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Abstract

Despite the abundance of research on the experiences of researchers with community-based participatory research (CBPR), there has been comparatively little published on CAB members' experiences. The goal of this research was to analyze the lived experiences of a small sample of CAB members in recent health-focused CBPR in Canada, with a particular focus on areas for improvement. We found that CAB members in CBPR experienced low perceived value from researchers due to communication patterns, education differences, and inadequate compensation. These issues may be mitigated through increased CAB member engagement throughout the research process, adequate compensation, and improved emotional support. This study demonstrates that if CBPR methodologies are to live up to their promise, it is crucial that CAB members are enabled to work in true partnership with researchers, receive adequate compensation that is meaningful to them, and are supported throughout the process.

Key Words community advisory board, community-based participatory research

“Very Similar to Having a Pimp”: Community Advisory Board Members’ Experiences in Health-Related Community-Based Participatory Research

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Introduction

Community advisory boards (CABs) are comprised of a group of citizens who are members of the community of interest and serve in an advisory capacity in community-based participatory research (CBPR); their members may share a common social position, place of residence, or identity, such as ethnicity or disease history.[1-2] Newman et al. [1 p1] described the purpose of a CAB as “an infrastructure for community members to voice concerns and priorities that otherwise might not enter into the researchers’ agenda, and advise about suitable research processes that are respectful of and acceptable to the community”. CABs are vital in CBPR, as they increase community engagement in studies through interactions with CAB members [3]; promote ethical conduct as well as the needs and the lived experiences of community members [3]; and play important roles in knowledge translation and application.[4]

Despite the established benefits of community involvement in research, there exists a gap in current literature on CAB members experiences; most of the literature on CBPR is from researchers’ perspectives.[5-14] There has been comparatively little published on CAB members’ experiences. That which has been published has largely focused on areas for improvement. In light of this limited but important body of work, we were interested in understanding if suggested improvements to CAB member-researcher relationships have been made. As such, in this study we aimed to centre the voices of CAB members and address the questions, “What are the lived experiences of a small sample of CAB members in recent health-focused CBPR in Canada. What areas of their experiences continue to require improvement?” In this paper, we provide an overview of current literature on CAB members in CBPR, as well as its shortcomings, and detail our methodology, methods, data analysis, and findings from seven semi-structured interviews with CAB members involved in CBPR in Canada.

Literature Review

Numerous researchers have explored the relationships between researchers and CAB members, demonstrating the importance of CABs and providing suggestions to promote healthy CAB member-researcher relationships.[5-14] Nevertheless, academic-community partnerships have often been founded on unequal relations of power.[12] The structure of CABs, while designed to be non-hierarchal, has often been reported to implicitly give more authority to the researchers.[12] Further, many CAB members enter the research process with preconceived beliefs regarding a hierarchy of authority, which affect their confidence levels and relationships with researchers.[12] CAB members have reported feeling that they have limited influence on research decisions, with no authority or legal power, as compared to researchers.[11] Power imbalances also may stem from the unequal scientific knowledge.[13] A multitude of resources are invested in the education of researchers; however, there are often few, if any, mechanisms in place for CAB members to gain scientific knowledge, such as formal health education.[15] This may result in CAB members feeling unprepared or under-valued.[15] Finally, researchers have often perpetuated power imbalances by monopolizing informational and financial resources.[13] The importance of pay has been frequently highlighted when analysing unequal authority, as the lower salaries and the lack of tangible benefits that CAB members receive increase feelings of inferiority.[12]

As a result, researchers have sought ways to ameliorate inequities in power between researchers and CAB members. Wolferman et al. [16] identified the importance of having frequent discussions between researchers and CAB members to evaluate and address CAB members' concerns regarding power imbalances. Chene et al. [6] and Safo et al. [12] identified actively allocating power as a solution to frequently reported dissatisfaction of CAB members regarding power imbalances. Providing continued training on research practices also has been identified as an important solution to increasing the knowledge and confidence of CAB members, further promoting equitable power and authority.[10,14]

Building Trust Through Transparency and Respect

Trust, transparency, and respect are foundational elements in developing healthy relationships between researchers and CAB members.[3,8,17] CAB members have reported researchers giving inadequate attention to building trust.[12] It is crucial that researchers and CAB members devote appropriate time to developing trusting relationships, as CAB members have reported feeling fearful of ulterior motives and of exploitation by researchers.[12] Trust can be established through procedures such as reaching an agreement before making decisions and implementing conflict resolution protocols.[5] Researchers should contribute the effort and the time to engage in team-building activities at each meeting, as well as regularly asking for feedback, which can promote trust in CAB member-researcher relationships.[5,12]

Researchers have also highlighted a significant lack of transparent communication and respect as contributing to feelings of disempowerment among CAB members.[5,12] CAB members in James et al.'s study [7] recalled that researchers resisted sharing information, thus preventing the community partners from being able to make informed suggestions for the research project. CAB members have also reported feeling that researchers have a significant lack of respect for the community members' interests, which left them with an overall distrust in research projects and prevented the formation of sustainable research partnerships.[12] Interestingly, James et al. [7] reported CAB members may also withhold information, consequently limiting the research's scope. CAB members, of course, are sensitive to power inequities, which may result in them circumscribing what they say. Embracing transparency and respect can provide safe environments to cultivate CAB member-researcher collaboration and progress towards shared goals.[5,7]

Researcher-Community Communication

Interactions between CAB members and researchers often suffer due to "outsider-insider tensions".[12 p7] Unintentional misunderstandings and ethnic differences can have significant effects on CAB member-researcher relationships.[12] Tangible research benefits, such as increased insight into the study, have been shown to result from effective communication with CAB members.[6,15]

Effective communication is required amongst members of a research team.[15,18] CAB members can act as liaisons between the research members and the participating community [15,18]; however, for CAB members to be able to connect researchers with communities, they must have sufficient support.[11] CAB members could be better supported through increased communication between meetings, such as email correspondence, and additional in-person communication with researchers.[15] Mwinga and Moodley [9] found lowered literacy levels of some CAB members; therefore, it is critical that researchers increase information availability by eliminating complex language from their explanations to CAB members.[6] This may also allow CAB members to better communicate with lay community members, educating them about the study and on health promotion behaviours such as HIV testing.[6,15,18]

Ethical partnerships between communities and researchers may be developed if researchers remain openminded and listen to CAB members.[18] In doing so, researchers can develop a critical understanding of the complexity and culture(s) of the populations with which they conduct research.[18,19] Diversity, defined as being composed of differing elements or qualities, must be viewed as a strength to enable the prioritization of culturally safe, inclusive, and equitable research practices,[6,8,19] which are crucial to ensuring the comfort and continued participation of community members.[15]

The above demonstrates that researchers have identified improvements that must be addressed in CBPR to better meet CAB members' needs. Importantly, the majority of these suggestions have been rooted in researchers' experiences and not those of CAB members, and thus these suggestions may fall short of achieving the desired outcome and may, in fact, perpetuate inequities. We questioned whether contemporary practices reflected the numerous suggestions to improve CAB member-researcher relationships that researchers have made and whether the proposed solutions were effective. As a result, we sought to centre CAB members' voices by learning about the experiences of a small sample size of CAB members who have been engaged in health-related CBPR in Canada.

Methodology

For this research, we used a trauma-informed CPBR methodology.[20] While Jumarali et al.'s approach [20] was developed for survivors of assault, trauma-informed care closely aligned with our goals when interacting with participants in our research. Some populations of participants, such as ethnic minorities, may experience vulnerabilities due to their social positionalities and are thus potentially more difficult to engage with through CBPR.[20] Trauma-informed care is a strengths-based approach to CBPR that centres participants' autonomy and encourages participant-researcher collaboration,[20,21] the goals of which are to promote participants' emotional safety, re-establish participants' control, support participants' coping methods, acknowledge participants' identities and contexts, and develop participants' strengths.[20,22,23] By employing a trauma-informed approach to CBPR, we aimed to respectfully establish engagement in our study with participants who have experienced marginalization.[20,24]

Forms of community engagement, such as empowerment evaluation, participatory action research, and participatory rapid appraisal, may directly engage with communities for data collection and program evaluation.[25-27] However, we focused on CBPR methodology because researchers who use this approach must centre community members in their relationships, respect the community members by taking a strengths-based approach, and prioritize the unique needs and contexts of community members, even when they do not directly align with the research process.[20,22]

We began by recruiting CAB members for our research. To avoid confusion between the CAB that informed this research and the participants in this research (who had participated in CBPR in Canada as CAB members), we will refer to the CAB for this research as the Overall CAB (OCAB). The inclusion criterion for our OCAB was that the individual had to have prior experience in CBPR as a member of a CAB in Canada. The second author used Twitter to recruit two OCAB members (the third and fourth authors), and she also recruited another OCAB member, a graduate student who met the inclusion criterion. The second author then met with the OCAB members to co-create and refine interview questions. Research then slowed considerably due to COVID-19, and some changes were made to our research team. The OCAB member who was a student graduated and felt they did not have the time to continue their role in the committee; the other two members remained on the OCAB. We also added another researcher (first author of this manuscript) to the research team to enable the work to be distributed amongst more people, which was necessary due to the impacts of a global pandemic. Both OCAB members from the community were remunerated $50/hour for their expert insights throughout the entirety of the project.

Methods

Our inclusion criterion for participants in our research was present or past CAB involvement in any form of CBPR in Canada. In doing so, we hoped to obtain a sample with a wide range of experiences. After receiving research ethics approval from the University of Ottawa, we recruited participants via Twitter and Facebook. We also emailed organizations that were known to do community-based work; these organizations shared the research opportunity throughout their networks.

We used semi-structured interviews to collect data. One of the strengths of this interview method, as compared to structured or unstructured interviews, is the balance achieved between free-flowing and directed communication.[28] Although more time-consuming than other research methods like structured interviews, semi-structured interviews permit greater openness and flexibility.[28] Namely, we had the freedom to add interview prompts in real time, to somewhat direct conversation, while the participants had the space to share meaningful insights.[28] The OCAB members worked with the researchers to co-create the questions.

The second author and the two remaining OCAB members for the overall research conducted the interviews (see Table 1 for participant profiles). The second author led six of seven interviews, with the OCAB members sitting in on interviews when available, asking further questions if desired. One of the OCAB members (the fourth author) led one of the interviews himself. Due to COVID-19 restrictions and a lack of travel budget, all interviews were conducted over Zoom videoconferencing software. The interview questions focused on three main areas: the focus of the CBPR in which the participants had participated; the participants' experiences and opinions of their work as CAB members; and the ways in which the research reflected the target communities' needs. We closed each interview by asking, "Is there anything I have not asked or anything you have not had the opportunity to say?"; this question was a critical acknowledgement that CAB members are experts on their own lived experiences.

In total, we interviewed seven participants: Four self-identified women and three self-identified men. Despite attempting to recruit participants from a wide variety of areas, all participants were engaged in CABs that focused on health-related issues. The interviews ranged in length from 41 to 102 minutes in length. We paid each participant an honourarium of $50. We transcribed all interviews verbatim and returned to each participant. The participants had the opportunity to edit them for clarity or to remove sensitive information. Two participants provided minor revisions to spelling of names of people or organizations.

Data Analysis

We used Braun and Clarke's reflexive thematic analysis (RTA) approach [29] to examine interview data from the participants. In 2008, Braun and Clarke [30] first published a paper on thematic analysis (TA). TA is a qualitative analytic method used to identify, analyze, and report themes within project data.[29-31] They later updated their approach to include "reflexive" in the name (i.e., reflexive thematic analysis) to emphasize the researcher's active role in knowledge production.[29] RTA is an adaptable and accessible type of TA, due to the flexibility of choices, such as the inclusion criteria of themes, which must continually be reflected upon by researchers and, if necessary, adjusted.[29,31]

The university through which the research took place has a university-wide licence for NVivo, qualitative data management software; however, it was only available to those who were registered system users, which required the user to be a student, faculty member, or staff member at the university. As a result, we could not easily find a way to code the data with the members of our OCAB, who lived in different provinces. After discussing this issue, we as a research team decided that the first two authors would do the initial coding of each interview transcript and construct initial themes from the data, and then share them with the OCAB for review and refinement.

RTA requires researchers to reflect on their own positionality. The first author is an early-career scholar who is a white, cisgender, heterosexual, middle-class woman of Ukrainian, English, and Scottish decent. The second author is a senior academic of English and Welsh decent. She is a white, cisgender, heterosexual, upper middle-class woman. The third author is a cisgender, heterosexual, upper middle-class woman of mixed Indigenous and European ancestry who is involved in community-health research. The fourth author is a cisgender heterosexual male of Northern European ancestry who is also engaged in community-health research. By engaging in reflexivity, we became sensitized to how our respective positionality influenced our research encounters, the choices we made in the research processes, and the interpretation of the results.[32] Locating ourselves allowed us to take measures to address the very CAB member-researcher power inequities we were exploring.

Guided by Braun and Clarke's six phases of TA,[30] we first familiarized ourselves with the data by listening to the interview audio recordings and concurrently following the transcripts, which were manually transcribed verbatim. We remained intentional about how our lived experiences affected our interpretation of participants' perspectives on their lived experiences as CAB members in CBPR. We tried to continuously acknowledge the ways in which our positionality influenced the knowledge production process. Next, we generated initial codes in the data by systematically reviewing each transcript with a focus on coding phrases related to our research question. Codes included self-value, community results, perceived value by researchers, unequal communication, tokenism, compensation, education, vulnerability, emotions, marginalization, and improvements.

Braun and Clarke [29,33] advised researchers that while the point of data saturation is impossible to reach, researchers may stop data collection once they have reached an appropriate depth of understanding – termed "theoretical sufficiency." We were cognisant of this throughout our analysis, and it informed our decision to stop collecting data after seven interviews. Phase three of our RTA involved generating the initial themes by sorting codes. We categorized the codes of self-value, community results, and perceived value by researchers under the theme "value." We used codes pertaining to unequal communication, tokenism, compensation, education, vulnerability, emotions, and marginalization to produce the theme "power inequities in the CAB member-researcher relationship." Finally, we used codes pertaining to "improvement" to include actions CBPR researchers may take to mitigate negative aspects of the CAB members' lived experiences.

Once the first and second author identified quotes that were representative of the main codes and some loose themes, the OCAB members offered their perspective on the data. Upon review, one OCAB member made no changes, and the second OCAB member suggested edits and proposed the re-categorization of one quote. This approach tightly aligned with Braun and Clarke's method of RTA.[29] After revising the results section again, we invited the OCAB members to review the findings a second time; one OCAB member had no changes, the other OCAB member provided more insight that greatly informed the discussion section.

Results

Using RTA, we constructed two themes that reflected the experiences that participants had as CAB members in CBPR: a) low perceived value and b) unfair compensation.

Low Perceived Value of CAB Members

Six of the seven CAB members in the study shared the view that CAB members are critical of research and bring significant value to the project. Yet, the CAB members often felt tokenized, undervalued, and excluded by researchers due to communication patterns and education differences. Sabrina, who has been a facilitator for a caregiver support network for almost 30 years, described the value she brings to a research project:

> I already come to the table with more expertise than the researcher… If I looked at the data, there is a lot of things that I would see that you [a researcher] wouldn't see. Right? That's the whole reason why you [the researcher] brought me on.

Despite the clear value that the participants felt they brought to the research, most participants revealed feeling tokenized by the researchers. Jenn, an Indigenous woman advocating for Indigenous peoples' participation in HIV research, described how working with non-Indigenous organizations had made her feel: "[The researchers] got to check a box … Can we consult with one person who self-identifies as Indigenous? Okay, we're good."

While ethnic differences promoted feelings of tokenism in some CAB members, others felt this way due to the researchers' communication, especially a lack of meaningful engagement with them. For example, Matthew, an advocate with lived experience in HIV research, shared, "In some situations, [the researchers] would want somebody, a community member, because it would look good on paper." Another researcher communication practice that contributed to feelings of tokenism was a lack of researcher acknowledgement of the value that CAB members contribute to the CPBR. Emma, a human trafficking survivor and advocate, expressed that researchers did not recognize the skills she brought to the committee and that she felt, "Infantilize[d] and … like a tokenized survivor who was just tossed this job because of my lived experience."

Many of the participants discussed how disparities in communication between CAB members and researchers perpetuated a hierarchical structure in the research projects. CAB members were often left out of key decision-making conversations, or, if they were present, communication barriers prevented their input from being taken into consideration. David, a CAB member for HIV research, shared his thoughts about being excluded from decision-making processes: "I thought I was supposed to be a part of those conversations, and I'm not … You don't get told until a decision gets made and its down the road. And you're like, 'how did that happen?'" Even when CAB members were present during research discussions, the language used in the communication often excluded them. Matthew spoke to the importance of researchers using accessible language when he stated that he had been on CABs "where it was heavily academic or heavily involving professional people that the language, the lingo, … even the acronyms are out of reach of ordinary people." As such, complex language resulted in feelings of exclusion.

Feelings of exclusion were also created by differences in academic achievements between CAB members and researchers. Four of the participants discussed how researchers did not value their lived experiences as highly as academic degrees, which contrasted greatly with the value that the participants placed on their own lived experiences. Participants felt that researchers' lack of value of their lived experiences limited the engagement with CAB members' contributions to the project. For example, Jenn noted that she believed her insights would have been valued by researchers more if she had achieved a higher level of education:

> Like, I'm considered an expert in a Zoom meeting, with all these leaders, but then when it comes right down to it… because I don't have a master's or a PhD. … until I have those letters behind my name … [I'm] just not going to be [seen] the same way.

The importance that researchers place on academic achievements was also displayed through employment opportunities. Matthew expressed his frustration when students with more formal academic training than him, but no lived experience, were hired to complete tasks on the research project he was involved with, noting, "I think a greater community involvement is as important as having grad students involved."

Disparities in education between CAB members and researchers not only affected the financial opportunities and occasions to contribute to the project, but they also negatively affected the comfort and confidence of CAB members. For example, Kendra, a CAB member for primary healthcare research, discussed how the differences in education levels have made it difficult for her to advocate for her community:

> I still get that nervous feeling if I go to the board, I say something in front of a room, because it is, like, my personal experience, and it's not from a school, and it's not from a type of science and stuff.

Emma, however, argued that power inequities may persist regardless of education level. She spoke about how a researcher treated her, despite her academic and occupational achievements:

> She had me do a tracking of my time based on … 15-minute increments. … I had to give her a log. … [A]t that point I had finished my master's, I had like 15 years as a community service provider and started my own non-profit, and I don't at all mind being accountable. But … it was really belittling.

When asked what steps researchers should take to help CAB members be meaningfully involved in CBPR research, interviewees highlighted the need for strong communication to feel meaningfully included and engaged in the research. For example, Matthew explained,

> People like [anonymized, the principal investigator] … would ask me questions: "Is there anything you want to say?", "Is there anything that…?" you know? They would come back to me …just to … make sure I am still engaged. …[That] is what I found very valuable, kept me engaged like: "How you are doing [Matthew]?", and things like that kind of stuff.

Participants also argued for the need to ensure that CAB members are part of the entire research process. Sam argued that there was a need to embed patient members of the CAB into every stage of the research:

> Involve CAB members from A-Z. So, you're thinking about writing a research proposal? Involve the patients at that point, absolutely. I guess that's where the advisory committee should be starting? … Right at the very beginning, and at every spot in between, absolutely …

Actively involving CAB members has significant benefits for the research project and the community. Sabrina noted that research results may be more meaningful to the community if CAB members have equal input as researchers:

> If [CAB members] were equal partners, right from the beginning, [researchers] would have … identified some of those gaps and issues, and those would have just been taken care of. And … the output would have been more meaningful.

Unfair Compensation

When discussing their experiences as CAB members, participants frequently discussed concerns they had with the

Table 1: Study participant profiles

Participant (Pseudonym)	Sex (Male/Female/Non-Binary)	Ethnicity	Type of CBPR CAB Experience	Number of Years Involved
1 - David	M	Euro-Canadian	HIV	27
2 - Emma	F	Irish	Human trafficking, social service provision	4
3 - Jenn	F	Indigenous	Indigenous health, HIV	15
4 - Kendra	F	Unknown	Patient partner, Primary Healthcare	5
5 - Matthew	M	Euro-Canadian	HIV/Hepatitis C Virus	3
6 - Sabrina	F	South Asian	Cancer	30
7 - Sam	M	White	HIV/AIDS, Myalgic Encephalomyelitis	10

compensation they received. Many interviewees spoke about researchers' lack of understanding of the emotional work that their role as a CAB member required, and how that was worthy of compensation. For example, Emma described one of her experiences on the CAB as "confusing and painful and jarring." Similarly, Kendra voiced the anxiety she experiences when sharing stories from her past:

> For many of us, like because it is anecdotal and the stories like it is what actually happened to us and that can be traumatic or that can be emotional. You know what I mean? Like, it's like so you're either reliving things or you're like telling things that are tied to different emotions… [S]o you're not only contributing like your time, but you're also contributing like your emotions and your stories. And that's a lot on people.

The participants discussed their desire for greater support from researchers due to the emotional vulnerability that comes with sharing their lived experiences with the researchers. For example, Emma contrasted two research projects she had been a part of – only one of which prioritized her wellbeing and was equity-based. She argued,

> [Researchers need] a much more … holistic sense and a recognition that when you're asking people to talk about things that are painful, you need to make sure that their minds and their hearts and their souls and their bodies are just being really wrapped in care.

Six of seven participants connected inadequate compensation to experiencing emotional distress. For example, Emma shared how current compensation practices can leave CAB members feeling exploited:

> The ways in which human trafficking survivors are compensated is often done in a way that's really triggering to financial exploitation and memories of being violently and financially exploited…[We're] being asked to engage in these power dynamic financial exchanges that I feel [are] very similar to having a pimp.

Beyond the importance of providing adequate compensation, it is also critical to consider the type of compensation that is being provided to CAB members. Emma spoke about how academic compensation from researchers, rather than financial compensation, contributed to the feeling of tokenism:

> If you're not [financially compensated], like, it's tokenizing, right? "Oh, you'll get this in your name if you want as like fifth author. But we didn't pay you." What is that? I mean, it's not like somebody who's struggling with homelessness … want[s] to be like a tenure track professor!

The CAB members felt that the researchers valued academic credentials over lived experience; for example, Emma was paid $5 an hour less than a research assistant with an undergraduate degree, even though she had 15 years of community experience. Sam, who has been on a CAB related to AIDS research, described the need for researchers to place a "dollar value" on CAB members to promote progress in CBPR, stating, "From that paid-for value comes validation, respect, so the researchers and doctors and people in the healthcare field, umm, I think they would view the value of patients, because there's a dollar value attached to them now." Nonetheless, participants felt that they were in precarious positions to advocate for fair compensation. Kendra reflected on conflicting feelings she experienced:

> So, it's that pressure of, okay, I shouldn't really do this for free, but I don't want to like say no to people and never be involved again. … So, I find like always tiptoeing around that stuff … when it comes to compensation, then, because I don't want to be the person who, like, spoke up too much or, you know, disagreed with their compensation policy or that kind of stuff.

Compensation was clearly a very loaded aspect of CAB members' experiences.

Discussion

By sharing some CAB members' recent lived experiences in health-related CBPR, we promote a more balanced discussion regarding the challenges of CBPR; previous researchers [1,4,14,17] have fallen short of having such discussions because they primarily focused on researchers' perspectives. We also demonstrate that CAB members continue to have struggles with CBPR. The findings from our study present a novel opportunity for researchers and CAB members to learn from the experiences, challenges, and successes of CAB members involved in health-related research in Canada. In this section, we first discuss the findings related to the hierarchy of knowledge, particularly how formal education and lived experiences contributed to tensions between CAB members and researchers regarding expertise. Next, we examine the findings related to CAB members' compensation from researchers and how they related to the broader challenges CAB members encountered in the research projects. Hierarchies of knowledge and inadequate compensation reinforce and legitimize power inequities between CAB members and researchers; in addressing these issues, researchers may better understand and respond to the needs of the communities they intend to serve.

Hierarchies of Knowledge

The underrepresentation of members of populations that experience marginalization (i.e., LGBTQ2+, persons with disabilities, BIPOC) in academia has been widely documented.[34,35] International efforts to advance the value of CABs in CBPR have gained traction as researchers have illustrated the benefits of community-informed projects and decisions based on lived experiences, which result in stronger research frameworks.[5-14] Notwithstanding such efforts, formal education level remains highly valued in academia, particularly in leading, conducting, and publishing research. Notably, participants in our study identified differences between researchers and CAB members in formal education levels and lived experiences as creating and reinforcing hierarchies. Indeed, four of seven CAB members we interviewed felt that they were less respected and valued by researchers at least in part due to their lower levels of achievement in academia. In fact, education attainment appeared to affect the opportunities CAB members had to contribute to the research.

Our findings show that some participants believed that their lived experience should result in them being at the top of the knowledge hierarchy. Statements such as "I already come to the table with more expertise than the researcher" illustrated how Sabrina viewed her lived experiences as more important than the researchers' formal education. Statements like this were made by CAB members after describing the hierarchies of research that left them feeling devalued. Clearly, there exists significant tension between researchers and CAB members about who is or is not a legitimate "expert." CAB members' calls for a reversal of the current hierarchy in CBRP would nevertheless perpetuate a hierarchical structure. Flattening the hierarchy, so researchers and CAB members have equitable positions in the research, rather than inverting it as some CAB members called for, may be a critical step to addressing both community members' and researchers' needs. Indeed, both forms of expertise are needed in CBPR.

To flatten this hierarchy, bidirectional education of the CAB and researchers must be implemented. Researchers in previous studies largely suggested educating CAB members on the research topic under study.[10,14,15] Suggesting that only one group requires education has harmful implications that further promote the tensions and inequities between CAB members and researchers. Ensuring that CAB members have the opportunity to educate researchers can promote respect and sensitivity for issues faced by the community, as well as provide the opportunity for community-identified respectful practices to be incorporated into the research design. Bidirectional education may result in power sharing and may minimize the differences in knowledge, allowing the CAB members and researchers to interact with greater understanding and respect.

Adequate CAB Member Compensation: Must Account for Emotional Costs

The findings from our study highlight the need for appropriate compensation for CAB members' time spent on CBPR projects. The CAB members in our research argued that current compensation methods are inadequate; the compensation or lack thereof that CAB members received promoted feelings of inferiority and even caused emotional distress for some participants. Comparatively, when researchers provided adequate financial compensation, CAB members described feeling valued and felt the research project itself benefited from the more equal dynamic that the compensation promoted. Feeling valued plays a particularly crucial role when considering society's negative perceptions of members of groups that experience marginalization who are typically the focus of CBPR.

Researchers have previously elucidated the importance of compensation for CAB members [12]; however, our discussions with CAB members illuminated that the types of compensation they were offered for their work may be due to, and continue to promote, unequal power relations with researchers. Indeed, CAB members are likely to have different values in relation to compensation than researchers. For example, Emma pointed out the importance of considering which forms of compensation might be most relevant to community members when she argued that a person experiencing homelessness does not care about authorship on an academic paper. While this may not be the case for all people experiencing homelessness, she made an important point. Further, power inequities affected the CAB members' comfort in advocating for more appropriate types of compensation.

The way in which compensation is provided is another key area to which researchers must be sensitive. Ensuring financial compensation is distributed to the CAB members by a third party, rather than the researchers themselves, could contribute to diminishing the power dynamic of financial exchanges that Emma identified as being problematic. Indeed, Emma's assertion that she felt much like the lead researcher was acting like her pimp when they paid her highlights the importance of careful management of this aspect of CAB members' research participation.

The findings from our study also illuminated the lack of consideration of emotional work in CAB member engagement and compensation. Previous research has identified challenges that CAB members face, including stigma, low literacy levels, and lack of support [3,6,11]; however, the emotional toll of research participation on CAB members in particular has received inadequate attention. As evidenced by the fact that three of seven CAB members felt that they experienced emotional distress in their roles on CAB, there exists a need for consideration of the emotional costs of participation on a CAB for CBPR. CAB members may be made emotionally vulnerable during their involvement in research projects. Given the lengthy amount of time that is often required for CBPR research to be completed, this may result in months if not years recounting potentially triggering experiences. Such emotional costs must be acknowledged, minimized, supported, and compensated. Importantly, CAB members expressed fears concerning advocating for adequate and appropriate compensation.

There are numerous ways in which researchers can address the emotional harms experienced by CAB members in CBPR. For example, sources of support that CAB members themselves identify as helpful must be available to CAB members, for free, and without requiring CAB members to first advocate for them. Further, CAB members who need to share and/or work with particularly sensitive information should receive compensation that aligns with the difficulty of such work (i.e., receive higher remuneration). By taking such action in CBPR, researchers can increase the accessibility of research involvement to community members and promote the emotional wellbeing of CAB members as well as respect for their contributions.

Limitations

As with any study, this one has limitations. We identified five limitations with our study. The first pertains to the CAB members only having experience with health-related CBPR. Although interviewing CAB members in health-related research created opportunities to focus on this area, our research may have been even stronger with broader CAB representation from other research fields. Our second limitation relates to the restrictions caused by COVID-19. As a result of them, we were unable to conduct in-person interviews. In-person interviews may have allowed us to develop a deeper, more trusting relationship with the CAB members we interviewed and a more intimate understanding of their lived experiences.[36] Importantly, however, our online interviews enabled us to interview participants from across the country at no cost to the project budget or environment. The third limitation was that we were unable to obtain access to NVivo software for our OCAB members; thus, they were unable to participate in coding the data. After experiencing this issue, the second author advocated for her university to eliminate this barrier. As a result of her advocacy, moving forward, all community members who are involved in university-related research will be able to access NVivo software free of charge through her university. We hope that this serves as a model for other researchers, even if it came about too late to be of benefit to this research. Our fourth limitation relates to potential self-selection bias in the participants.[37] We recognize that the CAB members we interviewed had largely negative perspectives on CPBR and thus may not be representative of all CAB members' views of CBPR in Canada. Finally, we recognize that there are limits to power-sharing within research processes dominated by Eurocentric knowledge systems.

Conclusion

By listening to a small sample of CAB members recount their lived experiences as CAB members in CBPR, we have promoted a more nuanced understanding of some CAB members' involvement in research and identified new findings, including the need for bi-directional training between researchers and CAB members; the importance of the distribution of payment to CAB members by a third party; and the need to recognize and compensate the emotional work of CAB members. The findings from our study present an opportunity for researchers and CAB members to learn from the experiences, challenges, and successes of seven CAB members involved in health-related CBPR in Canada. By sharing these results with others who engage in CBPR, we hope to play a role in fostering research spaces in which CAB members are respected, included, and valued for their vital contributions.

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Abstract

Formerly playing an assistive role motivated by virtue, obedience, and self-denial, nurses are now autonomous professionals with unique expertise, skills, and competencies. However, current recognition of the nursing role is far from optimal and perpetuates the invisibility of nurses' real work. This article examines one component of the situation: the non-recognition of the nursing role by nurses themselves. Hypotheses explaining this phenomenon, like the history of nursing and the lack of common language, is presented, as well as its impacts, followed by exploration of possible solutions.

Key Words education, history of nursing, language, nurse's role, vocation

Ending the invisible work of nurses: Reflection following a study about nursing support of relatives

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ALAIN LEGAULT

Nursing profession has evolved considerably since Florence Nightingale and religious orders, assistants and care attendants providing care. Pioneering nurses, as well as the possibility of university education among other things, have advanced the role nurses play, from that of medical assistant to autonomous professionals with distinct knowledge and skill sets whose expertise is complementary to that of other health care professionals.

In furthering the nursing profession and discipline, the importance of defining the essence of nursing has been advocated for decades.[1, 2] Clinicians, theoreticians, and researchers have strived – and continue to strive – to define the field of nursing and nurses' role and responsibilities.[1] Despite such advances, the value of nurses' work and nurses' key contributions to individual, family, and community health are still not always adequately recognized; such contributions are, in fact, often undervalued by the population, the media, and even within the health care system itself.[3]

As of 2021, in the midst of the Covid-19 pandemic, nurses have been on the front lines for months in an essential role. But, as argued by Waddell et al.[4], even though "[their] heroic actions (…) have been well covered during the pandemic, in the end, nurses were portrayed as victims, not as leaders" (p.3). The pandemic also putted forwards the superhero or angel narrative for nurses, which is not the recognition that is helpful to the nurses' position in the health care system and politics. First, it hides the problems related to the lack of nursing staff and resources, present for years, long before the pandemic.[5] Superheroes don't need staff or resources because they are sufficient at resolving problems on their own. Then, it takes away the emphasis on the skills and knowledge of nurses to put the spotlight on the vocation and their courage, which are words frequently used to talk about nursing. So the problem of non-adequate recognition persists.

We postulate that one of the golden rules of receiving adequate recognition is first knowing one's own worth. The minimization of the nursing role and nursing interventions by nurses themselves certainly contributes to perpetuating such nonrecognition. This nonrecognition has a major impact on the role nurses play and the power they hold in the health care system, on negotiating fair working conditions, on defining and recognizing their role, and even on the professional acts they may perform.[6] Therefore, based on examples from practice and research with nurses, this article aims to reflect on how nurses conceptualize and discuss their own clinical practice, the reasons and impacts of those conceptualization, and to suggest some possible solutions.

Ten relatives and nine nursing home nurses were interviewed during a study that aimed to propose an inductive theory of nurses' support of relatives making end-of-life decisions for residents living in nursing homes with a major neurocognitive disorder (for complete methodology and results, see [7]). The process of recruiting participants for this study was difficult at times. Many nurses considered that the responsibility of supporting relatives in the process of making medical decisions around residents' end-of-life fell to physicians and, consequently, these nurses said they did not intervene on that subject nor did they discuss those matters with relatives. Even nurses who agreed to participate in the study expressed, from the very first contact with the interviewer, their doubt about being able to help the researchers since they felt it was the physicians who assumed this role in their institutions. When signing the informed consent form, many of these nurses expressed their fear of having nothing to say on the subject, so much so that even the most experienced researchers would probably have questioned the relevance of proceeding with the interview and even the relevance of the research project itself.

Yet, the collected data was rich, from the very first interview with a nurse. Even though she claimed she did not offer relatives support in decision-making situations, in fact, it turned out that she intervened in ways that were key to relatives' decision-making process on a daily basis. By exploring relatives' fears, educating families, or intervening in other specific and intentional ways, the nurses were indeed making essential and obvious contributions that supported relatives in their decision-making process. However, one nurse-participant after another expressed, sooner or later in the interview, this same perception of not being involved in supporting relatives. And interview after interview, their answers to the researchers' questions showed exactly the opposite: the nurses' intervention strategies were quite specific and these relied on strong clinical judgment and advanced expertise, knowledge, and skills in end-of-life care, neurocognitive disorders, and family care. So, how can we explain this blatant disconnect between what nurses said they did and what they actually did?

Buresh and Gordon [8] discuss the phenomenon of how nurses minimize the importance both of their interventions and of the impact and central role of these interventions in maintaining patients' clinical condition. Multiple examples of nurses attributing the success of care to other professionals or to relatives' excellent bedside support further illustrate the phenomenon. The authors question why nurses downplay their expertise and find it difficult to recognize their skills and clinical impact.

Buresh and Gordon go on to shed light on the disciplinary discourse conveyed to the public that emphasizes virtue over knowledge and skill. This position would seem to be rooted in a religious history that has strongly influenced the development and values of the nursing profession. This might partly explain the observed phenomenon. Indeed, when nursing interventions were assumed by nuns, obedience, self-denial, and invisibility were among the expected "qualities" of nurses. It would seem that vestiges of this heritage are still be seen today, as nurses seem to still be influenced by the notion of virtue, which they have internalized. As Buresh and Gordon mention, "One way to avoid the danger of 'pride' is to give the credit to someone else".[8] In other words: nurses' work often remains invisible.

Other authors point to oppressed-group behavior to explain this invisibility. Developed by Freire [9], this concept states that in a given culture, a dominant group promotes its main characteristics as the only valid ones, to the detriment of the dominated group whose attributes are devalued[10] The dominated group comes to believe in its inferiority and find themselves in a state of obedience, silence, and invisibility, unable to make their needs heard and thus, rendering them unable to rise out of this dominated position.[11] It is possible that the dominant biomedical model sometimes places nurses in a position of inferiority. Nevertheless, the essential role nurses play in the evolution of patients' state of health is obvious, as illustrated in Adams and Nelson [12]:

> Physicians typically see patients only periodically and for short periods of time. Acute care nurses, on the other hand, are responsible for keeping people – often extremely fragile people – alive, comfortable, and on the path to healing twenty-four hours a day.

> In community care settings, nurses are likewise often responsible for ongoing monitoring, education, and assistance. The skills necessary for these practices do not simply arise "naturally" from a sense of sympathy, nor are they merely a somewhat degraded subset of the physician's skills. They are distinct, nursing skills acquired by nurses through education and clinical practice (p. 6).

Thus, some of the competencies nurses utilize to effectively intervene with patients are well defined, recognized, and valued most of the time. An example would be the skills and abilities enabling them to intervene effectively in situations of respiratory distress, hemorrhage, or when an alarm sounds on a patient's heart monitor. However, this is perhaps less the case for other components of the nursing role, especially those that are not quantifiable or that are difficult to measure. Henry [13] mentions the strong correlation between what appears on patients' charts (i.e.: quantifiable or measurable interventions) and what is perceived as fundamental to the nursing role, by nurses themselves but also by other professionals, administrators, and politicians. At the same time, the predominance in the current health care system of the biomedical model, its technical activities, and its language – in Canada at least and in many other countries – seem to overshadow any interventions that do not correspond.[14]

As a result, nurses can perform blood tests or administer treatments according to specific and measurable parameters, objectively recognize the results and their impact, adjust their interventions accordingly, and document it all in patients' files. However, nursing interventions devoted to coordinating and conceptualizing care, ensuring patients' safety and ongoing evaluation so as to be able to intervene quickly in the event of deterioration, supporting patients and their families in understanding the diagnosis and the treatments offered, reassuring relatives, etc. are difficult to quantify or measure. Most of the time, such interventions are not documented on patients' charts.[15] But all these interventions and many others are part of nurses' day-to-day work and are vital to patients' well-being and even survival. If these interventions are neither quantified nor measured, they do not appear on patients' charts and are also downplayed by nurses themselves, how can the full nursing role be recognized at its true value?

A recent conversation at the nursing station of a palliative care home is a good anecdotal illustration of the issue. When a nurse offered her help to coworkers, one immediately replied she did not need any help; her shift was so quiet she had just spent 15 minutes "chatting" with a patient's family. Asked what she meant by "chatting", she explained that she had opened a discussion with the family about how they experienced their mother's admission into palliative care. As a result, she learned that the elder son was struggling, while the younger son, who is uncomfortable with expressing emotions, did not wish to receive support, and that there was significant conflict between two other family members. All of this data allowed the nurse to adjust the patient's care plan accordingly and propose appropriate interventions to continue her care. Those 15 minutes were therefore anything but "chatting"; indeed, they were an important nursing intervention that would affect the very conceptualization of care for the patient and her family. So why did this nurse say she had "chatted" with the family, rather than claiming to have carried out an intervention with the family? What weight does each definition of these 15 minutes carry in understanding and explaining the nursing role?

Even from a strictly economic perspective, the allocation of funds to 15 minutes of "chatting" is by no means justifiable, whereas the actual intervention carried out was well worth such expenditures. Adams and Nelson [12] underline that a common and specific language is fundamental to better articulating the nursing role, in order to access economic resources that are appropriate and match the value of the work. In other words, the language used to describe nursing interventions has a significant impact on the recognition and value given to this work. This is also the case for the support given to relatives in an end-of-life decision-making process. Indeed, why should investments be made to train nurses in best practices if they themselves claim—and wrongly so—that they are not involved in this essential work? Could it be a case of what Watson [16] calls "the identity and boundary dilemmas" (p. 38) where nurses have difficulty finding the words to describe their role and in differentiating their unique contribution to the health care system from those of other professionals?

Ultimately, the questions are: How can nurses recognize the crucial nature of all aspects of their role? How can they adequately and accurately articulate their full role and interventions, in order to take their rightful place in the health care system and in the political sphere?

First, nurses from all areas of practice should ask themselves these questions—and, more broadly, reflect on the impact of their current attitudes and discourses—in order to find innovative solutions adapted to the reality of nursing practice.

Daiski [17] stresses that "change, in order to be appropriate and effective, needs to come from within nursing, be brought about by nurses themselves, and be achieved through greater advocacy for the profession" (p. 48). Recognition of their own contribution to the healthcare system is also essential to the advancement of the discipline and the nursing profession. Nurses are therefore key in this situation. Even though the nonrecognition of the full nursing role is a multifactorial systemic problem, every nurse has the opportunity to be a catalyst for change. By changing their own discourse about themselves, their role and their contribution to healthcare, nurses will inevitably contribute to an improved collective recognition of the nursing profession.[18] Also, rising their colleagues' awareness of these issues should not be overlooked.

Second, change undeniably comes with education.[17,19] Buresh and Gordon [8] urge nurses to emphasize knowledge, rather than virtue, when communicating with each other, as well as with other health care professionals, administrators, policy stakeholders, the public, and the media. Education pertaining to nursing history, including gender-related power issues nurses have faced that shaped the past and present dynamics in healthcare, is also vital to nursing empowerment.[18] Education is not just for nurses; educating the general public and especially the media is also an approach to consider.[8] Indeed, the media image of nurses contributes to the persistence of the status quo, as does the absence or infrequency of nurses as experts in the media, which also hinders recognition of their expertise and contribution.[20]

Moreover, in better recognizing their contribution and defining their role and interventions, nurses would benefit from having access and utilizing available research results. Obviously, evidence-based practice should be the norm. Therefore, access to research results that map nursing interventions and give words to professional interventions would help nurses make invisible work visible – and unconscious work conscious – so that nurses appreciate the depth and extent of their daily tasks and interventions. For example, the results of our study identified aspects of the nursing role that were fundamental to supporting relatives' decision-making process. These findings could help nurses understand the essential part they play in this support and give them words to describe their interventions. Research in nursing and the reduction of the research-practice gap are indeed vital to giving nurses the tools they need to describe and fight for the recognition of their full scope of practice.

These possible solutions are a starting point for reflection. Effective intervention on a systemic problem requires approaches that identify and target the other problematic aspects that perpetuate the situation. This reflection should therefore be continued to identify tangible interventions that lead to recognition of the full nursing role. Among other benefits, this would give nurses better access to the human and financial resources needed not only to provide quality care but to influence decision-making as well as political and administrative spheres. It is the general public who will gain most from better recognition of the nursing role.

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Declaration of author contributions
All authors made a substantial contribution to the article. SD wrote the manuscript. AB and AL critically reviewed the manuscript. All authors read, improved, and approved the final manuscript. The authors declare that there is no conflict of interest.

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3

Abstract

The relatively new method of autoethnography as valid research is used in this paper. The method combines a personal and introspective approach with the academic research method. By reflecting on her experience of psychosis, the first author (LF) attempts to show how psychotic symptoms, such as delusions or paranoid perceptions, have a symbolic meaning and could relate to previous traumatic experiences. She uses Winnicott's concept of the 'true' and the 'false' self and applies it to psychotic illness. Using auto-ethnographic details of her experiences, she indicates how trauma, and associated falsification of its understanding, led to distortion, i.e., a false reality, a symptom typically associated with psychosis. A brief comparison is then made of her experience to two other published auto-biographical cases. In light of this self-analysis and careful reading of key psychoanalytic texts, the author explores and explains what, in her experience, may lead people to act in a manner not typical of their true being and how this might explain the rare dangerous behaviour that can occur in some psychotic cases. The understanding of psychosis as 'madness' (i.e., to be without reason) is revealed to be due to lack of understanding of its possible underlying causes.

Key Words false self, psychosis, symbolic meaning, trauma

Does Madness Really Exist? An Autobiographical Analysis of Psychosis as a Response to Trauma and Not a 'Mad' State of Mind

LUCIA FRANCO & LINDSEY NICHOLLS

Introduction

We usually refer to madness as something utterly 'irrational' or 'insane'. In psychology, when people evoke madness, they are usually referring to psychosis. In his exploration of the work of Lacan, Leader [1] for instance identifies madness with psychosis, in all its forms. The two most severe forms of psychosis can be considered to be schizophrenia and bipolar mood disorder. We do know that several conditions such as paranoia and personality disorders have been considered as part of psychoses, and that some forms of depression also include psychotic elements. Alongside these understandings, it may be useful to consider the work of Christopher Bollas [2], a contemporary psychoanalyst, on whether psychosis is madness i.e., irrational behaviour. In a recent book on his clinical work with patients who suffered from psychosis, he writes, "It is important to make a distinction between 'psychosis' and 'madness'. Schizophrenics are psychotic but they are not mad . . . Madness refers to the creation of a chaotic state of affairs driven by the acting out of unconscious fantasies".[2,p.36] Implicit in this statement is that, for him, there is meaningfulness, not chaos, in psychosis.

As first author of this paper (LF), I have experienced psychosis and lived with the diagnosis of schizophrenia for a period of forty-six years. Through my experiences and doctoral work on the link between psychosis and trauma, I have other ways of viewing 'madness'. As result of my careful reading of core psychoanalytic literature and my own self-analysis and recovery, I believe that what characterises psychosis is what appears to be a lack of understanding of reality. The person experiencing psychosis faces a reality that others may not understand or relate to. While it can be confirmed by those who have been close to someone experiencing psychosis, that the often delusional, paranoid, or hallucinated reality of these people is a different reality from the one experienced by others, I suggest that those symptoms or manifestations are not irrational or insane. I argue and show that, once we understand what those symptoms are expressing and what they symbolically represent, they can acquire an intelligible meaning pertaining to the background of the individual experiencing those symptoms, including traumatic experiences.

To highlight this, I have begun this paper by concentrating on existing theoretical understandings of how, in psychosis, the 'true self' has been repressed and becomes hidden. I considered Winnicott's [3] concept of the 'true and false self' and how it relates to psychosis, and I included the contemporary work of Bollas and his understanding of what happens to the 'I' in psychosis.

In the later section of this essay, I have presented some auto-ethnographic details of my own case of schizophrenia, and I have attempted to show how my delusional, or paranoid, world had profound meaning and was the production of a 'reality' of trauma that had been denied—its understanding forbidden to me by the trauma itself. Because of this denial, the truth (reality) of the event continued to try and manifest itself in a 'psychotic' (i.e. symbolic) manner. I have briefly compared my case to two other published auto-biographical case studies, which indicated similar psychological processes. Finally, I have tried to explore a difficult area of psychosis, which is when people act in a manner different to their true being and can be threatening to themselves or others.

Theory: Winnicott and Bollas

The works on psychosis of Winnicott [3-5] and Bollas [2,6] are utilised to analyse the autoethnographic data through theory. Their work on what happens to the self in psychosis provides understanding and meaning to my symptoms and shows how these are relevant to understanding other psychoses. What seems common to Winnicott's and Bollas's observations and understandings is the fact that, during a psychotic illness, the 'true self', also called the 'subject' or the 'I', is unable, or has serious difficulties, to exist and be.

Winnicott (1896-1971) was a highly esteemed psychoanalyst, paediatrician, and theorist. He developed the concepts of the 'false' self and the 'true' self, and of being a 'good enough mother' (caregiver). Winnicott recognised that a mother could only be good-enough, since the idea of a perfect environment is an impossibility of life. In his understanding, a child who has not experienced a good-enough early environment, i.e., a good-enough mother or whoever takes her place, will be unable to develop a strong true self, but will instead be overwhelmed by anxieties. When the mother/caregiver fails to be 'good enough', the child develops a false self as a defence to cope with his/her reality. This false self is characteristically compliant, initially with the mother (or whoever is in her place) and will lack the ability to be spontaneous or creative.[3] Winnicott contends that we all need a false self to deal with life, i.e., in those social situations when we may need to conform or comply with external forces, yet the 'true' self would take over when the integrity or wellbeing of the subject is at stake.

In reading Winnicott's thinking on the true and false self, it appears to us that he viewed psychosis as characterised by the presence of a strong false self, which could overwhelm and overrun the true self. In addition, Winnicott [3] stated that "the more psychotic disorders are seen to be closely related to environmental factors" (p.10); in other words, the external realities and experiences of a person can induce psychotic episodes. As Alford [7] wrote: "Winnicott was interested in the way the very existence of the self is endangered by trauma: trauma at a young age, and later trauma that calls forth the false self in all of us" (p.264-5). If trauma leads to the false self and trauma is "closely related" to psychotic disorder, then the false self is strongly present in psychosis. It is our understanding that in psychosis the emergence of the true self is less likely to occur because it has been silenced or overshadowed by the false self.

The contemporary psychoanalyst Bollas (born 1943) is a widely read author and psychoanalyst. He has recently written of his analytic work with people who became psychotic, suggesting that if we can "Catch Them Before They Fall" (as per the title of his book), we can prevent the trauma of hospitalisation and explore, through dialogue, the events which could have triggered a breakdown. Bolla's views on schizophrenia are that it is a condition where the "'I'—the speaker of being—has departed".[2,p.76] He shows how difficult it is for the true self, in psychosis and particularly schizophrenia, to exist. In his recent book When the Sun Bursts: The Enigma of Schizophrenia' [2], he presents the case of Megan, one of his long-term patients: "At the time I noticed that only rarely did she use the first-person pronoun 'I', and it would be uttered in a rather surprising way, as if she were ejecting it".[2,p.69] Megan herself is quoted as saying: "I don't think I have been here all these years, just images and words and feelings passing through my mind. My mind was here but I was not".[2,p.69] Here Bollas is suggesting that the true self (the I) was absent during the period of Megan's psychotic illness.

After years observing what happens when someone becomes psychotic, Bollas writes: "We witness a splitting of the self:

a subjective transformation giving birth to a psychotic self, emerging from the destruction of the former subject".[2,p.93] Using Winnicott's explanation of the true and false self, I have understood this as the consequence of the false self, becoming central, and the true self, being hidden and/or repressed. My specific perspective and experience would suggest that the imposed distortion of reality had established itself and thereby destroyed my 'truth' as an individual.

I have attempted to show what significance this understanding of the power of the false self has, by presenting my own case of what was diagnosed as paranoid schizophrenia. I have particularly focused on a trauma I went through over forty years ago with my knowledge and understanding of how this has been central to my developing psychosis, and how for the healing process to occur, it required my facing and understanding that trauma, as well as the more general understanding of myself and my past experiences. I only gradually discovered the details of the following narrative over many years: initially, I did not remember the event, and when I remembered something, the terrifying and intentional violence of my attacker remained hidden from my memory which hindered and delayed an understanding of my response at the time of the attack, and instigated the subsequent years of symbolic psychotic symptoms.

Trauma and psychosis

In the past, the main focus in researching the causes of psychosis had been largely centred on finding hereditary/genetic factors. These have not been found as of yet, and many researchers in that area, such as Murray [8], recognise that there are likely epigenetic factors of interaction between genes and negative life experiences. The research in the field of genetic vulnerability is continuing.

In more recent years, many authors such as Morrison [9], Morrison et al.[10], Garety et al.[11], Jansen et al.[12], Larkin and Read [13], Chapleau et al.[14], Bendall et al.[15], Knafo [16], and De Masi [17] have argued that trauma or traumatic experiences can lead to psychosis, rather than genetic factors.

Not all people who have experienced trauma will develop psychosis, yet there is no conclusive research finding that has explained why that is. Are there protective factors? Or would it depend on the severity of the trauma? While this research continues, I have presented how and why, to my understanding, my experience of trauma led to psychosis.

Methodology

The methodology used for this paper, and my doctoral studies more broadly, is autoethnography, a recent development of qualitative methodologies. An early mention of it was found by Reed-Danahay [18] in an article by Karl Heider dated 1975. As a method, autoethnography interweaves personal, introspective accounts with academic research methods. It uses an analysis of the researcher's autoethnographic experience to shed light on the possibilities of other people's experience.

This method was chosen because it allowed me to analyse my subjective experience in an academic and scientific manner. Researching into the unconscious processes of other people (research participants) could have been potentially harmful. I could only use myself as subject. I am not aware of any other work exploring similar perspectives, consequently reflecting on my experience and my understanding developed over the years I could use myself in the depth I needed to explore how my psychosis formed. With this method I used psychoanalytic theory as a way of understanding my 'hidden from view' and/or repressed material. Using psychoanalytic-autoethnography is a recognised method; see for instance Garratt [19] and Midgley [20]. To read other autoethnographic works of people who experienced psychosis see Johnston [21], Fixen [22], Williams [23] and Casselle.[24]

I have tried to use my utmost honesty and integrity in doing this research, to allow the reader to be able to identify with the story narrated. I have remained self-critical and reflexive, with guidance and supervision throughout the research. These are also crucial aspects necessary for autoethnography.

Findings from this study cannot be generalised; transferability may be achieved by readers who can learn about themselves and others from an engagement with the work. Ellis [25], a key author in autobiographical methodologies, stated: "Our lives are particular, but they also are typical and generalizable, since we all participate in a limited number of cultures and institutions. We want to convey both in our stories" (p.751).

I have found in this way of working that I have gained insights out of an intensive analysis with an analytical psychologist (from the school of Karl Jung) for three years, followed by work with psychologists and psychiatrists, and many years of self-analysis. My intense work (three times a week) with the analytical psychologist gave me insight into my unconscious thoughts and associations. I learned to understand myself and my motivations. This three-year period of analysis, along with my studies and readings gave me the skills to introspectively continue my self-analysis.

I have had to utilise self-analysis over the years as professionals in the past were not interested or willing to support my desire to pursue the understanding of the trauma I had experienced. I have suspected that, in many cases, professionals thought my wish to explore my images of being raped were delusional. In more recent years I have worked with a clinical psychologist, who has helped me understand many of my symptoms, but this work with him could only occur after I had worked on my memories of the trauma and could articulate it more clearly. Through his careful attention to the details of my attack and subsequent psychotic experiences this has helped me reach my current level of mental well-being where I no longer experience the psychotic symptoms that have plagued me in the past. I have been able to make sense of my symptoms through the painful recalling of past events and working through their impact on my body and mind.

I started keeping a diary as soon as I could after the trauma as a way to try and process what was happening to me. Writing down my thoughts, feelings and what I understood them to mean helped me to cope, in part, with my struggle. I had a constant search trying to find the reason why I had suddenly become so unstable, confused, troubled, as I had been functioning and feeling well before. These diaries have contributed to my current doctoral research by recalling past ideations and allowing further reflection regarding their significance in light of theory and today's understanding. For example, in 1993, I wrote: "Those that are completely (I think) are also those that know. And those that know cannot say it." Here I recognise seemingly psychotic thinking that I now understand as indicating my feeling of not being my true self. My use of the words 'those that are' meant to convey my understanding then of being under the power of something, which today I explain as the false self being formed following the trauma. It was also a recognition of my not knowing what had happened, not knowing I had been raped. On the same day I further wrote: "It all feels very primordial. It is as if it is a primordial explanation of what reality is, 'magical'". I could not understand reality anymore, everything had become strange and difficult. These perceptions were, at the time, very frightening to me.

The following narration, although coherent now in its account of the events, has taken many years of analysis to uncover the truth of what occurred.

The Trauma

I was walking with someone I considered a friend. Nowadays I would call him a friendly acquaintance. He started saying how people did not understand me. I didn't think this was particularly true, but it made me think he was caring towards me, and it gave me warm feelings of trust towards him. We were walking amongst rocks in an isolated place. As I had climbed on a higher rock, he grabbed my ankle from behind and pulled me to the ground below. I fell backwards onto the rocks from a height of about 80cm to 1.3m (I cannot clearly remember). The impact was violent; I was surprised I had not broken a limb and that I was still alive. Had I hit my head on one of the rocks I could have died.

I did not feel pain, but that may have been due to the shock. I could not move for several moments as my body did not have any strength or coordination. I thought there was an explanation for my friend's behaviour but, as I finally was able to raise my head and look up, I saw him at a little distance looking at me with no intention of helping me. I realised then the gravity of the situation.

Several minutes later, when I finally managed to stand up and walk, I tried to walk away. I was still weak and unsteady on my feet. He prevented me from going. I started fighting him, but I soon realised that I stood no chance. He was much bigger and stronger. While we were fighting, he had an expression which, looking back on it now, seems bizarre: it was one of laughter and enjoyment, as if he was a superior male playing with a woman as a cat with a mouse. My anger welled up and, using the last bit of strength, I gave him a strong push, trying to take away that laughter. My thought was: 'You may kill me, but you are not going to laugh about it!'

As I thought this, the full awareness that I was about to die, and by a violent death, hit me; I started to be overwhelmed with fear and began to shake violently. He tried to reassure me by rubbing my arms. After a while he became quite agitated in reassuring me, as though he cared. This was utterly incongruous with my understanding of how someone intent on causing harm would feel towards his victim. His actions stopped me suddenly; they paralysed my emotion and my thought, and I painfully had to take into consideration that I might have been wrong in my understanding. My instinct of his destructive intentions did not want to listen, but the drive for survival and logic forced me to take this into consideration. I still did not give up on my not trusting him. For several minutes, this was followed by him withdrawing respectfully and me starting to feel reassured, and then him coming closer and my becoming afraid and shaking again. This continued for a long while.

I reached a point where I did not know what reality was. Was I facing death, or did I have a friend in front of me? Was there an explanation for his behaviour? I feared I was going mad; it felt like fear of total annihilation. I had to resolve the dilemma; my survival was at stake in that decision. It did not make sense that he would want to kill me. I then looked into his eyes trying to beg with my expression 'Can I trust you?' but I could not speak. His eyes showed anger initially, followed by what seemed to be his understanding of my silent question and he started nodding in reassurance. I capitulated and decided I had been wrong. As doubt still was in me, I forced myself to believe in him; I thought 'he is kind, like my father is kind', and projected onto him the image of kindness I had of my father.

As I accepted this 'distorted' reality, I was then overwhelmed by a sense of profound guilt, for 'I had accused an innocent man'.

When I completely calmed down, I thought things were going to be all right. He then took me by the hand and led me to the side to lie down. As this was happening, I gave up completely, I could not fight anymore, I was complying fully and unable to put any resistance of either thought or action.

I realised then that he wanted to have sexual intercourse. As he was putting me to the ground, in a hazy way, I thought: 'I am making love to a friend'. I didn't believe in the idea, but I had seen movies and read about it being a meaningful thing. As I thought this, I felt a strong pain in my heart, as if my heart was being wrenched from my chest.

I had for one moment, as he was coming closer, the image of him as he was in reality: an image of rape and violence. This disappeared immediately from consciousness, and it was replaced by guilt. My body could not participate in the act; I felt guilty for that, my mind was following the thoughts and meanings that had preceded the act, having forced myself to believe in him. As it finished, I was overwhelmed with retching motions, feeling sick at what had happened. My consciousness only thought of hiding it from him, for fear of offending 'such a kind friend'. I thought I had chosen the act, but I started chatting to him. I remember him having an expression on his face of ridiculing me.

I do not remember how I returned to the camp. I remember vaguely in the days that followed going around with my clothes soiled by the flow of menstrual blood and my not hiding that, not even the blood running down my legs. My attacker must have been in the camp in the following days, but I cannot recall his presence. The day he left with his brothers he called me to say good-bye and I waived back, not remembering what had happened. I met him once again a month or two later in a hotel in New Delhi and I remember saying to him that I could swim and did not need a life buoy. I am not sure what I meant; I think I meant something about my managing without help. It certainly was a strange thing to say. I did not see him anymore after that. I was told he was ill and I have had the fantasy since then that, maybe, from my odd conversation, he understood how he had driven me into madness and now he had become ill because of the guilt.

An analysis of the thought processes that occurred

It has become my understanding that his irrational behaviour is a form of psychological violence towards my emotions and my mind. Behind the conscious thought of 'making love to a friend', there was a deeper unconscious fear of him, but at the time, and for many years, I was not aware of this terror. My unconscious reasoning included the thought that 'I must do what he wants'. What I now know is that this fear had not gone away. The impossibility of his innocence had not vanished. It had gone out of consciousness, but the fear was still there, driving the force of the guilty thoughts I had experienced when I 'decided' he was not harming me. By feeling guilty, I was complying with the meaning he was providing to the situation. It was as if he was saying he was innocent, and his entire psychological and physical violence was forcing me to accept his innocence, something that my true self, somewhere deep inside, knew wasn't real.

To accept such a distorted reality, I had to relinquish my mind, as I could not trust my mind to be able to know what was happening. It was as though I had ended up putting myself in the position of an infant trusting the adult to guide me. I had put my whole being in his hands, trusting him like a child.

Why did I do this? I had become unable to trust my mind by his incongruous act of seeming agitated in reassuring me, as if worried about me, and the following skirmish. His reassurance and then my fear and doubt had all compounded on me as psychological violence. The process of recognising the reality and impact of this event has occurred over many years, through self-analysis, psychoanalysis and core reading psychoanalytic texts on thinking processes and on psychosis. It has been only recently, with the help of my present psychologist, that I was able to understand that the rapist was unable to take responsibility for his actions. I now understand that, somewhere in his mind, he was justifying his actions.

Through exploring the events which led up to the attack, and his actions afterwards, I have enough evidence, from various emerging details in therapy, that enabled me to reflect that he indeed must have had some serious psychological problems. His very expression and behaviour at the time of the attack had something deranged about it. My mind had received these incongruous acts like a blow to the head, as if being hit; I was unable to think it through. My mind had become paralysed through his violent actions. My rational thinking had appeared to be faulty, and fear could do the rest.

I now know that, within that thought – that he was a kind man (like my father) – was an attempt to make sense of things and complying to him. Therefore, having sex was performing an act of compliance, as if by choice. But that wasn't my truth, although I continued to hold this false belief for many years after this incident. I was 'thinking' entirely contrary to my true being. No part of my true self, if conscious, would have accepted the act.

The guilt as the act started was a guilt that was driven by fear, a guilt aimed at survival and, of course, a guilt that was complying with his meaning, obeying to him. Different levels of thinking were taking place, with the conscious thought consisting of guilt for having thought he was about to kill me. I now know that my body unable to participate was the only part of me that still knew the truth. Chatting to him at the end of the rape, I understood only many years later, was my trying to make sure he wouldn't still decide to kill me. Hidden underneath all that had happened, remained my fear that I could be killed at any moment.

From my psychological explorations of the traumatic event and its link to my psychosis, and through my autoethnographic doctoral work, it is now clear to me how I had become entirely split between an inner, unknown, unprocessed reality [26] of rape and trauma, and a conscious distortion of what had happened. Those familiar with Laing's work will be reminded of his notion of the 'Divided Self' [27] and his idea of what happens in schizophrenia. He postulated that, in schizophrenia, the person is given conflicting messages, the self becomes divided between these messages, and driven mad by the inability to resolve the dilemma. It has taken me over forty years to completely unravel the distortion and be able, now, to perceive the truth. The following section links the symbolic understandings of some of my dominant psychotic 'symptoms', gathered from my analysis and a review of the diaries I have kept for the past forty-six years.

My delusions and my understanding of their explanations

During each period of my acute psychotic illness, part of my delusions consisted of believing I was the daughter of God. I now understand how this delusional belief provided compensatory elements to my feelings of being inferior, but in particular, it related to my efforts to make sense to myself of the act of having intercourse with this man as an act of kindness and self-sacrifice on my part. My mission to save humanity, which was part of my delusion, was a continuous meaning-making process, wherein I was trying to escape the overwhelming sense of guilt and make sense of my self-sacrifice. This meaning-making can be explained as the mind's search for truth, a seeking of the explanation that has gone wrong.

Following my strong Catholic upbringing, the words condemning the great 'prostitute' and several similar passages, for example in the book of Revelations, were impossible for me to read for years, as I was identifying with them. I experienced a double guilt: the one caused by the distortion that had me believe the aggressor was 'innocent', and hence the guilt I felt for mistrusting him, and the real me who had thought against my own principles (even as my body remained paralyzed by what I now know to have been unconscious terror). While I was not conscious of any aspect of such guilt, it still affected me powerfully. Its main driving force were fear and the distortion that accompanied it. I have recognised that my moral principles, stemming from my upbringing and the religious and moral education I had received, played a part in my guilt. However, I do not think the events of my early childhood were the cause of my psychosis, and it is beyond the scope of this paper to explore those aspects further.

Amongst the hallucinations I experienced, there were images of: someone raping me; abusive sexual images; someone forcing me to think what he wanted or he would punish me; someone trying to possess me, often beside me in bed. I have come to understand that the reason I saw such images was because my mind was communicating to me the reality of the event in the only way it could, through images and symbols since I had never processed or digested what had occurred. In this regard, Bion [26] had explored how the mind can be unable to process traumatic events, and his own experience during WWI taught him how the mind can struggle in this regard. In his analysis of Bion's life and in particular his war experience, Brown [28] describes how being bombarded "by sensory fragments reduced Bion to vomiting in order to evacuate the sensory overload and must have also taught him, in retrospect, how the desperate mind madly discharges experience that cannot be abstracted" (p.1200).

I would experience my hallucinations most of the time, especially if I was under stress or tired. I understand them to be the constant attempt of my psyche to try and find my truth, which I needed in order to heal. During periods of my psychosis, I had feelings of anger towards my father for having created me, as if he had made me to be as he wanted instead of letting me be myself. I felt compelled to think and act through an imposed will. I now know these feelings were the outcome of the internalised obedience and sense of inner guilt that the trauma had formed in me. At the same time, I loved my father, and it was painful to experience these emotions. I eventually saw how these images were once again my mind trying to bring in reality by finding a 'culprit'. The culprit I had symbolically chosen (my father) was a safe one and I had indeed projected the image of him into the aggressor at the time. In order to be able to believe the aggressor had no ill intentions, I had consciously thought he was kind like my father was kind. After all, that is how he had been till then. Fixed in my psyche was a thought process, once again, not understood in reality. As the rapist with the trauma had 'created' a 'false me', a false self, I then perceived myself as having been created by my father. In these images and false beliefs (hallucinations) was the truth attempting to find expression.

My paranoid perceptions were usually ideas of people talking about me and making derogatory comments. I would hear the odd words being spoken or see people laughing and I would think they were talking derisively or laughing about me. I now see that in reality there were neither such conversation happening nor such laughter directed at me. At the time, I would have been too distressed and fearful to be able to fully attend to the conversation. Today, I understand I outwardly projected guilt onto others; I did not know its real origin hence it existed outside of me. During a psychotic episode, it was as if I was talking to and was spoken to by 'God'. In reality, the god in my delusion was the internalised rapist who existed as a form of supreme power in me. In later years, my recognising and defying such cruel god was the start, perhaps, of the challenge to the abuser's power over my mind.

Two autobiographical accounts of psychosis

As I had chosen an autoethnographic approach to my research into the link between trauma and psychosis, I identified two published accounts by authors who had written of their psychotic illness and recovery. I have compared these accounts with my own understandings, and they have extended my thinking into the possible causes of psychosis and the journey to recovery.

In his memoirs, Judge Schreber [29] refers to the idea of a 'soul murder'. Schreber (1842-1911) had been appointed as the chief justice of the supreme court of the state of Saxony (Germany) before developing his psychosis. In his book, he described his mental illness, his delusional ideas and his hospitalisations and treatments. In certain passages, Schreber spoke of thinking he had been a victim of this 'soul murder'. I find this description very apposite for what happened to me. I was murdered in my core being by being forced to deny my truth.

There is not a conclusive explanation of Schreber's psychosis, although many people over the years, including Freud [30] have investigated it. I interpret his use of the words 'soul murder' as his unprocessed perception of his inner experience. Maybe Schreber, like myself, was denied expression of his true self and had been forced to internalise and accept the will of another.

Similarly, in her autobiography 'The Words to Say It', Marie Cardinal [31] describes a 'thing' that controlled her in her psychosis. We find that this thing was her internalisation of her mother, and her mother's attitude towards her. It seems to me that this is akin to one's own self being taken over, the 'soul murdered'.

In terms of my own psychology before the trauma, which I have had to face to fully understand my reactions and my thinking, I recognised that I had to deal with my Catholic upbringing with its religious beliefs about sexuality and the impact those beliefs had on me in response to the trauma. Equally, I had to resolve ambivalent feelings towards my mother and idealisation of my father. I had to integrate my understanding and experience of both my parents, face my anger at their imperfections and reach an acceptance of their imperfect humanity. Both my religious education and my parental upbringing contributed to the formation of my personality, by giving me not only moral principles but also a sense of self and a way into life. This process enabled me to then look at the trauma, and helped me distinguish between elements formed out of my early life and elements pertaining to the direct consequence of the violence. This is an important distinction to make because each aspect of my life has had an impact on who I am and how I think. To be able to distinguish the consequences specific to the trauma, I needed to understand what stemmed from my upbringing and other aspects of my life; only then could I more clearly see and understand distortions in my thought. I could then focus on the entire psychological impact of the trauma.

The fear of and about psychosis

I now wish to address a particular area that is a cause of great anxiety and fear about psychosis; that is, the area when the behaviour of a psychotic person is contrary to their 'normal', 'true' being. I hope that by considering the underlying causes of the irrational behaviour of many people who become psychotic, it will eventually lead to a better understanding of why and how extreme forms of psychosis can even lead to (rare) acts of aggression and even to murder. I can only use my own example, and I do not claim to be able to fully explain other people's experiences, especially considering that each of us is unique and therefore each case needs to be considered in light of its individual history and psychology.

I have explained and explored above how I had been forced to deny my being, my mind, and accept the distorted thinking that the aggressor's behaviour had forced into me. I began to think as though I was possessed by him and under his complete power (it is worth noting how this fits with the ancient view of possession by spirits, which we now explain as psychosis). The fear of death, the psychological violence, and the inability to trust my own mind all combined into a conviction that my entire body and mind was under his control. Consequently, my thinking and emotions had adjusted to this distortion of reality, as a mind will constantly try to make sense of things. This meant that I believed myself to have willingly taken part in the sexual act. I believed somehow that I had loving feelings towards him (a false and extremely painful distortion, which took me a long time to overcome). I therefore believed myself to be a wanton sexual being. As mentioned earlier, I felt I had been created by the experience; a new false 'me' was formed in that distortion.

In the following years I found myself in several circumstances having sexual encounters with people which did not make sense to me. They were against my feminist principles, and I can only describe them as nightmare situations. One could argue that I had lost my self-esteem and that this was the consequence, which is also true. What I was eventually able to notice, however, was that each of these occasions had been triggered by a man's, sometimes even slightly, aggressive behaviour. If the man concerned had asked me for my consent, I would have been able to refuse. What was happening, I understand now, was that my fear was taking over: as a defence, the false self, created/formed the day of the trauma, was activated. I was using what I had learned that day about what I had to be to make it through a dangerous situation. One can imagine the consequences in terms of confusion with regards to my identity, my sense of guilt for such behaviour and the fear becoming greater —including fear of myself, of who I had become: someone whose behaviour I could not understand anymore and who had become immoral to my own eyes.

Freud's [32] concept of the compulsion to repeat has helped me in analysing these complex and contradictory emotions and behaviours. Freud postulated the idea of some people having a compulsion to repeat and re-enact a previous trauma as an attempt to process and resolve it. This notion of compulsion as a form of communication was explored further by Betty Joseph in her work on repetition compulsion. Joseph [33] wrote about the symptom of repetition compulsion, initially identified by Freud in the repetitive play that children used to 'work over in the mind an overpowering experience so as to make oneself master of it' (p. 17). Joseph stated that the enactment of the compulsion cannot bring resolution to the individual as it carries 'a particular balance between destructiveness and love, and how the very nature of this balance in itself can lead to no progress, but only to a blind compulsion to repeat' (p. 17).[see also 33, p.254]

These contradictions and agonies were within my own mind. How could I have acted so differently from what I had considered right? I did become quite confused about what was right or wrong; I didn't seem to be able to stay in one frame of mind. I would go from trying to cleanse my spirit and hold on to my thinking, to those moments when my mind would think differently, and I would act differently. When the distortion took over, I found that I had lost touch with my more sensible mind: my thinking was taken over by the false self. Of course, where sexuality is concerned, society gives different messages and values to what is appropriate and what isn't. I think, regardless of what is or isn't moral, those acts were immoral to me because they were not my choice but, rather, the result of an internalised violence. My inner reality about each of those encounters was of being raped again.

What I would like to leave as thoughts for the reader and academic community to consider are, firstly, an understanding that the mind can lose its lucidity, its grip on reality, because of having been taken over due to the abuse by another. My understanding is of the possession by the other that takes place as opposed to the more unconscious feelings of guilt, inadequacy, worthlessness etc. that occur in neurosis. Secondly, I wonder to which extent the mind can lose such lucidity. Knowing myself to have acted entirely against my true being, how much can someone else be driven to such extremes? I suspect only an entire life history could unravel the whole puzzle. I am not trying to justify people's behaviour, and I do not know if it is possible to lose one's mind to the point of not distinguishing what murdering means, but I do certainly think that it becomes very difficult to reason with one's mind when one is the victim of trauma, as I had been, and experiencing it under the power of another's mind.

In his Clinical Diary [34], writing about his patients B (Alice Lowell) and R.N. (Elisabeth Severn), Ferenczi described how, since their trauma, they were acting from the imposition of an 'alien will'.[34,p.17] He died before completing his work, but he seemed to be describing the same psychological effects, as that which happened to me, on these two women following their serious experiences of childhood trauma. My co-author (LN) and I argue that this 'alien will' may be, at least in part, the cause of the self-directed harm, internalised or externalised violence, and out of character behaviour people with psychosis may exhibit.

Conclusion

I have attempted to show how, in my case of psychosis, the psychotic symptoms were an indication of a true self that had been forced into hiding, repressed by the experience of extreme terror and psychological violence, and how a false self became a dominant form of reality in my life. It hasn't been possible to describe and explore my previous vulnerabilities, which perhaps made it possible for such a distortion to occur. However, I am certain that the main reason for the distortion lies in the trauma itself and the drive to survive. A whole case study would consider the way one reacts to a situation, but while I recognise that I did have some vulnerabilities, I do not think I had more than the average person. My recovery has required me to explore and face all of my past, not just the trauma. I could not deal with the trauma unless I was clear what part my own psychology had played in it, how my upbringing and past experiences were making me react to the trauma.

I think the description Bollas [2] uses regarding the 'split' in psychosis is the most useful in explaining the process I have uncovered. He states that '[w]e witness a splitting of the self: a subjective transformation giving birth to a psychotic self, emerging from the destruction of the former subject". [2,p.93] This statement has more meaning now and perhaps I have given a bit more understanding of why this can happen.

Similarly, Winnicott's explanation of the false self in psychosis [3] is an evident reality in my schizophrenia and, I think to some extent, in all psychoses, and I suggest that this can be particularly the case as a consequence of trauma. What we define as trauma can have many faces and explanations, and the purpose of this paper is to draw attention to the link between a terrifying trauma with an imposed false understanding and its effect on person's mind, their sense of reality and act to diminish or entirely repress their true self.

As I progressed in understanding and integrated what had happened to me, I have gradually resolved my psychotic symptoms. I have not had any psychotic symptoms for over two years, and I only have some lingering remaining feelings of guilt on which I am currently working and hoping to resolve. I remain with some remnants of fear towards men in general, that I suspect I will never be able to entirely overcome.

Alongside the recent movement of Mad Studies that started at Toronto Metropolitan and York Universities in Canada, this paper aims to recognise the expertise that stems from lived experiences of mental distress, and it works to challenge the discrimination that results from diagnoses of 'mental illness'. We hope we have succeeded in showing that psychosis is not madness, but that it is or can be a psychological response to one's traumatic experiences. More is needed to understand the reason why some people become psychotic, and we believe that their 'madness' will be always revealed not to be so. If psychosis is not madness, then the question remains: does madness really exist?

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