had to show care for the professionals in the room. I was not aware that they experienced a complex situation of feeling unsafe and mistrust ... (June 2016)

Reflecting on this moment, the criticism of care expressed in the study was not focused on the professionals, but rather on the care institutions that did not deliver democratic care (due to external and internal inspections, displaying pressure by insurance companies). Professionals and service users are allies in their desire for 'good care' which features attention, listening, contact and partnership. Unfortunately, this relationship can break under pressure, and this was apparent in our session. In a conversation with a psychiatric care professional, it was apparent that professionals were also aware of this disconnection:

Yes, you could say that we are also 'victims' of the system. That resonated with the team ... and in my head ... That's how it is. We [service users and professionals alike] must collaborate, instead of fighting. (October 2016)

In the report, the perspective of the least heard (in this case, the service users) were preponderant and the tone was activist and critical. The perspective of the care professionals was not adequately represented in the report because the organisation and individual professionals did not prioritise their role as co-researchers or sounding board members in the evaluation study. Besides, their experiences had already been abundantly described in earlier studies. Moreover, three of the team members were affiliated with a service user advocacy organisation, and had been trained to advance service user's critical views.

In retrospect, we argue that it would have been beneficial to include views from all stakeholders to ensure that the findings were balanced. Despite its difficulty, it is essential that the author of a report represents and remains equally distant from all parties. Foster agreement between stakeholder groups us a first step towards facilitation of the implementation of the findings in the care institution.

Critical moments: reception, rewriting, and reconnecting

Offering a one-sided picture

The results of the study were positively received by one of the funding organisation decision makers but other powerful entities sought to prevent us from disseminating the results. There was an unspoken fear that the contents of the report could be used by external entities to sanction the organisation, a fear justified by previous experiences. A team member stated in a one-to-one conversation:

I felt erased, that my existence was not welcome. I wonder: do [the director and managers] take mental health care service users seriously? Did they learn anything from this research? It is disappointing. (April 2018)

Another member reported:

Are they so ... is our experiential knowledge such ... I feel that there is a wall between what service users know and do, and the doctor and his or her responsibility. (May 2018)

In reflecting about this incident, we concluded that if the results had been less critical, the report would have been disseminated. After extensive deliberation, we chose to not publish the report as it stood, as its critical content could damage our relationships with mental health organisations. Team members are invested in promoting changes in emergency care practices, and our partnership with the commissioners and organisations is crucial to our ability to make any difference to the process of care.

One of the authors with an academic affiliation re-wrote the text of the report to obtain a better balance of voices; the professionals' perspectives were given a more prominent place, while the tone was made softer and more appreciative. The funding had been used up, so the rewriting was done in her own time and, regrettably, it became less co-productive and participatory. The draft of the revised report was sent to all team members, and discussed in one-to-one telephone calls. One of the authors decided to remove her name from the report, feeling that the report wasn't critical anymore and that a 'covert' message was insufficient to lead to change. In a one-to-one conversation, she explained that she felt that her activism had been erased, her criticism about the gender and power dynamics had been censored, and valuable knowledge had been lost. She felt she was no longer part of the team, making her feel lonely and left out.

Her withdrawal evoked many ambivalent emotions in the team who considered the rewritten report to be a 'workable compromise' that prevented the research from being unusable. The original report was published on the websites of the mental health care organisations concerned, as well as on our own website. Making the findings available to the general public was a fundamental democratic value of our participatory evaluation. We also received permission to share the findings publicly and to write academic articles about them.

New connections

Two years after publishing the 'Good-Care-in-Crisis'-report, this reflection on the micro-political and moral dynamics of the research, in addition to the reflection on the ethics of care in collaboration (Groot et al., 2018), healed the relationships between the team members, including the present authors. Presentations of the findings to groups in one of the psychiatric emergency care organisations helped to reconnect with a part of the stakeholders. Last month, we conducted a working visit to an innovative organisation in the field of mental health care that follows a service user-centred and -led mode of operation, together with a delegation of emergency care stakeholders, experts by experience, and academic researchers. With this group, we plan to do participatory action research that will improve emergency care.

Discussion

This article illustrates the complexity of relational dynamics in the co-production of knowledge in mental health care research. This reflection shows that, in hierarchical contexts such as psychiatric care and academic hospital settings that widely produce and uphold inequalities, dominant 'logics' can reassert the knowledge espoused by those who are already privileged. This is problematic because the complexity of problems in mental health care is such that it is not possible to solve them if mental health care organisations only focus on propositional knowledge as the 'true picture of the world' (Glas & de Ridder, 2018, p. 72) as we will not have access to different views to co-create

out-of-the-box solutions. Moreover, such an approach would harm service users, and their potential future involvement in research.

As we see it, power works partly through functional positions in societal hierarchies and organizations, such as researchers who have a vested role, function and interest in the production of knowledge. Within the production of knowledge, service users are relatively new as contributors and do not yet have a well-defined role and function. Traditionally service users are not conceived as knowers and having relevant and valid expertise (Crichton et al., 2017; Kidd & Carel, 2017). In addition, there is the more subtle process of implicit power enacted in social interactions and routines through the use of certain discourses and norms. Power and structures of inequality are thus not unilaterally oppressive and dominating. They are 'productive' as all people involved – in our case researchers, healthcare professionals and service users – are inevitably part of its enactment, and carry responsibility for the (re)production of inequalities. If researchers are using professional or technical scientific jargon, this can exclude users who do not express their concerns in that language. The concerns of users, often expressed in narratives, may not even be 'translatable' into a scientific discourse and lose credibility (Woelders, 2020).

To counter this silencing, researchers have to create room for an equal and fair dialogue, which can lead to resistance from and tensions with other stakeholders, who might perceive that the power balance and status quo is shifting (Foster & Glass, 2017). Any loss of connections with and among people is counterproductive to achieving mutual respect for all forms of knowledge and voices. We want to discuss one explanation for the relational dynamics and lost connections in this research in specific, namely epistemic injustice (Fricker, 2009, 2013).

The connections between those involved in the study of emergency care came under pressure at several moments in this study. Co-researchers with experiential knowledge experienced epistemic injustice – a concept coined by philosopher and feminist Miranda Fricker (2009, 2013) that denotes the reality in which people are wronged, specifically in their capacity as a knower. Co-researchers felt that their capacity as knowers was sometimes undervalued, and that their stories were deemed not worth listening to. In particular, they felt wronged in their capacity as knowers when they thought they were not heard in the dialogue session with professionals and academic researchers that took place in the reporting phase (testimonial injustice). Their perspectives on issues that were of great interest to them, and might affect them and other service users, were systematically ignored. The written culture in academia resulted in a situation in which a co-researcher with dyslexia did not feel in possession of the resources necessary to exchange and interpret her experiences (hermeneutic injustice) (Fricker, 2013).

This feeling of epistemic injustice was especially painful, given the expectations raised at the beginning of the co-production process in the research, and the attention placed on relationships. Although Glass and Newman (2015) state that participatory research is a way to fight against epistemic injustice, we saw it occurring in this study – sometimes very overtly (in the form of an unwillingness to publish a report), and sometimes more subtly (when academic researchers took the lead in writing a report). Paphitis (2018) has written that in the research process, colleagues, institutions, and/or project funders do not deem more participatory forms of knowledge generation and dissemination as valuable, valid, academic, or legitimate, and that standard academic outputs, produced without active collaboration, remain the key metric of success (Paphitis, 2018).

Finally, it must be admitted that the research team at times lost its connection with each other and other stakeholders involved. The re-writing of the report and the dialogue session can be seen as examples of the polarisation and disconnection in the process. This crisis of connection reflects the contemporary situation in mental health care in general and psychiatric emergency care in particular, which is characterised by fragmentation, power plays, and fear (Groot et al., 2019). Co-production in research can threaten daily routines in mental health care, and lead to withdrawal, resistance, and anger, and as a result, in situations where tensions grow and remain unresolved, people are inclined to respond with self-protection and increased control, rather than care and creativity.

Joan Tronto (1993, 2013) alerted us to the fact that if people respond in this way to threats and changes, they not only abandon their connections with others, but also with themselves, in a form of domino effect. Care ethicists and psychologists discovered that in addition to the common ‘flight or fight’ response to stress, there is another ‘tend and befriend’ option: coming together for solidarity, support, and advice (Visse & Abma, 2018; Way et al., 2018). This care-ethical approach has brought us to where we are now, and is a fruitful way to approach co-production. Co-production of knowledge includes ethical responsibilities and relational reflexive work. Collaborative reflection on relational processes can help to understand different perspectives and offer solidarity. We want to add that ‘tend and befriend’ is about a respectful connection with positive energy, in which people share a common understanding of the incidents that happened, and share a horizon and future perspective for change and action.

We would finally refer to Thomas-Hughes (2018), who also had the courage to share her experiences with ‘ethically messy’ issues in co-produced research. She concluded her article with the message that the issues documented in her paper were small features of an ambitious project. As in our project, she did achieve a significant level of power-sharing and facilitated meaningful dialogues.

Conclusion

This article offers in-depth insight into the practice of co-production in mental health research and experienced epistemic injustice. It is an essential human value to feel recognised in the capacity to know and the right to create your reality. In mental health care research, epistemic injustice can occur as a result of power hierarchies and established relationships. Co-production with service-users implies a change in everyday routines and relationships of power, and can be met with hostility or withdrawal, which can deepen the crisis of connection in mental health care. This article reveals that the co-production of knowledge includes ethical responsibilities, and relational reflexive work can prevent disconnection and fragmentation. Care ethics is a source of inspiration to restore connections, and can generate energetic, creative, and innovative solutions that go beyond run-of-the-mill knowledge and ideas to better meet the needs of all service users in mental health care. The ‘tend and befriend’ option of response to crisis could give guidance for all involved in the co-production of knowledge.

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