Offering Food ↔ Receiving Food, *Journal of Psychosocial Studies*, Special Issue, Volume 10, Issue 2, October 2017

An editorial tea party?

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Kati: I first became aware of the project when you, John, posted a message on ResearchGate about it, asking for relevant literature. I immediately thought of some of the very powerful lived experience testimony I had come across over the years. Much of this is referred to - rather damningly in my view - as 'grey literature': *materials and research produced by organizations outside of the traditional commercial or academic publishing and distribution channels.* John, you hadn't heard of this term and we had an interesting conversation about it which led to you asking me if I would be interested in coming aboard and co-editing this Special Edition with you.

Not ever having done anything like this before, I felt pretty nervous and apprehensive. Okay, I've co-authored and written a number of papers and articles over the years but co-editing a special issue of a journal felt very different. I've always had quite an ambivalent attitude towards writing – enjoying the finished result but going through a pretty tortuous process to arrive there. Was this going to be like that? Running alongside this apprehension though, and following several conversations with you, was an excitement and anticipation that we could perhaps bring together lived experience, academic and professional voices in creative, maybe even innovative ways.

John: I had been working for a while with a writing group of experts by lived experience and we had presented a poster on our 'Project Antigone' and some dynamics of working together that had emerged, at a conference of the Association for Psychosocial Studies in Preston in December 2014. Liz Frost and Helen Lucey invited me to consider guest-editing a Journal Special Edition on these themes. I liked the idea but I hesitated for a while, feeling I needed a co-editor for the kind of collection I had in mind, but recognising that it would be unfair to ask this of my anonymous co-workers on 'Project Antigone'.

When, Kati, you and I started to correspond on the theme of 'grey literature' around eating distress, it dawned upon me that you were the co-editor I was looking for. You and I had first met some years back through connections to the Henderson Hospital Democratic Therapeutic Community and continued our collaborations in various writing, teaching and consultation projects over the years. I also realised that you would be the ideal partner in a project to produce 'rainbow literature' as a retort to the 'closed shop' inherent in the disparaging term 'grey literature' (by which, at least in the domain of eating distress, is commonly meant: 'not signed up to established medical-model-driven research paradigms and therefore the 'wrong sort of evidence''...)

Kati: I'm not sure where the term rainbow literature comes from - John, I think you came up with this or did it come from somewhere else? - but I much prefer this description and I love your vision of the edition as some sort of challenge to conventional academic publishing norms and what is perceived as the ‘right’ evidence.

I have got strong views on (how little) the lived experience voice in literature is regarded and validated. I think it's becoming more visible and recognised but there is still an over-reliance on 'scholarly' academic papers and articles. If you have lived experience, unless you work in academia and know the ropes – or know someone who does and who can advise you – it's extremely difficult to get things published in this 'acceptable' format. Then there is the added problem of trying to identify, discover and locate material which falls into the 'grey' literature sphere. It often doesn't show up in conventional searches and unless you have the time and take the trouble to find and use alternative search strategies you can end up missing out.

John: I think the field of 'eating disorders' (I work on an inpatient unit for women and men diagnosed with anorexia nervosa) particularly epitomises the structural and societal problems associated with the disparagement of voices of lived experience. Despite some shifts in tone in recent years, sufferers who enter (or are entered) into treatment in the kind of service I work for are generally not felt to have anything reliable to say about their 'disorder' - they are felt to 'lack capacity' across the board - they are deemed to need 'weight restoration' before they can 'come to the table' as anything like equal parties to a conversation - 'disorder' is felt to be obvious but an effort has to be made to remember the possibility of distress. Very little consensus exists about what really helps in treatment - yet still the 'field' remains reluctant to ask 'unrecovered' sufferers what it is like 'being them'. We had better, therefore, find ways of asking the right questions in the right kinds of ways, to share an understanding of the experience of those people whom wider society hopes will be ready receivers of our 'offers of food'.

Kati: I absolutely agree with you, especially as there has been a move in recent years due to cuts and cost-effectiveness drives towards only treating as in-patients those who are at the severe end of the spectrum. I think this makes it easier for some to assume: if you are this critically (physically) ill, how can you make any rational or meaningful contribution to the care and treatment of your mental health? I've also found myself becoming increasingly 'anti' the biomedical/clinical worlds of diagnosis the older I get. Not sure why this is – whether it's simply the passage of time or a reflection of where I am currently with the world and myself. Regardless, I feel quite an antipathy towards any kind of medical diagnosis which has *disorder* as part of it.

I'm also interested in your use of the word 'sufferers' here, John. Knowing you as I do, I think you use this term as a way to convey the horrors of eating distress, rather than as any judgement on the person involved. And yet many of us in the survivor field see terms like this as implicitly disparaging, no matter the context in which they are used – adding to the power dynamic of the 'patient' as having no voice or relevance and the 'professional' as knowing all! That's why discussions such as the one we're having here are vital.

John: Ah! Thank you! A very important challenge - and language is indeed crucial. I welcome the opportunity to reflect again on my practice and revisit any assumptions. Another example of this is that I've previously written quite a bit about the term 'refusal', critiquing the imputations of 'deliberate-ness' that creep into the language around food refusal - only to discover that the term 'refusal' itself implies quite a bit more about the position of the individual who is being offered the food, than may justly be inferred. Perhaps a particular individual is not so much refusing food as finding themselves unable to resolve an agonised deliberation about whether they have any right to accept the offer ... I can't go back and re-write those pieces - but I hope I can keep thinking about these issues, going forward...

Kati: Oh yes! That way of seeing it does feel much more like it from my perspective. That’s the real value of having conversations like these – that they nudge and provoke us into reflecting on what we have thought or written and in the process can uncover the unconscious assumptions we are all prone to make. I think this has happened during our email conversations with our contributors. I’ve certainly stopped to pause and think about quite a few things. It’s really interesting that a few of our contributors commented on the ‘refusal’ term during our email exchanges and as a result we ended up changing the title of the whole project!

John: You Kati have made a massive contribution in this regard in helping me to steer away from some well-worn grooves of 'clinical' thinking that I might otherwise have slipped into the path of, despite my knowing full well that they go nowhere fast. Left to my own devices, for example, there might have been fewer more 'formal' pieces from voices of lived experience and fewer less formal pieces from experts by training in their various fields. And we might have insisted upon 'author biographies' from everybody, because somehow that's the thing to do and habit and pattern have us all in their grip in different ways ...

Kati: Yes, that was a fascinating process we went through around biographies, wasn’t it? It was something we didn't discuss together before you put the call out and on reflection we've agreed that perhaps it should have been! I know it’s the ‘done’ thing to provide author biographies for every contributor but I questioned this as I do really struggle sometimes with how much of myself I want to reveal in a very public space. Writing from the lived experience perspective strips away the layers of protection that come with a profession and status and at times makes me feel vulnerable and exposed. Similar dilemmas were experienced I think by some of our contributors when asked by us to draft brief biographical details: what to write, how much to disclose, what name to use? We didn’t want any of our contributors to feel uncomfortable in this regard and found ourselves questioning the validity and necessity of including biographies in the collection. In the end we opted to leave the decision up to each contributor.

John: This all said: I think we neither of us wanted the Special Edition to be about 'eating disorders', or only certain kinds of lived experience, but about the offering and receiving of food in a much wider 'psycho-social' sense. Take this headline and subhead from The Guardian newspaper (10 March 2017): "World faces worst humanitarian crisis since 1945, says UN official: Twenty million people face starvation without an immediate injection of funds in Yemen, South Sudan, Somalia and Nigeria". If famine in the post-industrial age is the result of a global withholding of available resources (as well as a reckless squandering of the potential of the planet to replenish its resources) then our exploration of the dynamics of offering food needed to cast its net wide.

Kati: I know I felt strongly that we should have as wide a spread and as equal a balance of voices as possible. I do feel that including lived experience accounts opens the door onto a vital perspective that is still largely ignored or side-lined in mainstream journals and publishing. I don't mean by this to make a judgement on other perspectives and I hope I (and by extension, we) haven't fallen into the trap of excluding some voices in our attempt to include others less heard. I don't think so. I think we've ended up with a wonderfully eclectic collection of pieces in an exciting range of different forms which challenge and provoke – no matter which perspective they are written from.

John: I also think there's clear evidence of the creative way in which the pieces have bounced off each other during the writing process. Voices of 'clinical' expertise have shared and explored aspects of their own food practices alongside voices of lived experience - in diverse and revelatory ways, to my mind at least.

In fact, for me there's a theme that has emerged in the process of the writing group that was not at all apparent to me when we started off down this road: namely, that everywhere in this Special Edition the reader, I believe, will encounter *voices* - sometimes recorded, sometimes reported, sometimes self-reported, sometimes ventriloquised, sometimes clustered in groups, sometimes very alone and surrounded by silence - sometimes unheard but imagined. Alongside our more visual image and imagining of a 'rainbow literature', we perhaps need an 'audio' image to convey something of the quality of a collection of *oral* histories.

Kati: Wow, I really like that idea! I can't quite remember how the idea of a 'collective' came about – whether it evolved almost unconsciously out of the way you and I were working together or whether there was a more formed intention. Quite early on – and with the permission of our contributors – we shared first and subsequent drafts amongst the group in the spirit of achieving some evenness in the writing process and hopefully creating a supportive and nourishing climate. This seemed to go down well. There were plenty of email responses of encouragement and subsequent thought-provoking discussions inspired by the informal (and safe?) peer feedback, commentary and back-and-forth which we had set in place.

John: I've been excited at various times by the creative possibilities of convening a writing group or a community of learning across disciplines, organisations, experiences and discourses. I've tried similar things before with other groups of colleagues in various kinds of writing projects but it's been a thrill to be involved and to watch as this particular process has taken on a life of its own. In our call for papers we evoked the 'Mad Hatter's tea party' from *Alice in Wonderland* to sketch the potential territory of a confusing offer that isn't really an offer and a difficult encounter that turns sour ('Have some wine,' the March Hare said in an encouraging tone. Alice looked all round the table, but there was nothing on it but tea...') I feel the various responses to our call for papers in their interplay with each other have taken us into spaces I hadn't previously imagined, let alone understood. It's been a great pleasure and privilege to be part of this.

Kati: Yes, for me also. This has been an engrossing, challenging and ultimately rewarding experience for me and I hope anyone reading the collection will be moved, inspired, provoked and moved again – as I have been throughout this process.