Supported Reporting of First Person Accounts: Assisting People Who Have Mental Health Challenges in Writing and Publishing Reports About Their Lived Experience

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Introduction

Knowing the lived experience of people who have mental health challenges is considered instructive and hence potentially helpful for other people who have mental health challenges and for other stakeholders, such as their significant others and mental health care providers. Publishing such lived experience in journals that are read by psychiatrists and other mental health care providers, policy makers, clinical researchers, and nonclinician scientists (who do schizophrenia research but are not commonly exposed to individuals who experience schizophrenia) as well as by people who have mental health challenges and their significant others, may be an important way to promote learning from, and empathy with, people who have mental health challenges. Such publication comes in various forms, of which the most well known of late is the first person account, which is a relatively brief report, usually focused on one or a few aspects of the lived experience of a person who has one or more mental health challenges or less commonly of a significant other of such a person.

By definition, the experts on lived experience of people who have mental health challenges are people with mental health challenges and their significant others, may be an important way to promote learning from, and empathy with, people who have mental health challenges. Such publication comes in various forms, of which the most well known of late is the first person account, which is a relatively brief report, usually focused on one or a few aspects of the lived experience of a person who has one or more mental health challenges or less commonly of a significant other of such a person.

Collective and cumulative experience of writing and publishing such first person accounts and of assisting in this process, ie, of collaborating in supported reporting of first person accounts of people who have mental health challenges. Our informed suggestions will be separately titled and elaborated on below, in an order following the order of steps of writing and publishing such first person accounts (although this order is somewhat flexible and may be circular rather than linear, depending on need for revision and resubmission of the report of the first person account).

Establishing a Collaboration

The first step is to establish a collaboration between the person with lived experience, who is the content expert, and a person who has published sufficiently in such journals, who is the process expert. The process expert may be another person with lived experience who has published first person accounts and/or a researcher who has extensively published other types of reports in such journals. Such a collaboration requires mutual interest of both types of experts, a level of comfort for both in working with each other and a clear and explicit agreement on what is the division of labor among both, among other things.

People who have mental health challenges may have various reasons for wanting to report their first person accounts, such as a desire to remove or reduce societal and professional stigma (and thus facilitate recovery of people with mental health challenges), a desire to help people—themselves and others—who have mental health challenges (and a belief that such reporting may indeed help), a desire to disclose their lived experience in public (to be fully “out of the closet,” so to speak), and a desire to be famous (although one first person account does not usually make the person famous). Other people who have mental health challenges and who have published first...
person accounts and/or research may also have various reasons for wanting to assist people who have mental health challenges in reporting their first person accounts, such as a similar desire to help people—themselves and others—who have mental health challenges (and, similarly, a belief that such reporting may indeed help) and a desire to empower people with mental health challenges who want to report about their lived experience. Whatever the reasons, both types of experts have to be interested in this collaboration in order for it to work. In addition, both have to feel comfortable working with each other in order for the collaboration to work. In our case, that level of comfort was achieved partly due to the fact that the process expert (the current paper’s first author) and the content experts (the current paper’s other authors) knew each other previously and trusted each other in relation to their expertise.

If no such previous familiarity is possible, it may be helpful to take some time to get to know each other before commencing such a collaboration. As part of that, the content experts can tell the process experts about some of their lived experience, and the process experts can tell the content experts about some of their research experience and can provide some of their previous research publications. After that, if both are interested in and comfortable with the collaboration, a clear and explicit agreement on what is the division of labor among them is useful, so that their work together is as effective and efficient as possible and in order to prevent misunderstandings during the collaboration as much as possible. In our case, as may be typical of such collaborations, the content experts wrote the first draft and presubmission revisions, and the process expert helped clarify the focus of the report, suggested journals (and their ranking) to submit the report to, suggested presubmission revisions, translated the report into English in one case, and—with student volunteer assistance (thanks are due to Martin Rotenberg)—formatted and submitted it online to the journal for review (note that the division of labor in relation to the current paper was similar, other than its first draft was written by the process expert).

Planning the Report

It is not uncommon for an idea to require clarification. This is the case for first person accounts too, as reporting lived experience, particularly in relatively brief reports, requires focusing on one aspect—or at the most a few aspects—of lived experience. It may be best for the content expert to focus on a relevant aspect of his or her lived experience and to clarify the focus in collaboration with the process expert. It is not always easy to do that in advance of writing drafts and revising them, so if the focus is not easily clarified from the start, we recommend drafting the report and clarifying the focus during the revision. In our case, the focus of one report was fully clarified before drafting the report, whereas the focus of another report, although relatively clear from the start, required more clarification during the presubmission revisions.

Reports, including first person accounts, benefit from some structure, which can be formal, as illustrated in separate sections, or informal, as illustrated in a coherent flow of the text from start to end. Whatever the preferred structure, it is best to determine it in advance, even if roughly, and fine-tune or radically change it as needed during presubmission revisions if needed. This should be done in a particularly collaborative manner, as content expertise and process expertise come together to determine the coherence and hence the structure of a report. In our case, one report was more formally structured, due to a more cognitive emphasis in the report, whereas another report was more informally structured, due to a more emotive emphasis in the report.

Another important part of planning the report is identifying which journal may be most suitable for it. This may be an iterative process, as such identification may be important for drafting the report, eg, in relation to report length, yet it may also be impacted by presubmission revisions, eg, if during such revisions content expertise requires a more lengthy report than is allowed by the journal that was initially identified. In our case, it was relatively clear from early on what may be the most suitable journal, both due to practical considerations such as length of reports allowed by the journal and due to content considerations such as variety of foci of first person accounts published by the journal in the past.

Writing and Resubmitting the Report

As surprising as it may seem, the least that can be suggested is about the actual writing of the report. This is partly due to the fact that writing such reports is a creative act that does not easily lend itself to specific suggestions, particularly in relation to such brief reports. That being said, process expertise can be helpful here by guiding content expertise in relation to standard ways of writing that may be most acceptable for publication, such as avoiding overly technical or idiosyncratic jargon and using grammatically and syntactically correct language if the content expert is not versed in writing for publication. In our case, one report also required translation to English, which was then reviewed by the content expert to suggest any refinements needed in the English version (fortunatley, the content expert was sufficiently versed in English to review the English version). That same report was also reviewed by a professional editor who is also a content expert, for editing across the 2 languages. Needless to say, critical yet constructive suggestions for presubmission revisions are required by the collaborating content and process experts in order to achieve a report that is both successful in being accepted for publication and
as effective as possible in achieving the aims of a first person account, as described above.

Submission of the report, online or by mail, as required by the journal, can be done by either expert or by someone else assisting with this step. In our case, as the content experts were not experienced in online submission to professional journals, the process expert assigned a volunteer student to submit the finalized reports. Both reports were accepted as is, i.e., without editorial request for postsubmission revisions. In cases where such revisions are requested, process experts may be very helpful in suggesting how to approach such requests and how to revise accordingly so as to improve the report while maintaining its original focus. In cases where journals reject reports, process experts, who are used to such rejections (which no researcher is exempt from), may also be very helpful in encouraging the content experts not to give up or shelve the report but rather identify another suitable journal, revise the report together according to the rejecting journal’s reviews of the report, if available, and submit the report to another suitable journal.

Conclusions

Supported reporting of first person accounts of lived experience of people who have mental health challenges is newly described here as a collaborative process of content experts—people who have mental health challenges—and process experts—other people who have mental health challenges who have published first person accounts and/or researchers with extensive research publication experience. Planning, writing, and (re)submitting are important parts of such supported reporting, which may lead to successful and effective publication of such first person accounts. Future research on such supported reporting, e.g., comparing support by other people who have mental health challenges who have published first person accounts vs support by researchers in relation to processes and outcomes of writing and publishing such first person accounts, may be useful.

References