LIVING A MAD POLITICS

LIVING A MAD POLITICS: AFFIRMING MAD ONTO-ETHICO-EPISTEMOLOGIES THROUGH RESONANCE, RESISTANCE, AND RELATIONAL REDRESS OF EPISTEMIC-AFFECTIVE HARM

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Lay Abstract

This thesis contributes to Mad theory by recording some of the things I learned while trying to survive in the world, community organizing, the academy, and social work education as a Mad person. To do so, I reflect on the existential and ethical questions I brought to my doctoral studies, the people, texts, and concepts that I found particularly good company during this time, and my Mad methods of living/doing/knowing. Three separate but interconnected articles then follow. These are about (1) moving with loneliness as a Mad student; (2) resisting unmet expectations as service user ethics, and (3) how pedagogical partnerships between students and faculty/staff can cultivate marginalized students' confidence in their knowledge. The thesis ends with a discussion of its overall contributions to how we conceptualize the psycho-emotional harms produced through sanism/disablism and the ways we understand what Mad knowledge is and how it is generated.

Abstract

Drawing on the theoretical influences of Mad and Disability Studies; philosophical conceptualizations of epistemic injustice (Fricker, 2007), ethical loneliness (Stauffer, 2015), and psycho-emotional disablism (Reeve, 2012; Thomas, 1999; 2007); disability/service user/feminist ethics; a decade of Mad Movement community organizing; as well as autobiographical illustrations and empirical data from two collaborative research projects, this thesis describes my efforts to live a Mad politics in the community, academy, and social work education. Central to this politics, and to the overall contribution of the thesis, is its focus on (1) the recognition and redress of affective-epistemic harms that are often ignored by legislative/social welfare approaches to in/justice; and (2) the generation and refinement of Mad knowledge/ways of knowing that respond to our own priorities as Mad people, rather than those of mental health systems. It contributes to these areas of Mad Studies theory in several ways: First, by recognizing and politicizing the often ignored affective-epistemic effects of abandonment and neglect Mad people experience from society, including loneliness, anger, resentment, distrust, low expectations of others and lack of confidence. Second, by seeking new conceptualizations (such as epistemic loneliness) and contributing to existing ones (like expectations of just treatment, psycho-emotional disablism) in order to more adequately interpret and attest to these harms and call for their redress. Third, by affirming emergent Mad moral and epistemological frameworks, especially those that manifest in the aftermath of harm and account for ontologies of knowing. Fourth, by developing Survivor/Service User Research approaches to analysis (listening for resonance, everyday forms of service user resistance, and ‘quiet’ data) that value affective engagements with data and perceive and respond to Mad onto-ethico-epistemologies in and on their own terms. Ultimately, this work calls for greater relational justice, and an expansion of what we owe each other.

Acknowledgements

Following Sara Ahmed's (2017) work to describe the feminist materials that have accompanied her as a diversity worker, below I name (some of) the people, places, and things that have offered me company as a Mad Studies scholar and contributed to the intellectual conditions needed to write this thesis. I do this as a form of recognition and acknowledgement, and in order to not "eliminate the effort or labor from the writing" (Ahmed, 2017, p. 13). It also offers the reader a map of the epistemological and moral communities within which and with whom the knowledge of this dissertation has been generated. As Rose (2017) writes in the context of Mad /service user epistemological possibilities, "the debates we have and the papers we produce are not the expression of private, individual thought but collective through and through because each contribution is only made possible by previous ones and anticipated ones" (p. 784). Barad's (2007) recognition of our mutual entanglement takes this even further:

> Re-membering and re-cognizing do not take care of, or satisfy, or in any other way reduce one's responsibilities; rather, like all intra-actions, they extend the entanglements and responsibilities of which one is a part. The past is never finished. It cannot be wrapped up like a package, or a scrapbook, or an acknowledgment; we never leave it and it never leaves us behind…
>
> There is no singular point in time that marks the beginning of this book, nor is there an "I" who saw the project through from beginning to end, nor is writing a process that any individual "I" or even group of "I's" can claim credit for. In an important sense, it is not so much that I have written this book, as that it has written me. Or rather, ''we'' have ''intra-actively'' written each other... (ix-x)

Likewise, the thinking in this thesis is not finished and cannot easily be wrapped up, and is only a small part of my ongoing responsibilities to those named and unnamed here. It does, however, begin to offer a window into (some of) the context and materials that have constituted 'me' (right now) and this thesis. This list is inevitably incomplete.

I was introduced to Mad Studies by Geoffrey Reaume in the fall of 2008, when I showed up in his *Mad People's History* class at York University (a course he describes in Reaume, 2006). The reason I appeared there was because my then Master's program adviser in the Faculty of Environmental Studies, Bonnie Kettel, encouraged me to enroll, and because Clare Freeman, my third year BSW placement supervisor in Hamilton and former student of the MES program, opened up the possibility of exploring ideas outside of social work and recommended that I go there. At the time, I was employed as a crisis worker at the mental health organization where I had completed my fourth year BSW placement and was slowly going crazy (again).

I didn't put the pieces together until later, but Chris Sinding had directed me to the consumer/survivor community writing of Kathryn Church (1995) the year before when she supervised my completion of an independent study in queer autobiographical writing. I had worked with Debbie Jones, a peer leader in Halton region, in the winter of 2008 on a service user-led evaluation of the organization where I worked. This was my first introduction to the idea of 'consumers' and 'recovery', and to the wider peer movement. These exposures and experiences would eventually converge – but my first recognition of Mad people as a political group, knowledge producers, and forming an area of academic study was in Geoffrey Reaume's class. I am part of an emerging generation of Mad activists and scholars who have found the Mad Movement via the academy - something that was not possible for the leaders who came before.

In that *Mad People's History* class, I overheard Jeremiah Bach talking about the Mad Students Society - a group I became involved with, crossing paths with many fierce

Mad students between 2009-2012. Several of us ended up presenting Mad analyses of LGBTQ mental health research at a Rainbow Health Ontario conference in Ottawa in March 2012 - which I think was my first experience of experiential and collective Mad knowledge generation, and of pesto-based pizza. Engaging in grassroots community organizing without any prior experience doing this was fun, freeing, frustrating - and all that could get me out of bed at the time.

My early days in Mad community organizing evolved through the companionship of Elizabeth Carvalho, autisticwolf, the Mad Pride Toronto Organizing Committee (2011-2013), and subsequently the Peer Recovery Education for Employment and Resilience (PREFER) collective of peer support learners. Adventures with Elizabeth Carvalho were especially important for figuring out (1) how to get me a suitcase library when I was too scared to obtain and use a library card and (2) the many uses of bookshelves - such as for organizing archival remnants of everyday life. Later on, conversations about peer support and Mad movement organizing with Andrea Phillipson, Florence Heung, Chelsea Rothwell, Vaishnavi Yogendran, and Rachel Cooper helped me put into words things I (in relation with others) was coming to know. (Thanks also to Rachel for the proposed dissertation title, *This is the Damn Lemonade.*)

Or, actually, perhaps this is not quite right. My earliest days of hanging out with fellow crazy people and organizing Mad community started with several friends in high school, and then my hospital buddies: Tina, Stuart, Camille, Diana, Mark, Martin, Michaela, Catherine, Bobby-Jo. This included hosting walks through hospital hallways, an adventure to locate ice cream cake and covertly light (unallowed in the hospital) candles, my first trip (with Michaela) to LGBTQ Pride and Mad Pride in Toronto. These brief but significant relationships taught me more about care and support than I ever learned through formal social work education. Persimmon Blackbridge's (1997) *Prozac Highway* and other queer/Mad personal narratives also structured my imagination of what could be possible in and through Mad community.

During doctoral studies at McMaster, my first four years were spent gathering and spending time with members of the new Hamilton Mad Students' Collective and Mad Pride Hamilton Organizing Committee. Robin Pittis was an especially important friend and colleague during this time - helping me sort handouts when I was too worried about fingerprints to remove my gloves. Calvin Prowse, Jack Page, and Tina were there from the beginning. (I'm especially grateful to Tina for help solving a hat crisis!) Jack and Crystal Berg offered intellectual company as fellow graduate students studying Mad and Disability Studies. F. John Serafino introduced me to Hamilton psychiatric survivor history and took me for a commemorative diagnosis dinner. The Mad student zine that a group of us created in 2014 has facilitated numerous connections and conversations, and I thank all who contributed (Mad Pride Hamilton, 2014).

Over the years, I came to connect with peers across a range of other configurations and informal groups: food and friendship with the Breakfast Club (Samantha Farrell, Chelsea Rothwell, Vieve Shanks, Meagan Walker, Jasper Walton); advocacy and belonging among members of the Disability Action Group, and undergraduate and MSW social work student friends - Helen Dam, Jessica Evans, Jessie French, Roche Keane, Cassie Liviero, Sarah, Shaila, Stacey Skalko, Tory, Noël Valade.

Roche provided many pep talks. Working with young people on the Youth Council of St. Joe’s Youth Wellness Centre turned me into an ‘adult’ (mentor). Through engagement with these peers, I began to recognize “how what happens to me, happens to others”, and to “identify patterns and regularities” (Ahmed, 2017, p. 27). They also became part of my survival kit – fellow crip killjoys, people to laugh and play with, to make up new wor(l)ds, to whom I didn’t need to explain myself. Thanks to Jasper for encouraging me to use markers, upgrade my colouring to more complex designs, and visit dozens of paint stores to collect a vast array of interestingly named paint chips. Both became important modes of creativity, connection with others, language for talking about the blues, and home-making decorations.

I have been lucky to learn and participate in the long history of provincial consumer/survivor organizing as a board member of the Mental Health Rights Coalition and Ontario Peer Development Initiative (OPDI). Attending my first OPDI board meeting was incredibly affirming – finally connecting me with Mad elders and movement historians and their delightful cynicism, frustration, and angry hope for things to be otherwise. A conversation with Allan Strong confirmed how doing autobiographical work is hard, and that maybe I shouldn’t continue writing an autobiographical dissertation. I am grateful for the opportunity to collaborate with others through the University of Toronto Department of Psychiatry and the Education Department of the Centre for Addiction and Mental Health on work related to the coproduction of psychiatry education and support of Service Users as Educators. My thinking about service user/peer/Mad ethics and epistemologies are indebted to conversations with members of those coproduction working groups, especially Kim McCullough, Rachel Cooper, Sacha Agrawal and Sophie Soklaridis, as well as those in Elisabeth Gedge's 2019 ethics seminar on feminist approaches to relational autonomy. Thanks to Andrea Daley and Lori Ross for their support as collaborators on a community research project described later in the thesis. It was during the coding of transcripts with Andrea that I began to feel Mad knowledge as a thing - and to recognize why and how I was reading transcripts in a particular way through my experiences.

Chelsea Rothwell drove me home a lot and introduced me to the world of grief work, bereavement, and palliative care. Facilitating Mad Grief groups with Chelsea and then later with C.A. Borstad Klassen through the Bob Kemp Hospice opened up new words and worlds. The two of them provided concrete, self-affirming examples of boundary-setting. Thanks to Jon Underwood, Sue Barsky Reid, and Bernard Crettaz for establishing Death Cafés, those from the Ryerson School of Disability Studies and the 100% Certainty Project for facilitating the cafés I attended, and the McMaster Palliative Care Division for hosting the 2018 Palliative Care Book Club. As well, much love to Jennie Das for travelling with me to visit dozens of political memorials in the Netherlands, and to Nel den Boer for hosting us in Houten.

Thanks are due those who provided regular real-life sustenance: John and David Das helped me acquire the technologies I needed to write, Mendeley kept me organized, Nathan Das built my bed. *Original Pizza* provided many extra sauce and pineapple dinners in the last year of my doctoral work. Sandi Hoecht, our weekly Tuesday ceramics ritual, and our fellow painters at HARRRP gave me a hobby. Indwell staff and tenants helped me create a home. Gage and Montgomery Parks, the Hamilton rail trail, delivery for my neighbourhood newspaper (The Point), my local grocery stores, and the Kenilworth Library Attic encouraged me to leave my apartment. Tea and pajamas encouraged me to stay in. Much of the thinking behind this thesis was generated on public transit – and so special thanks are due all of the bus /train drivers who drove me around, especially those who waited for me to (carefully) run across the street.

I am grateful for the mentorship of Joanne McKinley, who has witnessed the unfolding of my life for over a decade, and to the listening and affirmation of Marybeth Leis Druery, who has tracked with me the story of my PhD, and helped me name, process, grieve, and protest the violences I have experienced and their amplification /exacerbation by the violences of the academy. She also heard me talk through sadness /loss over the changing nature of my madness. I am the namesake of two others - Janke van der Valk Das and Aaltje de Bie van Genderen. The publication of my academic work under /through their names regularly calls them to visit. Janke taught me as a child that it was okay to go against the flow, and how to bake - very helpful skills for fostering relations with those I love.

As much as I hate the promotion of ‘sleep hygiene’ and its individualization of responsibility, this dissertation benefited from a daily schedule and friends’ reminders to go to bed. Grudging appreciation for the chemistry experiments of Nariman Mehta and AstraZeneca. Thanks to my past shrink who treated me with referrals to science fiction, Harry Potter films for support during sad times, and to staff and volunteers at the Juravinski who offered juice, cookies, and respect - a very different perspective on healthcare than those learned from the psychiatric system. As I interact with these medical systems and their obsession with data, I find myself regularly asking, “Is having more knowledge always better?” (Andriessen, 2008, p. 8). My thinking in this thesis would now reply, no.

Fellow PhD students in the School of Social Work helped me figure out how the institution works, and made the process less lonely: Lori Chambers, Yahya El-Lahib, Becky Idems, Elene Lam, Jake Pyne, Lisa Watt, Tina Wilson. Lisa for her extensive guidance and encouragement navigating sandwich dissertations, doctoral requirements, supervisors and committees, institutional politics, and for taking me to visit her favourite places in Hamilton; Tina and her cats for long and rambly walks, rosehip tea, bossy text messages, colour-coded calendar suggestions, embroidered pep-talks, observations of my temporal and habitual patterns, and her encouragement to create a citational army, an academic uniform of solid dark colours, and to keep a record of good things. Both came into my life when I needed help: Lisa, when I needed advice on teaching internships; Tina, when I needed help writing a response to a teaching evaluation. They became essential to my survival as a doctoral student by affirming my interpretations of abandonment and neglect that came to form the *Loneliness* paper and offering company/shared meaning that allowed me to experience and imagine how things could be otherwise. Thanks also to my non-social work PhD colleagues: Ashley Ward for conversations about Mad doctoral life, Alan Santinele Martino for recognition of the difficulty of doing Disability Studies in ableist social science disciplines, Irena Radisevic for mutual support during the writing process, Andrew Kloiber for needed commiseration about what to do when we're done.

Opportunity to act as the Research Shop Coordinator within the Faculty of Social Sciences and then the Office of Community Engagement and to work with Ailsa Fullwood, Dave Heidebrecht, and Cynthia Belaskie helped me acquiesce to the potential concrete usefulness of research, feel what it is like to hold a job unrelated to my 'lived experience', and reconnect with my dissertation. Sandy Preston's advice about wearing scarves helped me (sort of) pass unspoken academic dress codes, as has the chapter by Lynes (2003). Ann Fudge Schorman's suggestion to satirize the content and format of the required annual PhD student report led me to rethink how to recognize and represent Mad work in the academy that would be traditionally missed. Tara La Rose provided advice on blocking off time and writing in bursts. Amy Gullage encouraged me to celebrate small successes. Andrea Cole, Nick Marquis, Pearl Mendonça, Grace Pollock, and Pete Self were especially supportive staff members. The care and attention of our social work department administrators, Darlene Savoy, Lorna O'Connell, and Tammy Maikawa made the institution more human. Mills library staff learned my name, guarded my interlibrary loans, and helped me evade and reduce library fines.

Thanks to my supportive PhD supervisory committee, Chris Sinding, Amber Dean, and Beth Marquis: Chris for encouraging me to consider graduate school in the first place, and then getting me into, through, and out of the PhD - which turned out to be no small feat. Her most significant contribution to my doctoral experience and dissertation was the prodding, care, experimentation, advising, provision of poems, belief in my capacities, delight in reading my work that sufficiently mollified my fear and inertia that I could actually sit down and write. So, eventually, I did. Amber helped make explicit the politics of academic institutions and their processes - like how comprehensive exams are a test and perhaps it's less harmful to think of them this way than to fight them into something useful. She took me on walks through our shared Hamilton neighbourhood, welcomed me as a participant/learner into her English/Cultural Studies and Gender Studies and Feminist Research classrooms, and directed me to Miranda Fricker's (2007) work on epistemic injustice and feminist writing on haunting, sexual violence, and academia. She also sent me to Tina Wilson for help, which was exactly what I needed - a friend. Beth found numerous ways to loop me into professional development opportunities where I could both get paid and think together with her and colleagues - like research projects, co-written articles, campus networks and relationships. I am especially grateful for her openness about her own PhD /early career experiences, and her laughter. I desperately needed resonant examples of what academic life could look like - how it can be sustainably, ethically lived. ABC, in their different ways and contexts, provided this.

Working with Kate Brown, Raihanna Hirji-Khalfan, and Anne Pottier on accessibility related initiatives on campus and the creation of an accessible education e-book/training (de Bie & Brown, 2017) felt like the first time to have colleagues, and to be connected to a longstanding history of disability-related advocacy on campus. This significantly contrasted with other experiences of people treating what I was doing and saying as 'new'. Supporting Michelle Sayles' (2018) project of synthesizing and graphically representing this disability history helped position my campus organizing within a 40-year timeline. Kate also took me to the movies, gives the best hugs (squeezing all of my guts back inside), and has helped me learn what ‘respect’ feels like by ensuring I am properly credited for my work and contributions. Feeling deeply recognized and appreciated has encouraged and motivated me (in my own self-respect, in my dissertation writing, in my activism /community projects) and validated my interpretations of disrespect and exploitation. Her friendship has facilitated a kind of repair from damage that Dillon (1997) so beautifully and painfully describes.

Several collaborations with student, staff, and faculty partners through the Paul R. MacPherson Institute for Leadership, Innovation and Excellence in Teaching (related to accessible education, equity and inclusion in pedagogical partnerships) have also played an important role in my diversity work and thinking - and the gaining of confidence. Notably, conversations with Beth Marquis, Cherie Woolmer, and Srikripa Krishna Prasad. Affiliation with McMaster’s President’s Advisory Committee on Building an Inclusive Community (PACBIC) supported the development of my analysis of intersectional justice issues on campus. The Employee Accessibility Network of disabled staff and Disability and Mad Studies Reading Group of 2018-2019 offered space for discussion with interested others.

Meeting fellow scholars at the 2018 Disability Studies Conference in Lancaster (including reassuring conversations with Jill Anderson, Kathy Boxall, Lieve Carette, Stephanie Cork, Helen Spandler), the 2018 Network Of Interdisciplinary Women’s Studies in Europe (NOISE) Summer School in Utrecht, and the 2015 Canadian Disability

Studies Association and Canadian Association for Social Work Education conferences helped make Mad and Disability Studies a thing. Thanks are especially due Magdalena Górska, co-director of the 2018 NOISE Summer School, whose scholarship introduced me to Barad's (2007) work. Thanks also to Janice Hladki for welcoming me to sit in on course on *Embodiments: Disability, Subjectivity, and Visual Representation*.

In addition to taking Reaume's (2006) *Mad People's History* course in 2008, my approaches to teaching and development of ideas regarding Mad pedagogy have been informed by bus rides with Becky Idems as we travelled together to co-teach, and by social work, social science, and interdisciplinary students at McMaster, Ryerson, and Dalhousie Universities - especially students I regularly met with as informal members of a 'Lunch Crew' at Ryerson. I am deeply appreciative of the mentorship of Jennifer Poole and her support gaining access to sessional instructor positions, beginning with the inheritance of her *Critical Approaches to Madness and Mental Health* course (Poole & Grant, 2018). Opportunity to collaborate with Ameil Joseph on his sibling course at McMaster and review the syllabi of David Reville and Brenda LeFrançois has also had a significant impact on my teaching. (A brief bus ride encounter with Brenda at a conference affirmed how hard Mad teaching can be, and conversation with her as my external examiner affirmed the ethical difficulties of assuming positions within a violent institution.) I have appreciated working closely with Janice Chaplin and Jennie Vengris on a project to enhance equity/accessibility in social work field education, and as a teaching assistant for Jennie. Leading tutorials for Social Science 1T03 with Mark Busser and participating in the Inquiry 1SS3 teaching team have been helpful introductions to teaching explicitly about academic norms and conventions. This has informed my thinking on universal design and accessible education. I am extremely grateful that Marie Vander Kloet co-taught Education 750 in the Fall of 2015, and that I was able to learn from her social justice politics in that course. These experiences and relationships with students, colleagues, and mentors suggest that it is possible for us to have higher expectations of each other and the academy and that we should be able to expect responsive and inclusive practices.

Thanks to Shelagh Lynne Supeene (1990) for writing about going crazy at McMaster two decades before I would arrive here, and for leading me to also pick up *A Dialogue on Love,* (Sedgwick, 2000), which was sitting beside Supeene's (1990) work on the library bookshelf. Thank you to Eve Kosofsky Sedgwick (2000) for leaving these words in that book:

> A moment's realization, startlingly clear. "I've figured out what it means when I complain to you about things," I tell him. "Or to anybody. When I tell you how bad it is, how hard I've worked at something, how much I've been through, there is only one phrase I want to hear.
> "Which is:
> 'That's enough. You can stop now.'
> *Stop*: living, that is.
> And *enough*: hurting.
> "Like, 'I didn't realize how hard it was for you; you've done well; you've been through plenty; you're excused.'" (p. 69)

In addition to those words, I am not sure I would have survived the university without Rogers (1991), who became a reference I could cite for how psychiatric survivors can experience the power dynamics of the academy as similar to psychiatry: "the people who use the drop-in associate the [literacy] teacher's power with the power of psychiatrists" (p. 84). Thanks also to Horsman (1999) for leading me there, and friends and colleagues who helped redecorate the social work floor in Kenneth Taylor Hall over 2014-2015 (with blanket fort creations, pet rocks, magnet poetry, paper chains, colouring sheet displays, fun parties, etcetera), thus altering its echoes with psychiatric institutions. I am forever grateful to the feminists and sexual assault survivors who helped name the vibrations between gender-based violence and the violence of post-secondary institutions (Donnan, 2003; Heald, 1997; Horsman, 1999; Palmer & Ross, 2014; Rosenberg, 1997), those who write about ghosts, haunting, and spectral data (Doucet, 2008; Gordon, 2008; Nordstrom, 2013), scholars attending to trauma/emotion within doctoral studies (Lee & Williams, 1999), and Jill Stauffer (2015), for offering language/theory to name loneliness. The children's picture books *My Teacher Is a Monster! (No, I Am Not.)* (Brown, 2014) and *One Word from Sophia* (Averbeck & Ismail, 2015) got me through comprehensive exams and my dissertation research proposal.

My dissertation work was financially supported by Doctoral Ontario Graduate Scholarships, as well as the Dalley Fellowship, Hilary M. Weston Scholarship, National Educational Association of Disabled Students (NEADS) Student Award, and employment as a Student Partner with the MacPherson Institute, through which an article of the dissertation was written. Thanks also to the participants of the empirical research projects that comprise components of this dissertation, my co-authors, Beth Marquis, Alison Cook-Sather, Leslie Luqueño, Andrea Daley, Lori Ross, and Sean Kidd, and to those who read the entire thesis and talked it through with me: Chris Sinding, Amber Dean, Beth Marquis, Kate Brown, Rachel Cooper, and Jennie Das. I'm not sure I would have shown up to my dissertation defense had I not been so excited to see the 50 friends and colleagues who came to witness and colour /craft through the ordeal – including many of those named above. It meant so much to me that I could publicly thank all of you for your support.

Over the course of my graduate work, three bio-family members, a prominent leader in the Toronto survivor movement who helped me explore employment opportunities, a colleague from a consumer/survivor initiative, four friends, a neighbour from graduate student housing, an undergraduate student from the School of Social Work, and a ginger cat, Simon Best-Wilson, have died. I also grieve Mad friends whose passing I am not presently aware of - given how we often occupy the fringes of each other's lives and are thus not known or notified by next-of-kin - and the loss of other students from my campus whose deaths remain unacknowledged by the university. My dissertation questions of how to survive/in the academy, and how to be responsible in my Mad/disability community work and scholarship are made more urgent and raw in this proximity to loss. I did not expect to live this long, or to outlive my friends. In loving memory of Aaltje Van Genderen, Josien Skibo, Johannes Das, Diana Capponi, Raymond Cheng, Michaela Schmidt, Wendy Babcock, Robin Pittis, Olga Figura, Lisa Watt, and Olivia Bibby.

In the picture book, *Nightsong* (Berk & Long, 2012), we meet Chiro, a young bat who is nervous about flying into the night for the first time on his own; he is worried he won't be able to 'see' in the dark. His mother tells him, "There are other ways to see…other ways to help you make your way in the world" (p. 3). She says to "Use your good sense… the song you sing out into the world, and the song the world sings back to you. Sing, and the world will answer. That is how you'll see" (p. 3, 5). This thesis has been created through echolocation with those listed above (and a multitude of others) - books, places, the living, the dead. I sang, they sang back, we sang together. Thank you.

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Declaration of Academic Achievement

Paper 1:
de Bie (2019). Finding ways (and words) to move: Mad student politics and practices of loneliness. *Disability & Society*. https://doi.org/10.1080/09687599.2019.1609910

Acknowledgement: *My thinking and moving with loneliness has been made possible and bearable by good company over the last decade – a list too long to include here – and has been companioned by grief for the friends and neighbours with proximity to campus life who have been lost, a list that is also too long: Michaela Schmidt, Wendy Babcock, Robin Pittis, Olga Figura, Lisa Watt. It is in remembrance that I urge us to tell different stories about who we are and what we owe each other, especially at the university. In the context of this specific writing I wish to thank those who helped make this a stronger paper through their thoughtful feedback on earlier drafts: my PhD supervisory committee, Christina Sinding, Amber Dean, and Elizabeth Marquis; colleagues, Tina Wilson, Jennifer Poole, Rachel Cooper; and two encouraging reviewers. Thanks also to the kind attendees of conferences where versions of this material have been presented: Lonely Café participants at the 2018 Reclaiming Our Bodies and Minds Conference in Toronto and researchers at the 2018 Lancaster Disability Studies Conference.*

Paper 2: Resisting unmet expectations as service user ethics: Implications for social work: This paper, under review by the *British Journal of Social Work*, was co-authored with Andrea Daley, Lori Ross, and Sean Kidd. I brought to our early conversations about data analysis my coding of a theme of 'resistance' and then worked on the analysis of this section of the code tree to prepare a draft paper. My colleagues commented on three drafts of the paper as it was developed and revised.

Acknowledgements: *This project was funded by the Canadian Mental Health Association - Ontario, and administered by the Schizophrenia Society of Ontario. The authors would like to thank the other members of the project team, Taryn Tang, Loralee Gillis, Elizabeth Carvalho, our research assistants, Janina Komaroff, Sayani Paul, and project volunteer, Clayo Laanemets, for their support, and the participants for sharing their experiences. An earlier draft of this paper benefited from the thoughtful feedback of Christina Sinding.*

Paper 3:
de Bie, A., Marquis, E., Cook-Sather, A., & Luqueño, L. P. (2019). Valuing knowledge(s) and cultivating confidence: Contributions of student–faculty pedagogical partnerships to epistemic justice. In J. Hoffman, P. Blessinger, & M. Makhanya (Eds.), *Strategies for fostering inclusive classrooms in higher education: International perspectives on equity and inclusion* (35-48). Emerald Publishing Limited. https://doi.org/10.1108/S2055-364120190000016004

This paper was written in partnership with Beth Marquis, Alison Cook-Sather, and Leslie Luqueño. I brought to our early data analysis conversations my questions and ideas related to knowledge, and Fricker’s (2007) conceptualization of epistemic in/justice. As I moved forward as first author on a paper with this focus, we all contributed reflections on aspects of the data that revealed and elaborated this theme, and co-wrote some sections. I prepared the first substantial draft of this paper, led the team in discussion about how to develop the paper further, and created the first articulation of the conclusions. Authors Beth and Alison offered links to literature and supported development of the introduction and refinement of the conclusions. I drafted our response to peer reviewers and revised the results/findings of the paper, with feedback from Alison and Beth on methodological revisions.

Acknowledgement: *We would like to acknowledge team members Anita Ntem and Srikripa Krishna Prasad for their contributions to the wider project, Chris Sinding for feedback on an earlier draft, and our anonymous colleagues for their constructive peer review. This project received funding from the Student Partners Program at McMaster University and the Students as Learners and Teachers program at Bryn Mawr and Haverford Colleges.*

Introduction

In this thesis, I begin to articulate ways of living a Mad politics. Following this introduction where I further describe my research questions, theoretical influences, and methods, the thesis contains three stand-alone articles, and a concluding discussion. The articles appear in the following order:

Paper 1: *Loneliness*	*Finding ways (and words) to move: Mad student politics and practices of loneliness*	In this paper, I develop my conceptual framework, blending together writing on *epistemic injustice* (Fricker, 2007) and *ethical loneliness* (Stauffer, 2015). The paper describes how Mad students come to be abandoned as knowers and learners, and dwells with and politicizes the condition of loneliness these harms produce.
Paper 2: *Resistance*	*Resisting unmet expectations as service user ethics: Implications for social work*	This paper draws on interview transcripts and conceptualizations of predictive, normative, and ideal expectations to describe how LGBTQ people who have experienced psychosis resist unmet expectations of just treatment. It pays attention to quiet forms of resistance to recognize service user 'moral talk' and how the values underpinning this talk might be collectivized into ethics.
Paper 3: *Confidence*	*Valuing knowledge(s) and cultivating confidence: Contributions of student-faculty pedagogical partnerships to epistemic justice*	In this paper, students from equity-seeking groups describe the potential of pedagogical partnerships to contribute to epistemic justice on campus. The paper explores how partnerships can (1) create more equitable conceptions of knowing and knowledge that open possibilities for (2) fostering students' confidence in their knowledge and willingness to share it with others.

Research Questions

Emerging over the course of my doctoral experience and decade of Mad Movement community organizing, this thesis responds to four research - and living - questions:

- How can I survive/stay alive/sustain myself in the academy as a Mad scholar?
- What else is there beyond legislative/service provision frameworks for justice, such as those most commonly used to advance Mad justice (e.g. AODA, mental health care)?
- On what basis should I make decisions in Mad activism/work?
- What am I trying to 'do' when I teach (or write) Mad Studies?

Taken together, these questions, inspired by Ahmed's (2017) discussion of *Living a Feminist Life*, are about living and practicing a Mad politics in the community, academy, and classroom.

How do I survive / stay alive / sustain myself in the academy as a Mad scholar?

My dilemma on how to persist ranged from:

- How do I keep myself alert enough to read and write a paper?[1]
- How do I exist here, given the violence of this institution and its echoes with past violences?
- How do I create a research project for my dissertation that I can actually stand to finish?
- Why am I so lonely?

Based on these questions, I initially imagined my dissertation research to involve conducting an autobiographical 'year in the life' of Mad knowledge (Feb 2016-Feb

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[1] The answer to this was: Wake up and do some work. When tired, drink tea, and then go back to work. When tired, eat breakfast, and then go back to work. When tired, have a shower, and then go back to work. When tired, go for a walk, and then go back to work. When tired, eat lunch, and then go back to work… repeat.

2017), in keeping with the long tradition and contribution of personal (and political) narratives in mental patient organizing over hundreds of years (Reaume, 2006).[2] Contemporary Mad Movement scholars have also adopted autobiographical approaches (e.g. Carr, 2013; Church, 1995, 1997; Fabris, 2011; Shimrat, 1997). I had arrived at first-person narration of my experiences due to increasing grumpiness with forms of research that study others, including those that set out to study Mad communities. I was disinclined to involve others in the research via interviews or other methods as I was, at the time, deeply dismayed by public uses of Mad stories and could not imagine non-gross ways of gathering and working with these. I had participated as a subject in my share of research studies - none of which felt or became particularly useful - and did not want to do this to others, especially all of my peers / friends who would have happily participated (I received multiple offers!) to help me out. I also couldn't bear the burden of sustaining relations with research participants – I had become exhausted with inequitable care labour in the academy – and had dealt with several frustrating encounters with the Research Ethics Board that turned me off a research method that required talking to them again.[3] I did not at the time consider other possible approaches which, in retrospect, may have also been helpful; tracking how Mad knowledge showed up in daily life seemed like what I wanted to do, and I had a year's worth of notes to work with. However, at the time

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[2] For examples of the 'year in the life' genre, see Didion (2005), Rubin (2009), and Sankovitch (2011).

[3] Concerns were raised that using the name I am known by (rather than a birth name) might constitute a deception of participants and that my Mad Pride was insufficiently proud. When following the protocol for expressing concerns about a study approved by the ethics board, I was also informed that the Mad community has no rights as a community; we only have the right to choose or refuse participation in research as 'individuals'.

I was seeking to write autobiographically, this kind of thinking was incredibly painful. I did not have what I needed to do it well. My doctoral experience thus far had been anything but smooth, and autobiographical attention and writing was prompting me to dwell in difficult experiences and unresolved entanglements. Something needed to give.

A response to the above research questions is developed in the *Loneliness* paper, where I recount what it has been like as a Mad student in the academy and explore alternative ways of understanding loneliness that have enabled a form of endurance. The *Resistance* paper, although focused on service provision systems, also describes various survival/resistance strategies that service users devise and enact, which are further developed in the thesis' discussion section. My own experiences surviving psychiatry and academia informed this analysis. Lastly, the *Confidence* paper investigates the significance of bolstering students' assurance in their knowledge as a way to support the persistence of students from equity-seeking groups. The thesis ends by highlighting techniques for Survivor Research Analysis that may be more resonant - and thus sustainable - for Mad scholars.

What else is there beyond legislative / service provision frameworks to justice?

Over my time at McMaster, I have come to see, in a repetitive way, how accommodation systems fail; students are neglected and experience relational violence that cannot be addressed with human rights legislation or accommodation entitlements. For example, I would accompany students to accommodation meetings with professors, ghostwrite their emails asking for special consideration, take them to appointments with the human rights specialist. Receiving what they were entitled to via legislation and McMaster's accommodation process was inadequate for actually supporting them to achieve a positive educational experience, complete school, and access post-graduation opportunities. The other available remedy was to show up and ask for mental health services. During the 2015-2016 academic year, mental health services for graduate students at McMaster were cut. We had refused to pay an increased amount for these services without further transparency regarding the fee structure and resulting benefits. Graduate students mobilized to advocate for the reinstatement of these mental health services - which became the most visible mental health advocacy on campus during my time here.[4] While strategic and of benefit to many, the increasing clinicalization of student distress was worrisome, as was the lack of alternative demands or initiatives. In one meeting I attended, students were going as far as to suggest /threaten that without mental health services it was possible that we students would commit acts of violence. Whether it be access to accommodations or counselling, neither of these institutional

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[4] For reference, visit https://www.change.org/p/mcmaster-university-access-to-mental-health-services-for-mcmaster-s-graduate-students

responses felt at all adequate for addressing the abandonment of Mad students on campus. I also came to know and feel this abandonment because I was spending a lot of time supporting Mad/disabled students to get through the institution, a kind of unpaid relational labour that the institution itself was neglecting to provide.

My concerns were reinforced through part-time contracts in several related units on campus: our teaching and learning centre focused on faculty training as a strategy for improving practice, including in relation to accessibility; our equity/human rights office similarly mandated to provide public education on equity, monitor compliance with provincial accessibility legislation, and mediate in/formal human rights complaints; and our community-engagement office that works to be more responsive to community-identified needs, including access to the university for members of marginalized and historically excluded groups. Recognizing both the possibilities and limits of these roles and infrastructure in the university, I longed for other strategies - particularly ones that might be taken up informally outside of these offices, that I personally had agency to enact.

My own experiences as a doctoral student were certainly affected by formal processes around accommodation, and difficulty accessing mental health services; however, they were much more devastatingly impacted by the quality of my relationships with other people and narrow views on to whom and to what we're accountable. I became drawn to the writing of Jill Stauffer (2015) and her articulation of the inadequacy of legislative/procedural approaches to injustice and the need for more expansive ethical frameworks on what we owe each other.[5]

The limitations of interventions based in human rights legislation or service provision, and the need for alternative forms of human relating, are taken up in the *Loneliness* paper. In the *Resistance* paper, I theorize with concepts typically designed and used to improve service satisfaction to instead recognize service user resistance. By doing so, I shift the use of these concepts from a focus on service system interventions as the way to address needs or provide entitlements to an alternate emphasis on service user ethical frameworks. Likewise, the *Confidence* paper focuses on the quality and impact of interpersonal relationships between faculty and students engaged in pedagogical partnerships and the importance of these sorts of relational strategies for enhancing equity and inclusion. The concept of psycho-emotional disablism developed in the discussion section of the thesis concludes by attending to psychic and affective harms largely unaddressed by structural approaches to justice.

On what basis should I make decisions in Mad activism / work?

With limited proximity to Mad elders, the beginning of my Mad student organizing work on campus was often somewhat solitary. I would intuitively make

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[5] This aligns with, for example, the writing of Willimon and Naylor (1995), who argue for a focus on 'friendship' as a guiding metaphor for living well together on campus and mediating the creation of an "abandoned generation" of students. In reference to the work of Hannah Arendt and her engagement with Aristotle, Willimon and Naylor (1995) suggest, "[f]riendship is not merely some one-to-one intimacy. Friendship is the tough, long-term, often painful struggle to form community" (p. 95). It is "the basis of the polis, the first building block of the good society" (p. 95), where we find those with whom "[we] care to share the world" (Arendt, 1968, p. 24-25, as cited in Willimon & Naylor, 1995, p. 96). This encouragement towards 'friendship' and community, and away from the historical lonely isolation of academic work, is one way of calling us into different ways of relating to and imagining our responsibilities to each other.

decisions about how to prioritize, what work to do, whether to show up to particular meetings as a token, what to say, who to engage with, how to approach something, without much guidance from others or examples of how they have navigated these decisions. When I became surrounded by social work students and faculty in an academic School of Social Work, I found myself arriving at different perspectives, or feeling gross about something – without really being able to put into words or say out loud in a way that could be heard why things felt off or what was informing my own preferred understanding or approach. I also came to feel like I wasn't behaving the way it seemed I was supposed to in academic social work contexts – I wasn't trusting, hopeful, grateful, patient, happy. Unsuccessful attempts at articulating my disorientation made me feel even more wrong about my wrong feelings.

I think what I was needing were ways of understanding Mad knowing/knowledges and communicating these to others. I was also searching for ethical frameworks and visions of justice - guidance that could inform my decisions, strategies, and workplan, or against which I could critically examine what I was doing. In my conversations with other Mad students and social workers, I began to feel and affirm that various experiences or analyses were a 'thing'; I would say and hear, 'me too'. There were patterns to what we were encountering. Maybe my feelings of not belonging, doing things wrong, feeling lonely, being unsure of myself were actually components or characteristics of knowing Madly? Perhaps my feelings of distrust, pessimism, anger, resentment, impatience, sorrow, sadness, grief were meaningful and tied to emerging ethical frameworks?

As I participated in a range of equity/mental health committees, I began to recognize how I was often being asked to provide forms of ethical consult - such as assisting a clinician with apologizing to service users with whom they were collaborating. I was frequently talking with friends about relationship boundaries in peer support and encouraging young people in their systemic advocacy for better treatment. Perhaps part of my confusion over figuring out how to live was related to negotiating the ethical dimensions of Mad community life without Mad ethical training or an intentional Mad moral community. To make things even more complicated, in contrast to my usual reality of being treated as suspicious, lacking insight, unreliable, lying - as mental health systems tended to respond to me as a service user - I began to experience students, friends, colleagues, and mentees as trusting me. This was deeply unsettling: If people trusted me, I could cause them real harm.[6] I didn't trust that I <u>was</u> being (or could be) trustworthy, or that I already knew what it would require to do this well, and so I found myself looking for ethical frameworks that could support my engagements with Mad peers in ways that felt congruent with our movement histories. I needed to learn how to be trustworthy (Potter, 2002).

The papers that follow further develop these emerging ideas regarding Mad epistemologies and ethics. The *Loneliness* paper explores how dwelling with and learning to move with loneliness can be a form of Mad knowing, and how we might expand our

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[6] During one lecture, I shared Roger's (1991) observation that some psychiatric survivors come to associate their teachers with the power of psychiatrists, that I relate to this (have experienced those with power in the academy as shrinks), and that I worried about becoming a shrink to the students in my class. A student's reaction took me by surprise: they wanted me to know that they trusted me (or at least didn't distrust me) and were not treating me with caution or proactively protecting themselves from me (as I thought they would and should).

notions of what we owe each other beyond a campus-wide direction to refer Mad students to clinical services. The *Resistance* paper attends to the everyday moral talk of service users and how this talk might be further recognized as a form of knowledge and synthesized into ethical frameworks. The *Confidence* paper illustrates the ways collaborative student-faculty relationships might contribute to epistemic justice through the recognition of students' knowledge. It also suggests a revised engagement with knowledge production and exchange on campus may play a central role in equity and inclusion initiatives. The final discussion section of the thesis then builds on these ideas to further theorize Mad onto-epistemologies.

What am I trying to 'do' when I teach (or write) Mad Studies?

When I started developing course syllabi and teaching in 2015, I was in the position to make decisions about what Mad Studies is - and what key content students learning Mad Studies should know (or might want to know) or learn. My initial intuitive /hodgepodge approach to designing or instructing a course felt inadequate - I still didn't (consciously) know, for myself, what I was trying to 'do' when I taught. Other than students learning content or skills, what did I hope for Mad Studies courses in the academy to offer, accomplish, effect, affect?

In taking certificate courses in Education, I was asked to develop learning outcomes and make explicit to students what I was anticipating they would learn (and what I would presumably teach) by the end of a course - like one titled *Critical Approaches to Mental Health and Madness*. This always felt a bit impossible and strange - to assume I could predict and bring about a particular kind of learning, rather than admit to all of the learning /unlearning /experiences that would transpire over the life of a course not accounted for in the listed learning (and unlearning) outcomes. I started to ask students to create and submit learning plans at the beginning of the course (what they themselves wanted to learn) and reflections at the end (their description of what they had learned). This began to offer a wider range of ideas on what learning was taking place or could take place in the Mad Studies classroom.

I also thought about what I wanted and was longing for from Mad Studies for myself, and what I felt like Mad Studies could contribute. I began to see myself and my approach as about responding to loneliness - as I explore in the *Loneliness* paper. I have also come to imagine teaching and learning as about easing epistemic injustice – supporting students in gaining confidence in their knowledge and capacity to participate in knowledge production and exchange (as described in the *Confidence* paper).

Theoretical Influences

The papers that compose the 'egg salad' of the sandwich dissertation engage with three primary bodies of thought: Mad Studies; conceptualizations of in/justice (epistemic injustice, ethical loneliness, psycho-emotional disablism); and disability, Mad/service user, and feminist ethics.[7] Each of these is taken up more fully in the thesis papers, rather than through an overall literature review. Below I offer some preliminary context. My contributions to these areas are further reviewed in the concluding discussion section.

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[7] A sandwich thesis is generally understood as being composed of layers of bread (the introduction and discussion sections that set the context and draw out overall implications) that hold together three self-contained but interconnected papers submitted for publication as journal articles. In this thesis, I refer to those 'content' sections as the 'egg salad' part of the sandwich – my favourite food at academic conferences, and the vegetarian version of 'meat'.

Mad Studies

Mad Studies is an emerging field of inquiry indebted to and intersecting with disability, feminist, and other social movement studies. It takes as its principle source of inspiration the ways of knowing, being, and doing among self-identified and conceived Mad people and members of the consumer/survivor/ex-patient movement (Menzies, LeFrançois, & Reaume 2013). Rather than be significantly impacted by any singular Mad Studies (or Disability Studies) text, my work has been most affected by the expanding possibility of speaking about Mad Studies as a thing in the academy, and pointing to legitimate indicators of its existence - the design and delivery of *Mad People's History* courses (Reaume, 2006; Reville, 2013), the 2013 publication of the Canadian textbook, *Mad Matters: A Critical Reader in Canadian Mad Studies* (LeFrançois, Menzies, & Reaume, 2013), the creation of a Mad Studies stream at the biannual Lancaster Disability Studies Conference, and other grassroots and academic publications. The materialization of Mad Studies as a thing has opened space for thinking beyond normative approaches to madness and offered hermeneutical legitimacy.

My work is most indebted to my relationships with Mad-identified folks I have met through the Hamilton Mad Students' Collective, Mad Pride Hamilton, McMaster's Disability and Mad Studies Reading Group, Mad grief groups I've co-facilitated, Mad Studies classes I've taught. These learning communities have offered forms of company, solidarity, comfort, affirmation, and belonging, making myself and my work intelligible in the academy. While these groups carry 'Mad' in their names, I have not spent much time talking with others about Mad Studies. As Louise Pembroke, founder of the

National Self-Harm Network in the UK, has been quoted as saying, “we were not ‘sitting around talking about Laing’ – ‘our role models were each other’” (Survivors History Group, 2011, p. 7). There are several reasons why my participation in explicit conversations about Mad theory have been comparatively minimal: most in my orbit were not engaged in Mad Studies academic work or reading; many of my colleagues were in undergraduate studies where it was difficult to find or create space within their courses to engage with Mad Studies; we often needed to prioritize more urgent survival needs. Instead, I spent a lot of time ‘doing’ Mad approaches to living with those around me – ways that valued our experiential knowledge, challenged the limitations of mainstream psychiatric approaches to mental health, and created a delightful array of alternatives. My university library account has made it possible to borrow over 350 books at a time, install what feels like the entire library’s Mad and disability studies collection on my apartment bookshelves (and, when these filled up, my bed, couch, dresser, stacked on the floor).[8] Mad doctoral work isn’t just about reading the books but assembling them into a kind of cocoon.

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[8] Throughout the thesis I often refer to Mad/disabled students and Mad/disability studies – as opposed to writing as if these are distinct groups and disciplines. While Mad Studies and Disability Studies certainly have their own histories, traditions, and politics, they are essentially intertwined on my campus: Many students who could assume a Mad identity do not identify in this way, but rather associate with mental health/disability. While we initially had an informal Mad-specific peer support group, it was merged into the student union service by/for students with disabilities, where student issues related to disability, madness, mental health, and chronic illness are now taken up through one association. Similarly, we had a Madness/Sanism Working Group on campus too - but due to low attendance and the overlap in membership this group has, in recent years, been combined with our Accessibility/Ableism Working Group. When I teach a course on Mad and/or Disability Studies I often bring in the other discipline because, given the scarcity of these kinds of courses, students will not otherwise have opportunity to learn about it. And, perhaps most significantly, since there are so few of us working in Mad and/or Disability Studies, it’s incredibly lonely to only associate with one of these. I also identify as experiencing disabilities beyond madness, and so a discrete division between these disciplines doesn’t make much sense to my body either.

My work has also been influenced by several other sources of knowledge and support: First, dozens of (mostly queer) psychiatric survivor accounts that illustrated how Mad people can build theory and knowledge from our engagements with the world. Second, histories of our local provincial/national movement (Everett, 2000; Shimrat, 1997) and conversations with psychiatric survivor elders. These written and oral histories helped me affirm how the Mad student /Mad Pride work I was engaged in was part of an ongoing project; it was not 'new', which is how others in the academy made it seem when they did not know what I was talking about. Third, intellectual infrastructure that challenges how madness is taken up in post-secondary institutions. Margaret Price's (2011) *Mad at School: Rhetorics of Mental Disability and Academic Life* was perhaps one of the first texts I read that made it possible for me to substantiate Mad student analyses of our lives with a citation. Rather than feel like I had to keep explaining myself or repeat (boring) arguments, I could smile politely (or roll my eyes, depending on the audience) and refer people to the library. Fourth, the scholars engaging with Mad Studies through and within social work departments – Idil Abdillahi, Peter Beresford, Kathy Boxall, Chris Chapman, Ameil Joseph, Brenda LeFrançois, Sonia Meerai, Jennifer Poole, Jenna Reid, Helen Spandler, Jijian Voronka.

Within the dissertation, Mad Studies is the wider frame to which the *Loneliness* and *Resistance* papers explicitly contribute. It also shows up in each paper through discussions of Mad methods (moving with loneliness; listening for resonance, resistance, and quiet data), and in the separate discussion section on Survivor Analysis. As well, all three papers spend time politicizing psychic/affective states (that could be labelled as a form of madness/distress) and theorizing their relevance to justice-oriented projects: loneliness (in the *Loneliness* paper), resentment, anger, distrust (in the *Resistance* paper), and confidence (in the *Confidence* paper).

Conceptualizations of In/justice

The recently mobilized terminology of sanism has been instrumental in drawing attention to the violences Mad people experience in society. While perhaps most notably applied in legal systems where the term was conceived, Mad Studies has adopted this concept as its own (Cresswell & Spandler, 2016; Fabris, 2011; Poole et al., 2012). Scholars have also worked with the frame of epistemic injustice/violence alone and in combination with sanism (LeBlanc & Kinsella, 2016; Liegghio, 2013; Russo, 2016; Russo & Beresford, 2015).

In this thesis, I explore these and several other concepts that I have found affirming and useful in understanding and intervening in the mechanisms of injustice and resulting harms. In the *Loneliness* paper, I construct my dissertation's theoretical framework by working with the conceptualization of epistemic injustice refined by feminist philosopher Miranda Fricker (2007), and Jill Stauffer's (2015) discussion of ethical loneliness. Then, in the *Resistance* paper, I engage with moral philosophy and related writing on expectations of just treatment (Dillon, 1992, 1997; Potter, 2002; Stauffer, 2015; Tessman, 2005, 2009; Thompson & Sunol, 1995). The *Confidence* paper returns to Fricker's (2007) work to think more explicitly about epistemic forms of justice, especially those related to epistemic confidence. In my discussion below, I will also introduce the conceptualization of psycho-emotional disablism coined by Thomas (1999,

2007) and popularized by Reeve (2002, 2004, 2006, 2009, 2012, 2014, 2015ab) within Disability Studies. I have found these frameworks especially helpful because they recognize the limitations of structural/legislative approaches to justice, attend to relational dynamics, and account for the affective in a range of forms.

Throughout this writing, and in the company of other Disability/Mad Studies scholars, I regularly use the language of ‘violence’ and ‘injustice’ interchangeably when referring to the norms, structures, encounters, and ways of relating that contribute to disabled/Mad people’s experiences of harm. Although the term ‘violence’ connotes a range of scales and contexts and is itself ambiguous, I intentionally draw on it within this thesis to emphasize mechanisms of injustice that are commonly missed or misrecognized when they pertain to disabled/Mad people.[9] Mad people, for example, are often perceived as ‘violent’ - but our own accounts of victimization through violence routinely go unnoticed (Karni-Vizer & Salzer, 2016). Hollomotz (2013) highlights how the term ‘violence’, while commonly used to describe mistreatment of non-disabled adults, is frequently exchanged with the word ‘abuse’ in the case of disabled people (and other ‘vulnerable’ groups like seniors and young people). This differential recognition frames the wrongs that Mad/disabled people experience as (only) interpersonal rather than

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[9] This is of course an imperfect decision and, in some ways, contradicts my desire and work in this thesis to identify more precise and nuanced conceptualizations of harm. What are the possible troubles of collapsing diverse mechanisms and scales of oppression and degrees of overt attack into the language of ‘violence’? This question merits further attention in my ongoing work. For now I can say I came to this language of violence through my experiences of sexual assault as well as coercion/involuntary treatment within the psychiatric system. When I write about institutional forms of abandonment, neglect, and harm in the university, they echo against these encounters with bodily precarity. Perhaps by using the language of ‘violence’ I am suggesting, as other feminist writers have, that the ‘violences’ of the academy can resonate in particularly damaging ways for those who have experienced other forms of assault (Heald, 1997; Horsman, 1999).

structural, or treats us as developmentally/physiologically at risk and requiring protection from individual people who might take advantage as opposed to a population group systematically disadvantaged. Given the public acceptability and everydayness of disrespect towards disabled people, we can also find it difficult "to decide when the boundary between routine invasions and violence has been crossed" (Hollomotz, 2013, p. 62). Rather than draw this line here, I seek to witness regularly ignored violations as 'violence', especially those that fall outside of grounds on which someone could demand formal recognition or redress through established legislative procedures.

As Karni-Vizer and Salzer (2016) argue, in reference to the work of Teicher et al. (2006), subtle and "seemingly less overtly hostile" (p. 302) forms of violence (such as verbal belittlement) "can be just as harmful, or more harmful, than physical assaults" (p. 302). I engage with Stauffer (2015) to categorize the neglect and abandonment of Mad people - perhaps perceived as "less overtly hostile" forms of violence - as indeed violence that causes harm, a conceptual move endorsed by Whynacht (2017b):

> The violence they [women with the label of Borderline Personality Disorder who have been turned away from systems of care] have experienced is more difficult to discern - it is the violence of neglect and abandonment. This violence is rendered unintelligible in critical spaces that frame violence as an assault on bodily autonomy or freedom. (p. 59)

Whynacht's (2017b) larger point is that "notions of violence that rest on neoliberal ideals of individualist autonomy" are disablist, and that we need "to hold space for the creation of new languages to account for the affective violence of contemporary capitalism" (p. 66) – such as those related to abandonment and neglect. Stauffer (2015) suggests that while we may abstractly know what some forms of violence are (like torture or physical abuse), “those who have never been beaten, tortured, or otherwise dehumanized may lack the kind of understanding that brings to fore the *harms* of these crimes” (p. 12, emphasis in original). This lack of understanding of harms endured may be further impaired in a context where forms of violence – like affective/epistemic ones – are themselves less known and recognized. Consequently, I write about both ‘violence’ (in the abstract, conceptual, as systems, mechanisms, infrastructure) and investigate and dwell in the ‘harms’ they provoke, as articulated by Mad/disabled people. When Stauffer (2015) writes about a “kind of understanding that brings to the fore the *harms*” of injustice, she is referring to an understanding of the powerlessness /helplessness and destruction of personhood produced through human violence. As she explains, “when [harm] is imposed by another human being, leaving neither hope of the self’s resistance or another’s assistance, [harm] may destroy a self” (p. 15). Thus, the harms explored below are those that impact – via their affective/epistemic/moral properties - on Mad/disabled people’s selves as persons and as knowers.

Disability/Service User Ethics

My inquiry into Mad ethics is informed by Stauffer’s (2015) work with the writing of Emmanuel Levinas, Jean Améry, Eve Sedgwick, and Friedrich Nietzsche; a range of writing on disabled people’s contributions to ethics (e.g. bioethics, service user perspectives on boundaries, survivor research ethics, Mad/disability narrative ethics, disabled people’s engagement with moral philosophy), and feminist discussions of virtue theory and burdened virtues (Fricker, 2007; Potter, 2002; Tessman, 2005). This literature is reviewed in the *Resistance* paper.

Disability /Service User Ethics appear in the dissertation through discussion of creating more ethical and just relations (*Loneliness* and *Resistance* papers), and explicitly in the *Resistance* paper's attention to the moral talk of Mad folks and how this might be synthesized into ethical frameworks. Across this work, I am articulating alternative visions of how we might imagine our relationships and responsibilities to each other - beyond those entitlements protected through human rights legislation or institutional procedures to address and protect against injustice.

Methods and Materials

The thinking in this thesis was generated over the course of my doctoral studies, and alongside a range of other projects described above. Like Church (1997), "[w]orking for the movement and its objectives alongside survivors who became my friends, confronting the issues that arose in the course of the work, feeling and working through my own emotional responses: these activities became my method" (p. 307). In my case, the movement(s) I was most committed to were efforts to gather and politicize a Mad/disabled student community in Hamilton (broadly conceived, including youth moving into and out of school). I was also engaged in varied forms of diversity work to make life on Hamilton campuses (and access to employment /futures) more hospitable for these students. This diversity work included "[t]he work we do when we are attempting to transform an institution" and "[t]he work we do when we do not quite inhabit the norms of an institution" (Ahmed, 2017, p. 91). As another example of a Mad Method, Reville (2013) suggests the following recipe for negotiating the academy as a Mad scholar:

1. Find a way into the academy.

2. Find your way around.
3. Build alliances.
4. Bring in Mad students and teachers.
5. Find your way back out into the community again. (p. 179)

I have done my best to do this too while involved in initiatives that blur a perceived border between the academy and community.

My initial autobiographical approach is described in the first paper of the sandwich thesis. When I realized that the forms of analysis I was developing through my doctoral work (resonance; reading for Mad knowledge/labour) were being carried over to other data I was analyzing for related projects, these empirical materials came to form the basis of the remaining two papers of the dissertation. While these materials may seem somewhat disparate, they each offer a case (daily life, social services, participation in teaching and learning in the academy) through which to theorize a Mad politics. The specific methodological approaches taken in the *Resistance* and *Confidence* papers are further described in the papers themselves. There is a small amount of content overlap in the thesis as both the *Loneliness* and *Confidence* papers describe the conceptualization of epistemic injustice - each in relation to their specific focus.

Paper 1: *Loneliness*	*Finding ways (and words) to move: Mad student politics and practices of loneliness*	This paper draws on autobiographical illustrations from teaching Mad/Disability Studies courses, negotiating the academy as a Mad/disabled student, and organizing Mad student community. It was written between Spring 2017-Summer 2018.
Paper 2: *Resistance*	*Resisting unmet expectations as service user ethics:*	This co-authored paper engages with interviews with LGBTQ people who have experienced psychosis. The interviews were conducted by peer researchers, focused on un/supportive spaces and relationships, and analyzed using varied survivor

	Implications for social work	analytic techniques. Data for this project was collected in 2013-2014. Coding took place in the Fall of 2014 /Winter of 2015. Initial analysis was conducted in the Fall of 2015 /Winter of 2016 (when I was recovering from the depths of despair of comprehensive exams). Revisions occurred over the Spring/Summer of 2018.
Paper 3: *Confidence*	*Valuing knowledge(s) and cultivating confidence: Contributions of student-faculty pedagogical partnerships to epistemic justice*	This co-authored paper reports on interviews with students from equity-seeking groups who have participated in a student-faculty pedagogical partnership program. I participated in some of the data collection for this paper during the summer of 2017. Analysis /drafting /revisions took place over the Fall of 2017-Winter 2018.

Papers

Finding Ways (and Words) to Move: Mad Student Politics and Practices of Loneliness

Abstract: By blending the conceptual frameworks of *epistemic injustice* (Fricker, 2007; Kidd, Medina, and Pohlhaus, 2017) and *ethical loneliness* (Stauffer, 2015) and applying them to campus-based practices of ‘risk’-identification and ‘referral’, this paper describes how Mad students come to be abandoned as knowers and learners. I then dwell in and politicize the condition of (ethical) loneliness these harms produce by seeking to ‘practice’ it as a form of Mad knowing, and framework for visioning justice. Framing Mad student experiences in this way opens up several possibilities for epistemic justice: First, it offers additional language and interpretive resources for naming and protesting our experiences of violence. Second, it compels us to understand and attend to Mad student experiences of epistemic harm and to recognize how Mad knowledges are routinely generated in their wake. Third, it invites new ways of understanding and responding to these harms, and imagining redress.

Introduction

Over the last eight years, I’ve participated in moving multiple words around multiple campuses - madness, Mad Pride, Mad Studies, Mad students, peer support, social model of disability, *Accessibility for Ontarians with Disabilities Act* (AODA), accessible education, discrimination (not stigma), sanism (not stigma), Madulations (Mad congratulations), lunatictionary[10]... This movement of words has taken the form of presentations, workshops, peer support gatherings, lectures, living, fun, frustration - occasionally paid, most often not; and drawn on lived experience, self-identification,

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[10] As you might imagine, these last two were fashioned in Mad community: The first coined by Robin in January 2015, in response to a Mad student member’s listserv post. It prompted a full Madulation Party where we celebrated our accomplishments.

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community organizing, academic scholarship, legislation, history, concepts, making up new words. This past year, I had the pleasure of listening-in as thirty curious students came to see how assuming disabled people need “help” can be a form of violence, an understanding that arrived after an introduction to the word *microaggression* (Gonzales et al. 2015; Keller and Galgay 2010). An essential strategy for advancing accessibility, rights protection, and inclusion for Mad/disabled students, staff, and faculty has been to move different words around campus and to introduce alternative interpretive tools for identifying and addressing barriers and in/justice (e.g. Fovet and Giles 2015). Finding language with which to understand my experiences has also been foundational to my negotiation and survival of the institution as a Mad student, and my politicization, as other Mad/disabled and equity-seeking students similarly attest (Allan 2006; Aubrecht 2016; Lo 2016; Paterson, Hogan, and Willis 2008; Wolframe 2013).

In this paper, I bring a conceptualization that I’ve found helpful as a Mad student (abandonment and loneliness) to the library of interpretive tools for understanding violence - in particular, violences that occur at the university. To do this, the paper is broken into four sections: First, I blend the conceptual frameworks *epistemic injustice* (Fricker 2007; Kidd, Medina, and Pohlhaus 2017) and *ethical loneliness* (Stauffer 2015). I then apply them to campus-based practices of “risk”-identification and “referral” - including those from the literature and my own experiences as a Mad doctoral student - to describe the epistemic injustices that contribute to the abandonment of Mad students as knowers and learners. Following, I dwell in and politicize the condition of (ethical) loneliness these harms produce. I end by offering some ways into loneliness that do not pathologize it as (only) a problem, but seek to "practice" it as a form of Mad knowing, and framework for visioning justice. This work contributes to the broader political projects of politicizing Mad student distress and calling for the university to become a place where Mad students and scholars can be recognized and supported as knowers and learners. In the process, it offers alternative frameworks for understanding violence and imagining redress.

In this writing, I use the phrase "Mad students" to refer to students who share a personal connection to madness (as *Mad*, neurodivergent) and do not feel well-served by (are *mad*, disappointed, frustrated about, excluded from) the current discussion of mental health on campus due to its disregard for critical and alternative perspectives. I imagine this to include explicitly Mad-identified students - especially those engaged or desiring to be engaged in Mad communities or Mad Studies scholarship - as well as politically aligned students who may not identify as Mad, but have had personal encounters with mental difference, madness, trauma, sanism, psychiatrization and/or peer support as they interlock with other systems of oppression (Cresswell and Spandler 2016; for discussion on the use of the word M/mad, see LeFrançois, Menzies and Reaume 2013). While the university's contribution to epistemic harms that I describe below, and the condition of loneliness they produce, do not only affect Mad students, I am keen to develop Mad

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Studies theory about the experiences of Mad students in the university environment (following Jones and Lewis 2013; Lewis 2017; and others), and deliberately include insights from aspects of my own life to follow the intellectual tradition of Mad/mental patient autobiography (Reaume 2006).

Theoretical Frames

Epistemic Injustice

The conceptualization of epistemic in/justice has many points of connection with Mad Studies, a field of knowledge that has developed over hundreds of years of mental patient activism and gained roots in the academy over the last decade (Lewis 2017; Reville 2013; Rose 2017; Russo and Sweeney 2016). Mad Studies takes as its principle source of inspiration the ways of knowing, being, and doing among self-identified and conceived Mad people and members of the consumer/survivor/ex-patient movement (Menzies, LeFrançois and Reaume 2013; Russo and Beresford 2015), and scholars are working to better understand and describe Mad epistemologies - knowledges and ways of knowing (Beresford and Boxall 2013; Rose 2009, 2017). Given this focus on advancing Mad knowledges in the midst of a long history of disqualifying Mad people as capable knowers through the reification of biological psychiatry and its knowledge production methods (Lewis 2017), diverse efforts to theorize epistemological forms of injustice has, in recent writing, been identified as highly relevant to Mad Studies (LeBlanc and Kinsella 2016; Liegghio 2013; Russo 2016; Russo and Beresford 2015) and psychiatry/medicine

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(Lakeman 2010; Sanati and Kyratsous 2015; Wardrope 2015), as well as pedagogy, and higher education (de Bie et al. 2019; Gonzales 2015; Kotzee 2017).

The publication of Miranda Fricker's (2007) book, *Epistemic Injustice: Power and the Ethics of Knowing*, has sparked a decade of debate and conversation, including attention to how epistemic aspects of oppression have been discussed and documented by disability, feminist, critical race, and Indigenous scholars and community members for generations (Kidd, Medina, and Pohlhaus 2017). Epistemic injustice has been conceptualized as involving both testimonial and hermeneutical forms: **Testimonial injustice** occurs when an identity-related prejudice leads to being wronged in one's capacity as a knower, such as when people have their knowledge disqualified as a result of being perceived or conceived as Mad (Liegghio 2013; Sanati and Kyratsous 2015). **Hermeneutical injustice** refers to the inability to make sense of an experience due to a gap in available tools for the interpretation of social meanings. For example, the process of psychiatrization can suppress alternative non-biomedical interpretations and understandings Mad people have about our lives (Lakeman 2010; Wardrope 2015). As well, a lack of access to language - such as the word sanism to name the systemic prejudice and discrimination Mad people face - can constitute a form of hermeneutical injustice and prevent us from identifying and addressing harm (LeBlanc and Kinsella 2016). There are also **distributive forms of epistemic injustice**, for instance, how Mad/disabled students have inequitable access to "epistemic goods" like education

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(Fricker 2010, 175) and are much less likely to attend and complete postsecondary education, compared to our non-disabled peers (Statistics Canada 2012). Epistemic injustice carries a host of impacts and consequences, including a loss of confidence in one's knowledge and capacity as a knower, and exclusion from participation in knowledge generation and exchange (Fricker 2007), such as opportunities to contribute to decisions about what is worth knowing, what counts as knowledge, what can be known (and how), and who counts as a knower (Russo and Beresford 2015). Testimonial and hermeneutical injustices - the latter of which I focus on below - are foundational to other forms of injustice, and can initiate a series of harms (Lakeman 2010). This includes, as I describe (nuance, and revise) throughout the rest of this paper, a condition of ethical loneliness (Stauffer 2015).

Abandonment and Loneliness

Discovering and applying the language of epistemic injustice has been enormously helpful - at a conceptual level - for naming and understanding my experiences of violence as a Mad student engaged in epistemic pursuits within a university setting, especially more hidden and covert forms of injury. However, it doesn't fully describe what epistemic violence *feels* like for me. Language like "hermeneutical injustice" is clunky against my experiences of heartbreak, disappointment, loss, grief, and loneliness. In search of additional ways to understand what I've encountered, I have come to appreciate what Jill Stauffer's (2015) work on **ethical loneliness** can offer.

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Stauffer (2015), drawing primary on examples of state-sanctioned violences (ranging from survivor testimony of the Holocaust, South African apartheid, Indigenous genocide, and sexual violence, among other examples) and highlighting the limits of formal Truth and Reconciliation processes, describes an “ethical” form of loneliness as caused by: (1) the multiple ethical lapses in society that lead to the abandonment of a member of a persecuted group by humanity and/or those in position to support their life possibilities, and (2) the inability to hear the testimony of those so abandoned, including their articulation of harms endured and redress required. This abandonment and failure to hear results in the lack of an adequate and helpful response to this harm, a lost “capacity to expect just treatment or help in the absence of such treatment” (15), and a social condition of loneliness. The reason this abandonment and loneliness is so devastating is because our personhood/sense of self is not developed in isolation; it is cooperatively authored and impacted by the people around us. When these people collectively fail in their responsibilities to support us (or collectively develop storylines in which they do not carry responsibility to support us), and cannot hear our accounts of harm, we are dehumanized and our worlds and selves can be destroyed (Stauffer 2015).

Scholars are beginning to use Stauffer’s (2015) conceptualization in loneliness research to support the treatment of loneliness as a societal justice issue, rather than a medical one (e.g. Wong et al. 2017). Her frame is well-aligned with more nuanced scholarship on loneliness among people with mental health disabilities that resists

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positioning loneliness as only a problem, or "individual" concern (e.g. Andersson et al. 2015; Granerud and Severinsson 2006; Lindgren et al. 2014; Muir and McGrath 2018; Nilsson, Nåden, and Lindström, 2008), but has not yet been taken up in the Mad Studies literature. By drawing on Stauffer's (2015) work, this paper contributes to the politicization of loneliness through a Mad Studies lens.

Focusing on Harm

Although legal processes can and do play an important role in responding to injustice and recuperating people's humanity, and are used by Mad Movements as a resistance strategy, Stauffer's (2015) ultimate goal in putting forward the notion of ethical loneliness is to move us beyond a procedural approach to justice, which tends to focus on individual victimization, culpability, and institutional mechanisms of redress, as opposed to wider impacts and responsibilities. For example, the formal processes in place to receive Mad students' concerns and advance our inclusion are related to legal approaches to accessibility (policy, human rights, compliance, accommodation; see Gabel 2010; Titchkosky 2010), or clinical/social welfare approaches to distress (mental health service provision; see Baker, Brown, and Fazey 2006). Neither of these responses can hear or adequately respond to my experiences of existential loneliness on campus because they focus on mandated provision of rights/services by designated individuals, rather than offering a remedy for "a harm made possible only by widespread neglect of human responsiveness" (Stauffer 2015, 5). Likewise, hermeneutical forms of epistemic injustice are not perpetrated by individual agents (alone), but caused by a gap in collective interpretive resources (Fricker 2007) - such as the university's inadequate interpretation of Mad student as "risky" and direction to refer us to mental health services. Instead of focusing on procedural approaches that attempt to recognize and respond to (some forms of) harm, Stauffer (2015) encourages an emphasis on harm itself. She proposes that when we pay attention in this way, alternative understandings and responses to violence can emerge - including responses that rethink what we collectively owe each other.

Blending the conceptualizations of *epistemic injustice* and *ethical loneliness* can help us expose the epistemic injustices that Mad students experience within pedagogical contexts and relationships on campus due to a gap in hermeneutical resources: the ways we are misrecognized through institutional processes ostensibly designed to include us in the university, abandoned as knowers and learners by the many people who could encourage and support us in our epistemic pursuits, and marginalized in our access to resonant meanings and frameworks for understanding our experiences. This abandonment can, in turn, contribute to a devastating existential, ethical, and epistemic condition of loneliness. Framing Mad student experiences in this way opens up several possibilities for epistemic justice: First, it offers additional language and interpretive resources (like abandonment, loneliness, lost confidence and capacity to expect just treatment) for naming and protesting our experiences of violence. These interpretive tools can help us disentangle ourselves from pathologizing perspectives to further politicize (and collectivize) our experiences. Second, it compels us to understand and attend to Mad student experiences of epistemic harm. Dwelling in these harms and allowing ourselves to be moved by them, we can begin to recognize how Mad forms of knowing and knowledge are routinely generated in their wake. Third, by reframing and dwelling with harm, we invite new ways of understanding and responding to them and imagining redress, including the significance of recovering epistemic confidence, and restoring capacity to expect just treatment.

Abandoning (and Failing to Hear) Mad Students as Knowers

Although students with mental health disabilities report attending school and pursuing an education as a way to transition out of client/patient identities and into more valued student/worker ones (Ennals, Fossey and Howie 2015; Knis-Matthews et al. 2007), we continue to be treated as "risks"/patients on campus and undermined as students/learners. We are regularly interpreted as experiencing psychological trouble, rather than forms of violence like the *epistemic abandonment and loneliness* this paper sets to explore. Although a partial plotline, the section that follows uses the case of proliferating training/instructions faculty and staff receive about working with students with mental health disabilities to outline a series of ways Mad students come to be abandoned as legitimate knowers. At the core of this articulation is an unjust gap in available social meanings for understanding our lives and what we need as knowers and learners, which results from dominant interpretations of Mad students as risky (and/or sick) and in need of mental health services. This gap is deepened by the routine misrecognition and marginalization of "forms" of knowledge expressed by Mad students (emotion, personal disclosure, not knowing) as indicators of "risk" that need to be "managed".

As Saltmarsh (2016) describes, students (and others on campus) carry "risky humanity" - that is, a susceptibility to illness or injury from the conditions of the university (also see Peake and Mullings 2016), as well as a (high) potential to expose the institution to risk - the latter being the university's primary concern. These risks include the financial and personnel cost (in terms of both money and time) of providing us counselling and accommodation services (as well as providing everyone training on how to manage us), lost tuition from student attrition, legal complaints if the institution does not ensure disabled students' right to education and academic accommodation, or other liability and publicity issues in situations such as student suicide or institutional failure to fulfill a duty of care (Walker 2014). There is also the perceived risk that students with mental health disabilities will commit acts of violence, a myth that other critical scholars have dismantled (Martin 2016; Price 2011), but which influences the institution's actions nonetheless. While the university's provision of counselling and accommodations can be seen as an attempt to minimize students' susceptibility to illness or injury, "[t]hese claims of concern and support enable the institution to be seen (or to claim to be seen) as part of the solution to a perceived problem, while simultaneously attempting to manage the risky humanity of university students...” (Saltmarsh 2016, 176).

These claims of concern and support, and interpretations of Mad students as “risky”, get circulated to faculty and staff through trainings and resources. At my institution and many others, the therapeutic turn in education (Wright 2014) has led to campus-wide promotion of Mental Health First Aid courses and other “mental health literacy” materials (Lipson et al. 2014; Massey, Brooks and Burrow 2014), which are routinely developed and taught by non-Mad people and homogenize a Eurocentric medical/psychological interpretation of madness that focuses on identifying signs of “mental illness” and mediating risk by referring students to medical treatments and services (Davidow 2016; DeFehr 2016; Hickey 2017; Saltmarsh 2016; Switzer 2016; White and Pike 2013). Further, instructions for *Identifying and Referring Students in Difficulty* encourage faculty to pay attention to students’ emotions and related behaviours - like anger and agitation, fear and mistrust, “disruption” and “disturbance” from status quo expectations, different perspectives on reality, disengagement, and communication challenges (Student Wellness Centre 2017; for a satirical critique see Mad Pride Hamilton 2014) - as decontextualized, depoliticized, and individualized indicators of psychological troubles that carry a risk to both the student and the institution. Faculty are encouraged to “spot” emotion and code it as a problem (Goffman 1959, as cited in DeFehr 2016), and in this way, are given authority to “exercis[e] naming rights over the

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emotions, experiences, identities, and knowledges of distressed persons" (DeFehr 2016, 20). These biomedical/psychological naming rights eclipse other possible interpretations, such as those that recognize emotions as reactions and responses to complex social contexts and experiences of violence (Baker, Brown and Fazey 2006; Furedi 2004; Peake and Mullings 2016), which means that Mad students who are disturbed or (re)traumatized by entrenched and pervasive ableist/sanist ideologies on campus, or distressed as a result of everyday forms of institutional neglect, have become at risk of being perceived as psychologically unwell, and unheard in our articulation of experienced harms (Haley 2018; Tosh and Golightley 2016).

As Mad student emotions on campus become routinely labelled as psychological problems, they also come to be interpreted as irrelevant and disruptive to the cognitive and intellectual work of academic studies. Feminist scholars have drawn attention to the similar treatment of women's affect (Fricker 2007). McKinney's advice to faculty regarding student distress emphasizes this division of cognition and emotion:

> Often, as faculty members… we are geared toward interacting with students on an intellectual basis. We are eager and ready for a cognitive discussion of the subject matter of our course… Few people like to be surprised in any social interaction, and being surprised by a student who becomes emotional (veering away from the cognitive, which we more often expect) is no exception. (as cited in Guest Pryal 2015, para 8)

Given the interpretation that emotions are not intellectual, faculty and staff are directed to treat them as outside of their pedagogical role/skill-set, and to refer students expressing emotion to clinical services (Guest Pryal 2015; Jones and Lewis 2013; McNaughton-

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Cassill 2013; Price 2011; Saltmarsh 2016): "Send them to the campus counselling center. Make a referral, make a call, perhaps walk the student over there yourself - in whatever form, remove the excessive affect from the sphere of your teaching" (Price 2011, 167). They receive the message of increasing "clinical creep" and professionalization: that instructors are "not expected to take on the role of a counsellor" (MFotG 2018b), and that "only individuals with highly-specialized [clinical] training can help, support or understand individuals with psychiatric disabilities" (Jones and Lewis 2013, para 16) or expressing emotion or distress. Emotion and pedagogy do not and must not mix. Staff and faculty members' routine enactment of these instructions has the potential to unwittingly initiate a cascade of referrals and forms of abandonment - including referrals of students from the campus counselling centre to security/police for transportation to hospital (as Mad students worry about in Reid and Poole 2013), or to academic advisors for direction to drop courses, decrease course loads, or take a medical leave when perceived to be "unfit to study" (Burstow 2017; Hoffmann and Mastrianni 1992; Martin 2016). The overall result is that Mad students are regularly perceived as "not functioning as students" (Costopoulos 2017, para 4; also see Haley 2018 for a response), and subject to interference and diversion rather than encouragement with our epistemic pursuits.

Emotions are one identified "problem". The disclosure of personal experiences - especially when the disclosure itself is emotional, or provokes emotion in others - is another; both represent "non-intellectual" forms of participation. Faculty are encouraged to pay attention to students “disclosing too much personal information in the classroom” as a form of behavioural disruption and a “sign” that they are experiencing mental distress (McNaughton-Cassill 2013, 101), and told that a student disclosing “more information than is necessary” for an instructor to provide an accommodation is “over-sharing” (MFotG 2018c). These sorts of messages result in students with mental health concerns who disclose personal experiences in the classroom being perceived as having bad boundaries, sharing “inappropriately”, and needing help (Charles, Holley, and Kondrat 2017). By these standards, faculty and staff are again provided authority to “exercis[e] naming rights” (DeFehr 2016, 20) over Mad students’ personal testimony. Rather than hear the student, and recognize their expression as a mode of communicating meaningful knowledge, instructors are taught to read personal disclosure as an inability to filter one’s thoughts or a loss of control over what one is saying - “symptoms” of “not being properly contained” as a result of perceived distress or illness. Both emotions and disclosed personal experiences are coded as signs of distress, irrelevant to and disruptive of the postsecondary classroom, and indications of the need for referral.

In addition to the above examples of how the epistemic contributions of Mad experiences can be misinterpreted or misrepresented as a psychological issue, attempts at knowing and forming knowledge can also be missed when they are “quiet” and similarly unrecognizable as a form of testimony (Hookway 2010). One way I have experienced this as a Mad student is when I offer the testimony of “I don’t know” and this is taken as an absence of testimony, rather than an effort to participate in knowledge production or exchange. For example, when advisors have asked me what I want to do after completing my doctoral work, I have often responded, “I don’t know”. In this case, “I don’t know” can mean: “My experience in the world is as someone perceived to be incompetent, and as a member of a Mad community where desiring and living a future is not a taken-for-granted guarantee. I have no idea what the options are for my future. Can you help me imagine them?” When faculty and staff fail to recognize the expression of “not knowing” as an effort to provide testimony, they miss an opportunity to encourage someone’s epistemic pursuits. Testimony can also take the “quiet” forms of confusion (e.g. not understanding academic norms around personal disclosure), questions (e.g. about the unwritten rule of hiding one’s vulnerability in the university), and silence (e.g. when I stop participating in class because I can’t figure out how to behave/disclose “appropriately”). Students from other equity-seeking groups are similarly rendered “quiet” through the misrecognition of their knowledge, and often perceived as “stupid” or “incompetent” (Hsieh 2007; Lo 2016). The unique impact on Mad students is that saying, “I don’t know”, and having this expression interpreted as an absence of testimony, may lead to a better outcome than attempting to articulate ideas through emotion or personal disclosure; we minimize the chance of activating a referral response when our knowledge is “missed”, instead of misrecognized as “risky” or “inappropriate”. Saying “I don’t know” is also safer than honestly raising epistemic questions about “how to find my way in the world" (Davidson et al. 2010, 101), create a livable life, or *imagine* (not just plan for) a future, which are likely to flag as "psychological" in nature. Rather than recognizing these sorts of existential explorations as legitimate Mad ways of knowing and orienting to time (temporalities/epistemologies; see Kelly 2018), instructors are advised to keep watch for students' references to death or suicide as indicators of trouble (MFotG 2018a). Consequently, the *form* my knowledge takes puts me at risk of being misinterpreted and sent away - or ignored - as does the *content* of many of my epistemic questions.

From my perspective, when instructors are directed to enact their responsibilities to Mad students by referring us to mental health services - indeed, when not referring is seen as irresponsible, or uncaring - the abandonment of Mad students becomes institutionalized. This sanctioning of referral as the epitome of "just treatment" obscures other pedagogical and ethical commitments instructors and academic institutions might or should have to Mad learners, and erases consideration of our interpretations of what "just treatment" means and would require: the difference between "just (equitable, respectful, responsive) treatment", and "just (only medical) treatment". As a result, the increasing visibility of safeTALK suicide alertness stickers on office doors, Mental Health First Aid certificates on the walls, or squishy anti-stigma elephants on shelves and desks (see Mood Disorders Society of Canada 2016) are not reassuring symbols of people's ability to hear me and respond to my requests for (epistemic) support as a Mad student - even though that may be the intention behind the strategic display of these objects on campus.[11][12] Instead, they represent the weakened responsibilities staff and faculty have to me and my epistemic growth and development, the narrow stories they and the broader institution tell about what they owe us (Stauffer 2015), and how they can, following the training completion they so proudly display, renounce their pedagogical relationship to me at any time by interpreting me as requiring the realm of the therapeutic. These signs of mental health training also undermine the LGBTQ “positive space” stickers they are often placed beside, which started showing up on campus doors over a decade ago thanks to anti-homophobia activism (Newman, Bogo, and Daley 2008) (and which are now more regularly acquired by inheriting an already-stickered office door than training completion). What were once alternative rainbow spaces inviting personal disclosure of (LGBTQ) experiences, are now possible referral points to counselling. Rather than signalling welcome, indicators of exposure to mental health education reduce my

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[11] Or, as Davidow (2016) notes, stuffed Mental Health First Aid Koala bears, like ALGEE, the mascot named after the training’s key acronym. As she writes, “(I always love when tools to push people along the ‘mental health’ pipeline masquerade as ‘help’ and are marketed with cute little stuffed animals… don’t you?)”.

[12] Between 2016-2017, I propagated approximately 150 purple plant babies and distributed them to colleagues and acquaintances across campus (and the wider city). In an accessibility-related committee meeting on October 20, 2017, Alex Wilson shared with me how these have become a new symbol of positive space. Alex recounted a story of entering a faculty member’s office, seeing a purple plant baby (Alex has one of its siblings at home), and experiencing this as a sign of welcome.

capacity to expect just treatment in the university. They activate suspicion and fear, not trust.

These are some of the mechanisms through which the abandonment of Mad students as knowers and learners is achieved on postsecondary campuses due to overriding interpretations of us as “risky” and requiring clinical intervention, and dismissal of the emotional, personal, and “quiet” forms through which we try to develop and express our knowledge. While these epistemic harms - of being misinterpreted/not heard, not supported in my epistemic pursuits by many of those in position to help me, and of losing the capacity to expect just treatment as a knower in the university - are inflicted at school and pertain to my experience here, these power relations in the academy echo and aggravate other forms of injury I have experienced, such as those sustained through psychiatric institutionalization, sexual violence, and heteronormativity (Donnan 2003; Heald 1997; Horsman 1999; Palmer and Ross 2014; Rogers 1999; Rosenberg 1997). Reverberating together, these harms significantly impact my experience of learning and knowing in the university. This investigation contributes to other politicizations of student “distress” - such as the conceptualization of “racial battle fatigue” to name the distress Black male students experience from misandric microaggressions (Smith et al. 2007, 2016) and “burnout and compassion fatigue” to describe the exhaustion, loneliness, and attempted suicide of queer student activists of colour (Vaccaro and Mena 2011).

My reaction to these harms is not contained to the specific individuals who post mental health stickers on their doors, or those who have directly (intentionally or unconsciously) referred me away or in whose classes I have felt it unsafe to express emotion or share experiential knowledge; and my need for response is not limited to holding individual people accountable. Stauffer's (2015) work would suggest that everyone at the university is implicated in these messages about and responses to Mad students; they reflect a collective story about what we (do not) owe each other (and how little we owe each other), what we owe Mad students and those experiencing distress, and how we are called to interpret, hear, and respond to such expressions. The institutional demand for these narrow interpretations (of Mad students as "risky", emotion/disclosure as "not knowledge", and referral as the extent of our responsibilities to each other), and the lack of resistance to them, is a betrayal of Mad students and all others who experience distress from systemic oppression on campus.

Politicizing Mad Student Loneliness

Over the last six years, I have regularly used the language of *loneliness* to describe some of my experiences on campus, like those named above, which has resulted in a variety of reactions. In one instance, I was asked if my loneliness had something to do with not having a partner at the time - suggesting my loneliness was personal, not systemic. As I coordinated a Mad student peer support group that grew to 200 members, dozens of whom I considered friends, it felt like non-Mad people around me were

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becoming increasingly confused about my enduring loneliness: What was so wrong with me and my competencies in relationships that I could have “lots” of friends and still be lonely? Loneliness was for first year undergraduates, and I had been on campus for several years: Shouldn’t my loneliness have dissipated by now? Or, the hardest to refute: All graduate students are lonely; writing a dissertation is lonely for everyone. And yet, *lonely* always felt like the best word I knew to describe what I felt, and different from the loneliness of the average grad student (Hill 2018). It just proved completely inadequate when trying to explain myself to neurotypical people around me - in part because my discussion of loneliness involved emotion, personal disclosure, and statements of “I don’t know [why I am so lonely]”, all of which, due to the mechanisms described above, put me at risk of being unintelligible and unheard in my articulation of harms.

As Aubrecht (2016) observes, resiliency-promoting campus contexts ensure that “expressions of grievance, distress, and dissent are subject to interpersonal and administrative processes of individualization, depoliticization, and pathologization” (190). The university interprets loneliness as a psychological problem caused by individual and interpersonal deficits that can be treated by cognitive, self-management, and social skills interventions (Andersson et al. 2015; Mann et al. 2017; Newlin et al. 2015). It creates pamphlets with these messages and distributes them to students (e.g. University of Newcastle 2011; University of Wisconsin 2017). Due to the dominance of psychological ways of approaching loneliness, and a lack of other interpretive tools, I found myself bereft of adequate alternative meanings with which to understand and describe my experiences, a form and consequence of epistemic injustice (Fricker 2007; Lakeman 2010; Wardrope 2015). I felt harmed by campus approaches to mental health. And I felt lonely. What I was missing was a way to describe how these relate.

And then I came across Stauffer's (2015) work, which helped me explain how abandonment and loneliness are ethical and justice issues that will not be resolved with two more friends or corrected thinking patterns. Perhaps I am experiencing a condition of loneliness caused by multiple epistemic injustices that have led to my abandonment as a knower and learner and the loss of my "capacity to expect just treatment or help in the absence of such treatment" (Stauffer 2015, 15). Perhaps being abandoned by those in a position to explore how they might help me "produces a loneliness more profound than simple isolation" (5). And perhaps the campus context that creates this condition of epistemic loneliness here, compounds with other forms of violence and resulting lonely conditions I have endured. What if, when I say I am lonely, I am trying to articulate how there is a *discrepancy*[13] between what the university, in its current arrangement, has chosen to provide, and what I want and long for (Nilsson, Nåden, and Lindström 2008), what I feel like Mad students deserve, what I imagine to be possible, what I want us to be

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[13] I admit to having taken this word from the cognitive discrepancy model of loneliness described in the psychological literature (Stein and Tuval-Mashiach 2015). Until we further develop our own theorizations, there may be some ideas there worth working with.

able to expect, what I am working to create? What if loneliness is a way of saying that the examples of living in the world that I have access to, and the models of holding and honouring responsibilities to others, do not feel good enough, or resonate with who I want to be?

When I take loneliness seriously as a form of violence and harm, it emerges as a sense of *lostness*, *loss*, being *at a loss*. Abandoned as a knower and learner at school, this place and these people that could explore how they might help me, but have neglected the opportunity to, do not want to, have chosen not to, have refused to, I am left disoriented and unintelligible. I lack a shared sense of meaning, where "the world means the same thing to others that it means to me", as Stuewe-Portnoff (1988, 548) elaborates:

> [W]hen my world is pervaded by a problem you don't recognize, or issues that are of no consequence to you, a gulf opens between us. When the meaning domain you inhabit differs in fundamental ways from mine, I experience us as existing in different worlds. When disparate meanings separate me from others, a warm body, or even a crowd of them, will not be enough to alleviate loneliness.

I am missing an epistemic community and relationships with people to whom my observations, interpretations, and ways of knowing are understandable, and from whom I can expect (and reciprocate) just treatment - where we share a similar recognition how injustice manifests and is maintained, and what just treatment requires.

Consequently, I come to worry that the content and process of my knowing is wrong - disordered, disruptive, inappropriate, a problem. I am bereaved of "confidence in [my] ability to evaluate [my] surroundings" (Stauffer 2015, 63), "make sense of the

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world" (Fricker 2007, 163), and pursue my epistemic goals (such as figuring out existential questions about living, finding a way to contribute to social and scholarly communities and wider justice efforts). When I cannot trust my own knowledge or ability to know - because it is not shared, confirmed, or developed in relation with others - my capacity to determine the trustworthiness of others or to expect just treatment from them is also diminished. I begin to lose faith in my understanding of "just treatment", and any guidance it has provided for how to act in the world.

My understanding of abandonment and loneliness has evolved over time as I pay attention to my experiences, including both those of loneliness and contrasting moments when my relationship with loneliness shifts, and I feel accompanied, "with" others, in a space of shared meaning, recognized as a knower, in a resonant genre of relating where I am treated with respect. These feelings regularly emerge when hanging out with other Mad/disabled students to vent about our experiences surviving on campus and visioning what could be different, and I have found great company in these mutual relationships. The writing of Mad student peers, such as Supeene's (1990) book about feeling lonely, going crazy, and coming into a critical analysis of psychiatry as a grad student on the same university campus as me two decades before I would arrive here, are also great companions. These connections have provided a form of epistemic community (Code 1987; Potter 2002) - helping me validate my observations and interpretations of Mad student life as (in many ways) collective and shared. I also think about my first staff job on campus, where I felt recognized and respected as a knower, and where my employment supervisor didn't interpret my testimony of "I don't know" [what I want to do in the future] as a lack of interest or ability, but as a desire for epistemic help; she responded by sending me a job posting, imagining a viable future for me in related roles, and encouraging my consideration of career opportunities. Similarly, when I started working on an intentional student-faculty partnership project and had an example of what it could look like to rethink the academy's normative power hierarchy and ways of relating to students through collaboration, other campus contexts in which I felt powerless began to feel concretely discrepant (see de Bie et al. 2019). Instead of feeling "referred away" or like I could only be related to through a clinical dynamic, I had access to reciprocal relationships with people who respected and supported me as a knower and colleague (as I supported them). Rather than worrying that my emotions would be "spotted" and treated like a problem, I was supported in using my emotions in data analysis, for example, to spot resonant and significant themes.

These ways of relating have helped me experience and conceptualize what "just treatment" might look and feel like (not being referred away, reciprocal rather than clinical relationships), and affirmed my assessment that I have been harmed as a Mad knower through the university's abandonment and neglect. In these relationships (and a host of other ones), I have begun to recover the possibility of trusting and holding confidence in my observations, experiences, knowledge, and I am starting to develop alternative interpretations of Mad students like myself as capable knowers and important contributors to knowledge production, rather than “risks” to be managed. While Stauffer’s (2015, 171) investigation into ethical loneliness focuses on widespread rather than individual culpability, and the need for broad redress, she concludes by emphasizing how our interpersonal relations with each other - like those described here - do change us, and how “time and other human beings might make it easier *or* more difficult for the past [harms] to be past. More difficult. *Or* easier”. These were some of the human connections through which my “past” harms began to echo differently.

Practicing and Being Moved by Loneliness

When I politicize and spend time with loneliness, rather than attempt to contain or resolve it, it has a lot to teach me about what I want from “justice”, and I have come to consider it an essential quality of how I approach knowing Madly and creating Mad knowledge. Fricker (2007) argues that epistemic injustices lead to a literal loss and erosion of knowledge, and prevent knowledge from coming into existence, and I confirm and grieve that this occurs in the ways described above and a host of other ways. At the same time, so much of my knowledge has been developed in the presence of, in desperation over, in reaction and contrast to the loneliness that I experience as a Mad knower and learner; many Mad experiences (especially those related to abandonment and loneliness) and ways of knowing are sharply tied to oppression, though oppression is not all that we are (Nicolazzo 2017). To consider getting rid of loneliness or sending it away

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breaks my heart, as this only sustains the treatment of loneliness (and myself as someone living loneliness) as a problem, and further facilitates hermeneutical injustice by failing to recognize this emergent loneliness as a form of Mad knowledge. Indeed, the most significant contribution of Mad Studies to considerations of loneliness may be a refusal to pathologize it. Perhaps, instead, proper redress requires recognizing and "being moved by" loneliness, just as Dolmage (2008, 24) describes Universal Design and accessibility in the classroom as "ways to move" as opposed to fixed practices. Stauffer (2015, 2) does not reimagine loneliness in this way, but this kind of interpretation and orientation to loneliness does resemble her broader description of "revision" (in the wake of harm) and "rebuilding" (after loss) as about shifting "how the past resonates in the present". In my own revision and rebuilding, I propose shifting how loneliness resonates so that it is not only vibrating along a frequency of harm.

It seems to me that loneliness (and the harms and losses through which loneliness arrived) has come to exist in my life as a sort of companion species - attached to me, and I to them (Haraway 2008; Lindgren et al. 2014; Nilsson et al. 2008). As a companion, loneliness informs how I relate and spend my time, and has driven me to gather corporeal company by investing extensive energy in student organizing, peer support, building a sense of mutual community (Rovai and Wighting 2005). It has compelled me into a more oral, experiential, and intuitive form of knowing/knowledge than I otherwise would have found. This follows from my understanding of how mental patient and peer movements

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have been propelled by the momentum of loneliness for generations, as the naming of "We Are Not Alone", the 1940s peer support group founded at the Rockland State Hospital in New York State, reflects (Reaume 2002). As it is, how I know, what I know, and who I come to know with is directly informed by loneliness. Loneliness, for example, has influenced my work with other Mad students to create a self-published (maga)"zine" about our experiences at school. Several of us played with images of doors and chairs on campus to depict their associations with abandonment and being alone (places to hide and cry) and having company (places of friendship and peer support) (Mad Pride Hamilton 2014). These experiences of loneliness, isolation, and support formed the basis of campus walks I've given during trainings and orientations - an "alternative" perspective to community than tours by the campus recruitment office that market neurotypical belonging (e.g. Sandberg 2015). Being moved by the species of loneliness has shifted how I engage at/in the university - both in terms of my relationships, as well as my embodied and affective work to name and understand personal and shared experiences.

As a companion co-instructor, loneliness informs my teaching philosophy and how and what I teach, especially in relation to Mad/disabled students. In talking with them and reading their writing, I keep lookout for indications of what they are longing for - and how the context of a course might meet (some of) those needs, such as opportunities for solidarity and belonging (Jones et al. 2015; Stern 2018). Students not uncommonly identify a goal of feeling more confident having a conversation with friends and family about experiences with mental health/madness - an incredibly helpful signpost for orienting to the kinds of loneliness they live with. With these students in mind, I am working to be better company as an instructor, and am encouraged by examples from other Mad professors doing the same (Poole and Grant 2018; Poole et al. 2012; Price 2011; Reid and Poole 2013; Reville 2013). I read about Karp (2001, 21) welcoming a student to camp out in his office for a few hours because that was what she needed ("I feel like I'll go crazy if I'm alone today. I just can't bear to be alone."), and what he could provide, and think: This is the kind of instructor I want to be. I come across Timile Brown's (with Price 2008) reflections on how the introduction of emotions and personal disclosure of distress into the classroom by an instructor eased her sense of aloneness, and seek to foster such a space that actively delights in (rather than discourages) emotional and personal ways of knowing (Ohrstrom 2005). I think of my own and other Mad students' needs for words and ideas to understand and politicize our experiences (Aubrecht 2016; Paterson, Hogan, and Willis 2008; Wolframe 2013), and try to offer alternative languages and frameworks as forms of company. Living, working, teaching with loneliness as a companion has guided me - painfully, but guided all the same - into ways of being that align with who I (think I) want to be(come) and carry me along in my epistemic project of creating and living a future and reimagining "just treatment". Loneliness is not an absence of knowledge, or lost capacity to know, but a way of knowing in the world that I want to gain skill and confidence in. It is also deeply exhausting, haunting; although I am finding ways to move with loneliness, I also spend plenty of time stuck.

Conclusion

This paper has developed an interpretation of loneliness as both a painful condition Mad students experience when we have been neglected as knowers, as well as a state of political and ethical possibilities - where new knowledge and ways of knowing can be created. To suggest both realities of pain and creation allows us to recognize understandings of harms endured and redress required that are invisible to legislative justice frameworks, and to avoid pathologizing the impacts of harm as (only) a psychological problem. When we do this, we welcome alternative interpretive resources, emergent Mad epistemologies, more responsive and responsible ways of relating and being in the world, and glimmers of how things might be otherwise – which contribute to epistemic justice.

It will take a broad range of changes to fully respond to the epistemic harms and loneliness that Mad students experience. Some of these are institutional, but more is needed: "In order for any large and complex recovery to succeed, ...a large number and broad range of persons will have to learn to tell themselves different stories about who they are and how they come to owe things" (Stauffer 2015, 110) to Mad students as knowers and learners. To change our stories, we might return to our referral practices. Post-secondary institutions regularly treat Mad students with a definition of "refer" that

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means: “to send or direct for treatment, aid, information, or decision” (Merriam-Webster Dictionary 2018); “to hand over or submit for information, consideration, decision” (Dictionary.com 2018). If we are to ease loneliness and seek epistemic justice for Mad students, we have much to learn from the other possible meanings and applications of this word, such as its Latin origins as *referre* - “to bring back”, “to relate”, “to carry” (Harper 2018; Merriam-Webster Dictionary 2018). The discrepancy between these definitions is significant. What would it mean and look like to shift from “sending away” and “handing over” to bringing back, relating, carrying? What might Mad students be able to expect from revisioned relations like these?

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Resisting Unmet Expectations as Service User Ethics: Implications for Social Work

Abstract: This paper takes up a call from activists and scholars in Mad and Disability Studies to pay more explicit attention to resistance. Drawing on interviews with sixteen LGBTQ people who have experienced psychosis and their encounters with un/supportive spaces, and on conceptualizations of predictive, normative, and ideal expectations, we describe three ways they resist unmet expectations of just treatment. These include: (1) defending self-respect through resistant thinking and resentment; (2) reducing discrepancy through lowering expectations of just treatment from others; (3) and protecting selves through distrust and self-reliance. This paper makes several contributions to existing literature: It expands our understanding of the 'everyday' forms of resistance that Mad people/service users engage in, particularly those that are 'quiet' and risk being missed. By paying attention to quiet forms of resistance, we come to recognize the everyday 'moral talk' of service users, and opportunities for collectivizing the values underpinning this talk into ethics. Supporting the creation/affirmation of service user ethics is one way for social work to respect and acknowledge the legitimacy of Mad knowledges, especially their developing visions of justice and moral relations.

Introduction

Although social work is based in a set of values and ethical codes reflective of the social justice mandate of the profession (Chu *et al*., 2009), and relies on these codes to 'protect' service users, users are rarely involved in the formation and revision of these moral norms (Doel *et al*., 2009; O'Leary *et al*., 2012). This gap is consistent with arguments that social work has failed to significantly engage with service user knowledge in the development of social work theories and practice frameworks, or to create an inclusive profession that welcomes social workers who identify as Mad/service users (Boxall & Beresford, 2015; Poole *et al*., 2012; Wilson & Beresford, 2000).

There is a need to respect and encourage the development of service user perspectives on ethics as a way to both support Mad knowledge creation and challenge social work's patronizing claims about what is in the 'best interest' of service recipients. As a place to start, psychiatric survivors and people with disabilities (the 'service users' we emphasize in this writing) are beginning to contribute their views on user-provider boundaries (Beresford *et al.*, 2008; Cossom, 1998; Grant & Mandell, 2016; Heyward, 1993), bioethics (Beresford & Wilson, 2002; Newell, 2006), narrative ethics regarding the telling and use of personal stories (Costa *et al*., 2012; Newell, 1998), research ethics (Faulkner, 2004; Holland, 2007; Sweeney, 2016), and values and ethics in peer support (Crepaz-Keay & Cyhlarova, 2015). Additionally, disabled people's lived experiences are being taken up in moral philosophy, including the domains of 'virtue theory/ethics' (Clifton *et al*., 2018; Swift *et al*., 2002) and feminist 'ethics of care' (Morris, 2001; Wendell, 2013), as well as applied and descriptive ethical discussions of moral experiences, injury, and agency (Edwards *et al*., 2014; Molendijk, 2018; Myers, 2016). Brodwin's (2016) work, for example, initiates a conversation between philosophy's abstract and distant ethical principles and 'experience-near' psychiatric survivor testimony, making salient how this form of life writing is full of everyday, experiential 'moral talk' that is infrequently synthesized through "systematic language and… disciplinary rules of evidence and proof" (p. 188) into 'ethics'.

This paper attends to the everyday 'moral talk' of individual interview participants from a project on LGBTQ/Mad people's experiences of un/supportive spaces and relationships to fashion some ideas about collective service user ethics. By drawing on the analytic techniques of resonance, reading for resistance, and 'quiet data' described further below (de Bie, forthcoming), our approach aligns with Mad(ness) Studies, a nascent field of knowledge in the academy that privileges inquiry inspired by and grounded in the ways of knowing, being, and doing of members of the historical and contemporary consumer/survivor/ex-patient/Mad movement (Menzies *et al*., 2013). When we took up the call of Mad activists to "listen… for stories of resistance and opposition, collective action and social change" instead of individual storylines of illness and recovery (Costa *et al*., 2012, p. 96), we encountered examples of service users expressing grimly low expectations of being treated in a just manner. We stayed with these interview excerpts to explore how participants engage in 'moral talk' about what they deserve and how they protect themselves from unhelpful help, and to show how participants continue to maintain a claim on just treatment, even as they reduce their predictive expectations that just treatment will occur (Tessman, 2009).

Methodology

Project Background

This project initially came together to address a lack of research on the experiences of LGBTQ people with psychosis labels, especially research that engages with LGBTQ/Mad communities (e.g. Pilling *et al*., 2017). After convening our multi-organization team - comprised of researchers from LGBTQ and consumer/survivor communities, service providers, and researchers with specialization in the intersections under examination - we collectively identified a focus on the places, spaces, and relationships (broadly understood) where participants feel un/supported.

The study took place in Canada and received approval from all research ethics boards to which team members were institutionally affiliated. Participants were eligible if they were over the age of 18, identified as LGBTQ, had experiences with psychosis, and lived in the geographical areas of the study. They were recruited through LGBTQ networks, mental health organizations, and service user groups. Face-to-face, one to two hour interviews were conducted using a semi-structured interview guide, with questions focused on participants' encounters with supportive and unsupportive spaces as related to their interlocking LGBTQ and psychosis experiences. Interviews were conducted by two team members and one research assistant who identified as psychiatric survivors, with two also identifying as LGBTQ. All participants provided informed consent; interviews were digitally recorded, transcribed verbatim, and then anonymized to protect confidentiality.

Participant Demographics

Sixteen people agreed to participate, with demographic information obtained for fifteen of them. Thirteen participants lived in a large urban centre and three lived in a smaller city nearby. The fifteen participants ranged in age from 19-56. At the time of the interview participants identified as male (5), female (6), Two-spirit (1), questioning (1), genderqueer (1), and as a female-to male trans person (1). Participants self-identified their sexual orientation as gay (5), lesbian (3), bisexual (4), queer (1), asexual (1), pansexual (1), unsure (1), and with multiple sexual identity terms (1). Over half of the participants were single at the time of the interview. Ten participants identified as white, two as Indigenous, and three as non-Indigenous racialized (Southeast Asian; Black Caribbean; African/European). Participants' access to education varied, ranging from completed primary school to completed post-secondary education. Approximately 85% of participants were living on low incomes and 75% received government welfare/disability benefits. Participants had acquired 'psychosis' labels between 3-30 years prior, most commonly bipolar, schizophrenia, and schizoaffective 'disorders'. Two thirds identified as experiencing substance use concerns related to alcohol, cocaine, and/or crack-cocaine.

Analysis

Half of the research team [AD, AdB, CL, SP, TT] engaged in individual review and collective discussion about a subset of the transcripts to prepare a coding framework reflective of our varied readings of the data. The code of 'resistance' was identified by Alise, the LGBTQ/Mad researcher on the team, as essential to how they were initially reading the transcripts, based on 'resonances' they felt between the data and Alise's own peer experiences and knowledge. Other service user researchers have described a similar approach, drawing on personal resonances with the data to inform identification of research themes (Gillard *et al*., 2013; Voronka *et al*., 2014), which contributes to efforts in Disability Studies to more explicitly attend to resistance as a common theme across diverse paradigms and movement strategies (Peters *et al*., 2009). An additional sensitizing concept that informed our analysis is what Voronka *et al*. (2014), a team of peer researchers, refer and pay attention to as "quiet" data - the data that are not necessarily quantifiable and might get overlooked by non-peer researchers as irrelevant or evidence of symptomology (p. 257). Applied to our code of ‘resistance’, we listened for examples of everyday dissent that might be otherwise ignored or pathologized instead of more visible/overt forms of resistance such as those that explicitly “voice” concerns or involve an “exit” from services (Clarke, 2007). Alise was particularly moved by the effort it took participants to access and negotiate ‘supportive’ spaces and relationships, and evade and protect themselves from ‘unsupportive’ ones - a kind of labour and skill that was unanticipated by our interview questions, but that strongly echoed Alise’s own experiences.

Practically, a research assistant coded the initial transcripts and team members gave feedback on these codes and reflective excerpts to revise the coding scheme further. The research assistant then coded the rest of the transcripts with the aid of qualitative software (Dedoose). Alise took the excerpts compiled under the ‘resistance’ code and worked with them in analysis, which involved returning to the full transcripts to read for other examples that may have been missed during initial coding. Other team members were involved in commenting on this early analysis as it was being developed. Through these forms of engagement with the transcripts, each other, the literature, and through writing, we arrived at the analysis below.

Findings: Resisting Unmet Expectations of Just Treatment

Drawing on the conceptualizations of predictive, normative, and ideal expectations, we describe three interrelated themes: (1) defending self-respect through resistant thinking and resentment; (2) reducing discrepancy through lowering expectations; and (3) protecting selves through distrust and self-reliance. **Predictive expectations** are those derived from personal experience and other knowledge that reflect "the realistic, practical, or anticipated outcome… [that] matches what users actually believe will happen in a service encounter" (Thompson & Sunol, 1995, p. 130). **Normative (moral) expectations** are those "taken to represent what should or ought to happen" (p. 130) - such as what is believed to be deserved and/or socially endorsed. **Ideal expectations** reflect aspirations, desires, preferred outcomes, and the "user's perspective on the potential for a service" (p. 130). While the concepts of predictive, normative, and ideal expectations are regularly used in research on patient expectations of, satisfaction with, and overall evaluations of healthcare services, we work with them to explore how service users resist what they determine to be inadequate or harmful care.

Defending Self-Respect through Resistant Thinking and Resentment

Participants defended their self-respect through anger, naming violence, identifying treatment they do not deserve, and disagreeing with misinterpretations of their experiences. In the excerpts below, participants express anger about harms experienced personally and as witnesses, and in their anger - often marked by profanities - frame and label these harms as injustice (sanism, discrimination, ignorance). Following, they often suggested what sort of treatment should have occurred instead, and/or exit the situation, refusing to condone it.

> *I wasn't making a scene or anything [at the nightclub] but they kicked me out because they assumed that I was on drugs, but I wasn't on any drugs. I was just in*

> *a crisis. And they were very sanist like when I tried to explain, they were like, "Yeah, we don't want your crazy here". And I was like, "Well, fuck you. I'm boycotting your place" and I never went back to the [name of nightclub].* (Participant 14; here and below, text is bolded to highlight points of analysis)

> *It's the frontline staff that have* **the ignorant problem***… you want to hear, you wanna hear a good one? I'm standing there [at the women's residence] one time… this woman came in and she'd been battered. She was like, she had bruises on her face... and she's in line getting some tea, and… getting something to eat I think. And the staff member was like, "Oh, you gotta go put on your, on shoes," …and she's like "I just wanna cup of tea," like she was just so exhausted, so… Instead of the staff member saying, "Oh, can you bring down some slippers for so and so, and just get her calm and nice, and, you know, safe feeling," she exasperated her to a point where this woman just threw her tray across the kitchen, went upstairs, grabbed her stuff, left… set the place on fire, and left. The ambulance came, ...the people were evacuated... all because this staff member didn't say, "Oh, can you get her some slippers?"* (Participant 4)

As we see in the first excerpt, some participants drew on identity-specific language like sanism, a form of oppression targeting those labelled with or perceived to experience mental health concerns (Poole *et al*., 2012), or homophobia/biphobia to describe experiences of harm. More commonly, participants used general terms - uneducated, ignorance, bias, assumption, stereotype, judgment, intolerance, prejudice, bigotry, abuse, violence, attack, power, hate crime, stigmatization, marginalization, discrimination, oppression - to explain the characteristics of unsupportive encounters. Many participants also bluntly disagreed with the interpretations of 'expert' others – expressing clear opposition to how they have been pathologized and misrepresented, and asserting strongly held alternative perspectives, a discursive form of resistance commonly advanced by psychiatric survivor counter-narratives (Lee, 2013; Morrison, 2006).

Several noted the contradictions between service providers who claimed to offer non-judgmental support and openness to listening, and participants' actual experience of 'care' received. As they explained: *"a lot of that discrimination does come from people who say they're going to help you"* (Participant 2); *"a lot of places don't always stand behind what they claim, like 'Oh feel free to come and discuss… with us… we're here for you'"* (Participant 1). Additionally, participants explicitly named situations as "wrong" and "not what they deserve" and applied normative standards for what they should be able to expect in terms of just treatment. By doing so, they asserted their own moral worth and self-respect as human beings, declaring that they are "worth more" than how they have been treated (Dillon, 1992; Middleton, 2006).

> *Here [in participant's city], you have to live in fear [of violence for being LGBTQ], which* ***I don't think is right. I think it's utterly wrong*** *that you should have to live in fear in your own city, but that's the way they are here…* (Participant 11)

> *I'm employed as a [position] for [social enterprise employing people with mental health concerns] and it's a very welcoming environment but I don't feel like I belong there because* ***I don't feel like I deserve*** *to get paid less than five dollars an hour for my work.* (Participant 16)

In these ways, participants are engaging in "resistant thinking" (Riessman, 2000, as used by Frederick, 2017) by recognizing their experiences as resulting from forms of violence perpetrated by others, rather than condoning situations as inevitable, fair, or their fault. Beyond cognitive or discursive responses, they are also protesting through resentment, which Dillon (1997) defines as the anger one feels when one has been "wronged in a way that affronts one's dignity" (p. 230), one's essential worth as a person. Under this definition, anger is not pathologized as a problem. Rather, to not resent or otherwise protest unjust treatment might be conceived as "fail[ing] in our duty to protect our self-respect" (Middleton, 2006, p. 67, referring to Boxill, 1995). These affective reactions can be understood as calls for confirmation that the harms identified are a mutually recognized violation of shared normative expectations of just treatment, and for the restoration of moral relations (Stauffer, 2015). Recognizing and respecting anger, resentment, being "sick and tired" as a just and resistant response to injustice may be especially important to psychiatric survivors whose anger has been treated as an irrational individual problem requiring correction (Lee, 2013).

Reducing Discrepancy through Lowering Expectations of Others

At the same time as it animates, holding on to this much justified anger can be exhausting and cause personal harm, making it necessary to protect one's energy and emotions by detaching and carrying on (Browne *et al*., 2011). Several participants also worried about losing control of their anger and consequently harming others, which led them to evade enraging situations. In this context, finding a different way to "carry on", as Participant 3 expressed, can be understood as a moral response and form of resistance: *"The reason why I'm feeling so negative about things is because of the fact that I don't feel good about how I've been treated by other people. But I can't, you know, just carry on like that for the rest of my life"*. Below, we explore how participants "restrain" hidden emotional work (Frederick, 2017) by lowering/revising expectations through: predicting or “not being bothered” by unjust treatment, reducing their aspirations of support, “taking what they can get”, and “putting up with” limited care.

Participants have not given up a claim on what they “should” be able to expect, but they did come to realistically predict - oftentimes with feelings of fear and/or frustration - unjust treatment. Participant 2, for example, explained: *“I mean, I live my life convinced that I’m gonna get beaten up one day. Not like uhh… if it happens, it’s more like, when is it gonna happen, kind of thing”*. Similarly, Participant 4 developed a philosophy about the chances of running into a service provider who is ignorant versus supportive as *“basically a hit and miss thing. If you hit, you hit. If you don’t, you move on to someone else you like”*. In these excerpts, participants expressed little control over the likelihood of inadequate support.

Some expressed ways that they are no longer “bothered” by violence, a finding that also appears in literature on why LGBTQ people do not report incidents of hate crime - dismissing them as “minor” or “part of LGBT lives” (Browne *et al*., 2011, p. 749). For Participant 8, the intensity of being bothered by poor treatment seemed to have decreased over time - suggesting that their attachment to a particular outcome (acceptance by others) has loosened. Instead, self-acceptance becomes more important:

> *I used to mind that [getting weird looks when with partner], in my early stage [of coming out], but now that I, it’s been 10 years for me, over 10 years, so I don’t mind it anymore. I’m cool with that. ...you know how people are rude, they still can’t accept that’s what we are and everythin’ else, but I don’t care anymore. It doesn’t bother me anymore.*

Participant accounts reflected their low aspirations of support from others based on what their experiences suggested was ‘realistic’ or practical to expect. As Participant 5 shared, “*I would want people just to under - just to listen. It’s a big start, eh?*” They moved away from “understanding” as the goal, to listening as what they asked for. Participant 6 similarly expressed a desire for a “little bit” of care: “*[I]t would be nice if they [social workers] could… care a little bit. That would be nice”*. Several described the ultimate indication of a supportive encounter as *“not being treated any differently”* due to their social identities, which is a far stretch from responsive care that recognizes, respects, and responds to difference as opposed to treating everyone the same.

In their work on the expectations of police held by people with mental health disabilities, Watson *et al.* (2008) suggest that “[g]iven their negative expectations [of police], participants evaluated interactions positively if they simply were not abused. Being treated well, for example, with kindness, concern, dignity and voice, was icing on the cake” (p. 456). In a similar vein, in research on the “good stories” of lesbians receiving cancer care, Sinding *et al.* (2010) describe how receiving perfectly ordinary care *without having to fight for it* is taken as a “gift” rather than an expectation or entitlement. Given the low expectations of participants in our project, having people “just listen” or “care a little bit” may be received as “icing” or a “gift”. Participants may also be gesturing towards situations that could be easily resolved by simple kindnesses, such as in the example described above about the woman in a residential service who was visibly suffering, said she had been battered, and was calling for the smallest discretion:

"I just wanna cup of tea." This request was not met. Participant 4, who witnessed this encounter, suggested staff could have resolved the situation by simply asking someone to "get her some slippers". What service users need - and describe not receiving, despite how little it would take in many instances - is some basic care in contexts where rigid procedures seem to not listen, understand, or care, and end up causing unnecessary additional suffering.

In some contexts, service users may "take what they can get" and live with the reality that they will not be accepted everywhere they go and that people will often not know how to meet their needs (Poteat *et al*., 2013). When they are accustomed to not expecting much from others, the predictable presence of even one supportive person can be deeply reassuring and offer a sense of security (Klevan *et al*., 2017).

> *I'll take what I can get. If I can come up to you as this [with gender stuff], and just keep the rest [mental health stuff] away, that's fine by me.* (Participant 6)
>
> *I don't necessarily need to feel like I need to go, like everywhere I go I have to be accepted. ...I just mean that if I were to have an issue, or were to have a problem and were to need somebody to talk to, I know that at those two places…I could feel comfortable to talk openly.* (Participant 1

Participants also described "putting up" with healthcare providers in order to get what they needed "to function", a decision that takes places in a context where "options are running out" (Participant 2) and appropriate and affirming care required to flourish is not readily available. Sometimes this involved shutting down, or shutting up and not naming harm or difference (Browne *et al*., 2011). In this case, relying on someone in a moderated or restrained way has fewer consequences than not relying at all.

> *He's a bit more open to me talking about it [trans identity], so with him, it's like I put up with it, because I've been through so many psychiatrists…my options are like running out, and I don't want to go get a new one, so it's just like you kind of just shut up and let them ramble on. And then, just kind of know for yourself like, "No, this is the way it is for me, and I can't change their mind in this aspect, so as long as I in the end get what I feel is necessary for me to function properly, like that's fine."* (Participant 2)

Rather than amplifying the gap between what they deserve and what they experience, as participants do when they express anger and resentment over unjust treatment, maintaining low expectations can *reduce* the felt discrepancy between what they anticipate - in both a predictive and moral sense - and what occurs. Scholars refer to this as "bring[ing] their expectations in line with an anticipated (lower) outcome" (van Dijk *et al*., 2003, p. 507), often to reduce a felt sense of disappointment. In line with research on LGBTQ people who take personal responsibility for their own safety in order to evade conflict (Browne *et al*., 2011), lowering expectations may reduce someone's felt sense of tension or devastation in situations of unpredictable and unreliable support.

This is an approach significantly more accessible than the reverse of achieving outcomes aligned with their expectations, which at the very least involves difficult conversations with powerful others, and, at the other extreme, requires a transformation in social relationships and the organization of social and health services. By lowering expectations, participants affirm what they experientially know to be a probable outcome, and apply this cognitive and affective knowledge to their expectations of future treatment. In this way, it is a form of validating one's own knowledge and intuitions, rather than negating or denying them, an essential feature of self-respect (Dillon, 1992). While social movement organizing has been understood by some as about “raising expectations” (McAlevey & Ostertag, 2012), these findings suggest that reducing or revising expectations for just treatment may also be an important, albeit quiet and unrecognized, form of opposition and resistance.

Protecting Self through Distrust and Self-Reliance

Participants protected themselves in a number of ways, including through: exiting a situation, setting limits on disclosure, and relying on themselves instead of others. Among people we talked to, some outright discontinued affiliation with unsupportive people rather than downgrading or “putting up” with low expectations - a type of resistant “exit” from relationships well described in the social service literature (Clarke, 2007): *“It just seems like my family believes that, they want to believe what they believe [about participant being gay] and that’s it, and nobody will help them or change that thought. So I stopped going to my family for help”* (Participant 12). Some similarly left prescribed treatment or services: *“I feel better when I go off them [medication] for a while, right? I smoke a bit of weed, and I’m fine, you know. I just sort of keep myself calm”* (Participant 7).

Others set firm limits on how open or vulnerable they wanted to be - refusing to give away what others claim is something they “need” to know, and asserting their right to privacy.

> *I’m very upfront like if someone was asking me an intrusive question... I would sort of set up my boundaries where I would say, “Well, I’m not comfortable with that question…”* (Participant 13)

> *I wouldn't [disclose] in the other [agency]. They don't even know I smoke [crack]. No need for them to know*. (Participant 1)
>
> *I know how to use the truth. I don't have to tell you everything, and I don't have to lie to cover it either. I can tell you the truth and keep the rest to myself because it's private*. (Participant 9)

Several participants held low expectations of being believed (especially due to their psychosis label) or supported if they did disclose, and expressed a general sense of suspicion and distrust, which other Mad Studies writers recognize as a common resistance strategy (Morrison, 2006; Lee, 2013). Collectively, participants subverted traditional notions that transparency with service providers is necessarily possible, safe, or helpful for service users (Brown & Calnan, 2013; Potter, 2002), as Participant 6 suggests in the two excerpts below:

> *...same old shit you always get from social workers or, you know, those kind of people who are there to wheedle stuff out of you, but they're not really useful like to you… like they don't care. ...you can't trust them.*
>
> *I: Ok, so you think if you started speaking to people about both, like all parts of your identity that would be too much for them?*
> *P: Yeah. And me too I guess, knowing that someone has that kind of ammunition. …to heap both [gender identity and mental health experiences], you're just, you're giving them a lot.*

The metaphors used here are provocative: "wheedling stuff out" and "ammunition" - describing the role of the service user as one of protecting and shielding from manipulation and attack by withholding knowledge about themselves. Although "getting stuff out" of the service user is commonly perceived as a desirable outcome across social work interventions (Sinding *et al.*, 2012), participants and other activists articulate important practices of "keeping stuff in": Chamberlin (1998), for example, suggests that when service users are able to lie (or restrict disclosure) effectively, they are better able to protect themselves from the mental health system. Our participants similarly described ways they are protecting their stories and information in relationships.

At the lowest end of the continuum of expectations of others, some participants rely on only themselves for support: *"I mean, I gotta back myself up. There's nobody else to back me up... When it comes to support, I become what I needed"* (Participant 9). When participants assert confidence in their own self-reliance, and do not highly depend on others, they minimize the impact of whether or not someone comes through for them or meets their expectations for just treatment. This offers a kind of "bracing" from how vulnerable they are to being negatively impacted by others (van Dijk *et al*., 2003), and can ease feelings of anger, reinforce self-control, and offer hope (Bell & Nkomo, 1998 referencing Scott, 1991). While there are notable benefits to self-reliance for those who routinely experience harm in relationships, it is important to underline how the situations of 'self-reliance' noted above are not freely chosen and desired by participants, but experienced as the only alternative - more accurately characterized as 'self-protection' than 'self-sufficiency' per se - when supports are inadequate. In this context, self-reliance can also be a burdened virtue that diminishes one's personhood and restricts disclosure of pain and vulnerability (Bell & Nkomo, 1998; Tessman, 2005).

Discussion

Social work has much to learn from service user resistance: It is justified, and has an ethic to further self-respect and protection. Through resistance, participants stand in opposition to experiences of ‘care’ that are, in their views, unethical and not what they deserve, and ultimately reject the ‘morality’ of available supports (Potter, 2002). When we attend to resistance from service users, we can appreciate these responses as developing moral norms, and are called to engage in practices to sustain our own trustworthiness (as individual workers, as organizations), and to take concrete steps to repair broken trust and relationships (Potter, 2002). This means, for example, not pathologizing service users for an ‘inability’ to trust, not questioning their evidence to assess whether their distrust is ‘warranted’, and not assuming ourselves trustworthy - especially when abiding by ‘ethical’ codes - but actively working to be trustworthy.

This paper makes several contributions to existing literature: First, it expands our understanding of the ‘everyday’ forms of resistance that service users engage in, particularly those that are ‘quiet’ and risk being missed, and arise at the intersection of LGBTQ identity. This includes anger/non-compliance/disagreement, which are often pathologized, as well as several forms of opposition through muting and unsaidness: the reduced intensity of emotions when participants lower their expectations, the stories that are not disclosed when participants distrust, and the supports that are not requested when participants “take what they can get” or rely solely on themselves. Second, by paying attention to quiet forms of resistance, we come to recognize the everyday ‘moral talk’ in which service users engage (e.g. identifying treatment they do not deserve, getting angry about experienced harms, labeling harms as injustice), and opportunities for collectivizing the values underpinning this talk into ethics. By better understanding service users' moral norms we can further determine how to be responsive to them as advocates and service professionals (Entwistle, 2009).

Supporting the creation/affirmation of service user ethics is one way to respect and acknowledge the legitimacy of Mad knowledges, especially their contributions to visions of justice and moral relations. Given concerns about how service users and their knowledge risk being "viewed as a resource to be ignored, trawled, plagiarized or co-opted in order to support academics' theorizings as and when it suits them" (Wilson & Beresford, 2000, p. 562; see Boxall & Beresford, 2015, for a recent reflection on the lack of change over time), we recommend service user ethics be further developed by service users themselves. Social work is in a unique position to support social work students, practitioners, and scholars who identify as prior/current service users to engage with survivor communities around moral norms and ethics and to see about how these might inform (or resist informing) social work ethics and practice. As learners and workers who have inherited codes of social work ethics, as well as developed experiential modes of service user ethical knowledge, they regularly live at and negotiate the constructed boundary between them.

This is one way for social work to take up calls to more fully engage and ally with psychiatric survivor movements and Mad Studies - given how our stated social justice values and ethical codes align more closely with survivor politics than traditional medical approaches to madness/disability (Joseph, 2013; Poole *et al*., 2012). It also addresses Sweeney's (2016) concern that a consumerist approach to increasing efficiency, effectiveness, and satisfaction with services - which professional 'evidence-based' approaches are prone to emphasize - is not expansive enough. Instead, she encourages survivor researchers to engage with Mad Studies by "conduct[ing] research that furthers the development of our own knowledges, rather than becoming involved in mainstream research that seeks merely to access our views of existing services" (p. 48).

Limitations

Due to the small sample size, exclusive recruitment from two urban centres, and the emergence of resistance as a subcode that was never specifically investigated through our interview questions, it was difficult to determine how the diverse demographics of our participants impacted their modification of expectations. For these reasons, transferability is also limited. Investigation into Mad people's resistance efforts and practices around expectation-setting, moral norms, and ethics could be taken up more intentionally and directly.

Conclusion

In their review of conceptualizations of resistance, Hollander and Einwohner (2004) identify "opposition" and "action" as the two common features across a diverse range of examples. Our discussion above would suggest that amplifying and revising expectations satisfy both of these conditions, albeit quietly. Participants "oppose" and “act” on unjust treatment and unmet expectations by: defending their self-respect through resistant thinking and resentment; reducing discrepancy through lowering expectations; and protecting themselves through distrust and self-reliance. Taking place on a largely individual, interpersonal, and locally-confined scale - or the scope of the “everyday” - their responses are partly epistemic in their affirmation of experiential knowledge of predicted treatment, emotional in their reduction of disappointment and negative affect, and relational in their alteration of trust and boundaries. Their resistance involves significant amounts of work, and merits understanding and recognition. The development of service user ethics, and the contribution of Mad/disabled/service user social workers to the creation of these ethics, paves the way for our profession to respond more responsibly, and indeed to honour, the moral norms that service users draw on and activate to guide their interactions with us.

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Valuing knowledge(s) and cultivating confidence: Contributions of student-faculty pedagogical partnerships to epistemic justice

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Abstract: This chapter draws on data from two studies, one in Canada and one in the United States, focused on the experiences of pedagogical partnership as described by students traditionally underrepresented and underserved in higher education. These students argue that such collaborations with faculty hold promise for creating more inclusive and responsive practices. Using the concept of epistemic justice, we explore how partnerships can facilitate epistemological forms of equity and inclusion by (1) creating more equitable conceptions of knowing and knowledge that open possibilities for (2) fostering students' confidence in their knowledge and willingness to share it with others. We argue that partnerships — in their epistemic, relational, and affective impacts — are one powerful way to recognize underrepresented and underserved students as "holders and creators of knowledge" (Delgado-Bernal, 2002, p. 106) and to bring about greater epistemic justice in higher education.

Introduction

Equity and inclusion work on postsecondary campuses has often been advanced through human rights and accessibility legislation, the development of services to enhance the success of marginalized students, and instructor efforts to infuse equity into course curriculum. In this chapter, we introduce the concept of epistemic justice (Fricker, 2007) and the practice of pedagogical partnership to focus on epistemological (knowledge-related) forms of injustice often ignored by structural mechanisms like legislation and services. This approach encourages us to create opportunities for mutual and reciprocal relationships (as opposed to service provider/user ones), and to meaningfully involve students as equal and important partners in equity and inclusion work.

Drawing on interview data from students who have participated in two partnership programs (one in Canada, one in the United States) and belong to equity-seeking groups, this chapter describes how students and faculty members can work together as partners to make teaching and learning more inclusive, thereby repositioning students from those who receive or inform knowledge to those who co-create it (Cook-Sather, Bovill, & Felten, 2014; Healey, Flint, & Harrington, 2014; Matthews, 2017). Partnerships can recognize and reposition underrepresented and underserved students as “holders and creators of knowledge” (Delgado-Bernal, 2002, p. 106) by reconceptualizing knowing/knowledge production in the academy in a way that bolsters epistemic confidence and students’ comfort sharing and contributing what and how they know. While a concept like ‘confidence’ may be classified as an individual-level or psychological outcome, and thus not necessarily central to broader conversations about equity and inclusion, this chapter investigates its political significance.

We begin with background context about our project and methods, and introduce the interpretive framework of epistemic justice and the practice of pedagogical partnership. The majority of our discussion then draws on participant comments to illustrate how partnerships can begin to advance epistemic justice on postsecondary campuses.

Project Background, Research Question, and Methods

This chapter emerges from broader research into two extracurricular pedagogical partnership programs, the Students as Learners and Teachers (SaLT) program at Bryn Mawr and Haverford Colleges in the United States and the Student Partners Program (SPP) at McMaster University in Canada. SaLT invites undergraduate students to take up the paid position of pedagogical consultant to faculty, and student-faculty pairs work in semester-long partnerships to analyze, affirm, and, where appropriate, revise the faculty member's pedagogical approaches in a course as they teach it. Partners explore a wide range of pedagogical issues, such as addressing complex classroom dynamics, facilitating engaged discussion, and designing effective and inclusive assessments (Cook-Sather, 2014). Like SaLT, the SPP engages students as paid partners who work collaboratively with faculty/staff to enhance teaching and learning. One (recently developed) stream of this program is based on the SaLT model, and sees students and faculty working together, with support from a team of student and staff educational developers, to co-design courses and/or analyze classes as they are unfolding. A second, larger stream focuses primarily on student-faculty co-inquiry on Scholarship of Teaching and Learning (SoTL) projects, while additional components of the program establish partnerships focused on curriculum review and quality enhancement, or pair students with institutional grant holders to work on SoTL research or departmental change efforts (Marquis et al., 2016a; Marquis et al., 2017). Students in both programs have access to additional training and support (e.g., connected to course design or research methods) relevant to their projects.

The qualitative methodology of our broader project included research ethics board-approved, in-person and/or online interviews, and invited all students who had engaged in SaLT or SPP and identified as a member of one or more equity-seeking groups (e.g. racialized students, LGBTQ+ students, students from religious minorities, disabled students) to participate. We gathered eight interviews from students at McMaster University and 31 from students at Bryn Mawr and Haverford Colleges. While we do not know for certain why fewer students from McMaster participated, the shorter history of the program and the fact that equity has been a more recent focus may have contributed. Data were transcribed and are being analyzed using constant comparison/grounded theory (Creswell 2006; Glaser & Strauss 1967) to identify themes and trends regarding how partnership programs might contribute to the development of more equitable campuses. Themes are being generated through the first step in the constant comparison method: identifying a phenomenon (Glaser & Strauss, 1967), followed by open coding: “the process of breaking down, examining, comparing, conceptualizing, and categorizing data” (Strauss & Corbin 1990, p. 61).

While operating in unique ways, both SaLT and SPP seek to facilitate inclusion through the recruitment of students from equity-seeking groups and student allies to work with faculty on a range of pedagogical research and classroom projects. Although neither program explicitly prioritizes hiring students from historically marginalized groups, many equity-seeking students have participated in the programs since their inception. Likewise, while our larger research project did not ask student partners questions with epistemology and epistemic justice in mind, Alise began to feel these themes in the data as they resonated with their own experiences (Voronka et al., 2014) as a student from equity-seeking groups and previous reading/writing they had done in the area (de Bie, forthcoming). In keeping with the overarching equity frame of the project and striving to make the research process responsive to the knowledge students bring, we posed for ourselves the following subquestion for exploration: How does the framework of epistemic justice illuminate and situate students' perspectives on the potential of pedagogical partnerships to promote greater equity and inclusion? To address this question, we used narrative analysis, which "seeks to put together the 'big picture' about experiences or events as the participants understand them" (Schutt, 2016, p. 194), to organize statements that fit within the interpretive frame that epistemic justice offers.

Epistemic Justice as an Interpretive Framework

Epistemic justice offers a framework for naming epistemological/knowledge-related mechanisms of harm and its redress. Within this framework, epistemic injustice takes several forms, two of which are of particular relevance to this discussion. **Testimonial injustice** occurs when an identity-related prejudice leads to being wronged in one’s capacity as a knower (Fricker, 2007), such as when students are not seen to have expertise and value as knowers and producers of knowledge, and are only positioned as learners/receivers of the knowledge of others. **Hermeneutical injustice** refers to the inability to make sense of an experience due to a gap in available tools for the interpretation of social meanings. For instance, when students have been marginalized in accessing the language and social behaviours to understand how knowledge creation works in the academy and how to participate in it. Epistemic injustice can cause a loss of confidence in one’s knowledge and capacity as a knower, and results in exclusion from knowledge production and exchange (Fricker, 2007).

As universities are places of knowledge production that carry an ongoing history of determining who counts as a knower, what counts as knowledge, and how knowledge is generated, epistemic justice is a highly relevant concept for the academy. Consequently, scholars have drawn the conceptualization of epistemic justice into literature on pedagogy and higher education (e.g., Godbee, 2017; Gonzales, 2015; Kotzee, 2017), as well as writing on collaborative approaches to teaching, learning, and knowledge production (Campano, Ghiso, LeBlanc & Sánchez, 2016; Glass & Newman, 2015).

Pedagogical Partnership as a Practice

Pedagogical partnership is a set of practices that embrace students and faculty working together to shape their educational environment, approaches, and outcomes

(Bryson, Furlonger, & Rinaldo-Langridge, 2016; Matthews, Cook-Sather, & Healey, 2018). Proposing three underlying premises of student-faculty partnership—respect, reciprocity, and shared responsibility—Cook-Sather et al. (2014) define partnership as "a collaborative, reciprocal process through which all participants have the opportunity to contribute equally, although not necessarily in the same ways, to curricular or pedagogical conceptualization, decision making, implementation, investigation, or analysis" (p. 6-7; see also Healey et al., 2014). Such a process is enacted within 'an ethic of reciprocity': a "process of balanced give-and-take not of commodities but rather of contributions: perspectives, insights, forms of participation" (Cook-Sather & Felten, 2017, p. 181).

Although equity and inclusion are not always explicitly stated goals or outcomes of partnership, repositioning students as partners by definition complicates the power hierarchies that characterize higher education (Bovill et al., 2016; Crawford, 2012; Mihans, Long, & Felten, 2008; Seale, Gibson, Haynes, & Potter, 2015). There appear to be many similarities between partnership approaches and broader initiatives for social justice and inclusion, especially related to epistemic justice and the valuing of diverse knowledges (see Cohen et al., 2013; Cook-Sather, Cohen, & Alter, 2010). Scholars are beginning to articulate how partnerships may be especially significant for students who identify as members of marginalized groups because their knowledge has been consistently undervalued (Cook-Sather, 2018, forthcoming; Cook-Sather & Agu, 2013; Cook-Sather & Luz, 2015).

The practices of pedagogical partnership that we focus on in this discussion include classroom-based partnerships supported by both SaLT and SPP and research-focused partnerships that constitute one strand of partnership work through SPP. For both forms of partnership, student partners were not necessarily majoring in the fields of their faculty partners, and the focus of each partnership was developed by the partners. Student comments presented in the remainder of this discussion illustrate how partnerships of this sort can be an important part of working toward epistemic justice in higher education. In keeping with the spirit of partnership, we endeavor to strike a balance between sharing student perspectives directly through illustrative excerpts and co-authored analysis and reflection.

Project Findings: Promoting Epistemic Justice through Pedagogical Partnership

Below we highlight student perceptions and experiences of how partnerships: (1) create more equitable conceptions of knowing / knowledge that (2) foster the development of epistemic confidence—students' comfort in and excitement about sharing their knowledge.

Creating More Equitable Conceptions of Knowing and Knowledge

Students described a variety of ways in which pedagogical partnerships contribute to creating more equitable conceptualizations of knowledge by shifting dominant understandings of who counts as a knower, how knowledge is produced, and which knowledge is of value.

Who Is a Knower?

Student partners began to affirm their own capacities as knowers. By working in partnership with faculty, they came to see their partners as people who do not know (and should not have to know) everything, and who are not the only knowers in the academy. Rather, faculty are human beings who continue to work and learn over time, just like students:

> Professors aren't just people on a pedestal who have to know everything and can do everything and will do everything. They are just people who are working really hard. …[as a result of the destabilization of power dynamics in partnership work] I feel so much more ownership over my experience as a student. I feel like I've been given a platform to say, "No, I know things and I need things and other people also need things, and I can be in tune with that." (Participant 7)

Faculty contribute to this recognition when they acknowledge that students know things they themselves do not, making it possible for students to begin to claim ownership over their own knowledge and ability to know, as Participant 6 expresses: "For the most part, I felt my perspectives were valued [...], the professors would say, 'Oh I never thought of it that way or never thought to question that.'" Students also unlearn that their contributions are not valuable. Participant 4 described how their experience as a member of a racialized group led to "second guessing" their knowledge and ability to "measure up" to other students. They commented on having to "unlearn" this and to see how "[my] contributions can be valuable." In this way, partnerships recognize (and encourage students to themselves affirm) students as valued knowers.

How Does Knowing Work?

Partnerships also provided students with opportunity to learn about and participate in the process of collaborative knowledge production. Several students talked about how, through partnership, they gained access to some of the 'secrets' of the university, such as insider perspectives on academic norms and "behind-the-scenes" conversations about teaching:

> [I]t's really a good opportunity for the teachers obviously but also for the students getting that insider perspective into academia. I feel like I knew some things already, but if you come into this environment not knowing, like first-generation students, getting that insider perspective [from a professor] is extremely helpful. ...I just feel more confident in understanding why my teachers are doing things the way they are doing them. You are in the middle of an exercise and you're like, "Ha, I see what you are getting at there. I know where you are going with this." And it's like, "Oh, I know something!" (Participant 11)

By their own accounts, having access to this knowledge helped participants learn more effectively, communicate with faculty, and feel more confident negotiating campus:

> I think I learned better. Talking with faculty let me see some of the hidden rules on how assignments were constructed or lectures were conceived or discussions and helped me recognize the deeper learning goals faculty had. Having that info helped me translate assignments or syllabi I was given. It helped me to ask better questions in class and of assignments as well. (Participant 6)

Along with affording students 'insider' knowledge, partnerships also invite students into the coproduction of knowledge, where they learn how knowledge works from participating in its creation. Rather than being relegated to roles as 'receivers' of or ‘informants’ to knowledge generation, students are actively involved in the formation and circulation of meaningful ideas:

> The group was very welcoming and always asking me so what do you think [name] specifically. (Participant 8)
>
> [My partner] was open to feedback and saw it as a collaborative and mutual relationship…I remember one class she had asked me how to think about how to lead a discussion without already having the answers to some of the questions. (Participant 10)

This approach furthers epistemic justice in two ways: First, by offering students language/interpretive resources for understanding the context of knowledge production, a hermeneutical form of epistemic justice (Fricker, 2007) that some scholars would refer to as “de-mystifying” the academy (de Bie & Brown, 2017; Lillis, 2001). Second, by inviting students into knowledge production as active and meaningful contributors, a testimonial form of epistemic justice (Fricker, 2007). Both can support the development of students’ confidence in their knowledge and facilitate greater involvement in knowledge production.

Which Knowledge Has Worth?

A final theme related to developing more equitable conceptions of knowledge involved reevaluations of the worth of particular knowing/knowledge processes, purposes, and products. After participating in partnership, students began to identify the significance of passion, emotion, and early formation of ideas as components of knowledge. Student partners re-evaluated the ‘qualifications’ necessary for knowledge production and participation in partnership. Some argued that qualifications should no longer be based solely on how much education or prior experience someone has, but can also include how passionate they are and what they want to learn from their involvement: "[Participating in partnership] is about passion, like, what are you willing, what are you wanting to learn, what are you wanting to get out of your time at [university]" (Participant 5).

In a similar vein, students described how their feelings were valued in partnership as a legitimate contribution and source of knowledge. As one student partner explained in reference to a conversation she had with Alison in her role as director of SaLT, contributions are not just about disembodied "intellect," but embodied experiential engagement as well:

> Something I have really appreciated about...the partnerships that I have been a part of, is the vulnerability is two sided. I remember saying, "I don't know, Alison, I'm feeling really emotional about it," and you were like, "Why don't you just name that and work from there?" And I was like, "Oh! I can say how I'm feeling and have that not be the only thing that comes out of my mouth. I can work with that and through that and be honest about where I am." (Participant 7)

Participants also described the value of contributing early, still-forming ideas that could be fleshed out collaboratively. When knowledge production feels more 'honest,' partners contribute ideas at initial stages, and have more opportunity to build knowledge together:

> I remember meetings when [my faculty partner] and I would talk, being very fluid and open to interpretation. It was really a philosophical discussion, not an output discussion: you give me feedback, I decide whether I am taking it, end of story. And I think that speaks to the respect that somebody gives a student. It's not like I had a job to do and I did either a good bad or bad job. She was really interested in

> my thinking about the process and about her work and about what it meant. (Participant 10)

These quotes suggest that the way we frame and invite knowledge in academia matters to students. When pedagogical partnerships broaden the interpretive frameworks available for recognizing and assigning worth to knowledge, they embolden students as knowers and advance epistemic justice.

Fostering Epistemic Confidence

In this section below, we share examples of how students came to gain "epistemic confidence" (Fricker, 2007) through their participation in partnership—that is, the courage to generate and use their knowledge.

Gaining Confidence

Like students quoted in other pedagogical partnership literature (e.g., Cook-Sather & Luz, 2015), participants in our research described gaining confidence in their knowledge and ability to know, learn, and contribute as a result of participating in partnership:

> I am more confident in what I know: I know what I experience and there is value in that. Just because I am not a professor doesn't mean I don't know what is going to work for me as a student. …And that's been really helpful in my relationships with other professors. I get to bring up the conversation. I get to be a part of it. I don't have to have all the answers, but I do know more than I thought I did. (Participant 9)

Students described feeling more grounded in what they know, and the value of their knowledge, rather than focusing on the things they do not know. One student noted that

“[I]t’s more helpful to...be prepared to talk about what you do know rather than being caught up in getting all the information” (Participant 5).

Working in a supportive team was also positioned as important to developing this confidence, as was having opportunities to teach others. This suggests there may be something about a “student” role, especially when conceived in a way that comes with little power, that makes students doubt they have knowledge. Having opportunities to transition into a teaching or consultant role, and to see the development of their skills as a researcher, helped students recognize and value what they know: “being able to ... show [a fellow student partner] ...how you do a focus group. ...Things like that have given me more confidence and made me feel like, oh, look, I can do things” (Participant 2). The confidence students gain through working in partnership carries with them to the work they do in other contexts:

> [W]hen I go back to the research project where I’m the most junior, I don’t feel as much insecurity about doing research. So it’s like okay, I feel more like I’m an equal partner in the whole structure than “Oh, she’s just like the lowly grad student” …I guess I’m thinking of myself less as a student and more just as a researcher. (Participant 5)

These quotations underline how pedagogical partnerships can nurture student confidence and encourage the identification of other strategies for boosting self-assurance.

Sharing Knowledge

When students felt heard, valued, and like their ideas were taken seriously, their willingness to share their knowledge(s) with others was positively impacted. As one student partner put it: "I was more aware of my own identity and my own experiences and what I can contribute. I think I felt stronger and more empowered to give my voice. I felt like I had more to contribute in my own classes and just talking to students" (Participant 3). This is especially important for students from equity-seeking groups who, given experiences of epistemic injustice, are often prevented from participating in knowledge exchange (Kotzee, 2017). Participant 2, for example, spoke about how their participation in a partnership program supported their comfort in coming out as queer in heteronormative professional/academic contexts. Another student noted:

> So typically in academia, being a brown Latino from like this working class family with a limited linguistic ... code … those experiences have all shaped also how I interacted with professors in research teams. I always felt, you know, not heard enough or like my ideas were not fully taken seriously or treated as a token almost. ...And for this project, it was very different, right? …I feel my ideas are appreciated, or you know people actually try to understand them, like where I'm coming from here. Like it's a different way I'm received and it impacts my willingness to share my ideas — I think and speak up. (Participant 8)

Students described becoming confident to voice their ideas within the partnership, but also in the classroom, in conversation with other students, and in broader teaching and learning contexts. Having the opportunity to work in partnership helped students gain confidence not only in sharing their own knowledge, but also in acting to encourage the voices of their peers. In one student's words:

> I could use my voice with awareness and become more of an ally and advocate and work to create space by making connections among my peers, or asking for input based on outside conversations we'd had, or just recognizing when some people weren't having an opportunity to speak. Especially in small group

> discussions, where there wasn’t a faculty facilitator within that space, I began to feel I could take on that role. (Participant 6)

In this way, students are involved in extending the epistemic benefits of partnership beyond themselves to other students, and beyond their particular project to other teaching and learning spaces. This recognition carried beyond the classroom, too, to conversations with professors outside of class:

> It also just gave me agency to talk to my professors. I had a professor last semester who would sit there and monotone slides. And the slides weren’t very good. ...We are having small group meetings, and I was talking to one of the groups and they were like, “You should say something.” And I was like, “OK, I can say something. I can do that.” (Participant 11)

One participant also talked about how the experience of having their own voice heard made them want to facilitate this for other students as a future professor. In their mind, this will include using a partnership approach to challenge traditional capitalist labour relations that exploit students and extract their enthusiasm.

> One thing that I learned from having this experience as a student partner is that there is an alternative to this crappy way of doing research assistant work. One that is <u>not</u> about making students not passionate about the project, treating students as just cheap labour… Like this is a lesson that I'm taking … in the future if I ever become a professor ... that's how <u>I</u> would like to engage with my students. If I ever have a research assistant it’s like I want to actually have this person feel meaningful in the project, and feel that they have a voice. (Participant 8)

The perspectives offered here illuminate how individual students, when supported in developing confidence in their knowledge, can make significant contributions to epistemic justice, and equity and inclusion more broadly, in their classrooms and on campus.

Discussion

In this chapter, we have endeavoured to make two central contributions to the growing literature on equity and inclusion in higher education. First, we offer Fricker's (2007) conceptualization of epistemic justice as a generative frame for recognizing the 'epistemological' as highly relevant to equity work in higher education. Secondly, we draw on our participants' experiences of participating in pedagogical partnership programs to suggest that such programs offer one strategy for working toward epistemic forms of inclusion.

Participants' narratives highlight the persistent epistemic inequities that structure higher education: marginalized groups (and students) not taken seriously as knowers; the 'secrets' of university operations unexplained; exploitative relationships with student researchers; exclusion from meaningful participation in knowledge exchange; 'rational' argument as the centrally valued mode of knowing and expressing knowledge; and a focus on knowledge products rather than processes, with narrow evaluation of worth. In contrast, our participants suggest that student-faculty pedagogical partnerships have a range of significant knowledge-related impacts for students from equity-seeking groups. They encourage both testimonial and hermeneutical forms of epistemic justice by positioning students as legitimate knowers and knowledge producers, and facilitating their entry into the processes of knowledge creation and transmission in the academy (a form of cultural navigation; see Strayhorn, 2015).

Perhaps most significantly, participating in partnership can result in greater epistemic confidence for students whose knowledges have been traditionally marginalized. While easily subsumed into individualized, psychological frameworks of ‘self-esteem’ and ‘assertiveness,’ and ignored within broader conversations about equity and inclusion, confidence can be politically significant. As Fricker (2007) argues:

> The various ways in which loss of epistemic confidence might hinder one’s epistemic career are...that it can cause literal loss of knowledge, that it may prevent one from gaining new knowledge, and more generally, that it is likely to stop one gaining certain important epistemic virtues, such as intellectual courage. (p. 136)

When people lack epistemic confidence, they can be prevented from developing and contributing knowledge, and, thus, blocked from being who they could have been. With this in mind, partnerships are not just about “recognizing” or validating that students have knowledge (that was there all along), or inviting students to co-produce new knowledge—both of which focus on equity as a process of ‘adding’ and ‘creating.’ By fostering students’ confidence in their knowledge and capacity as knowers, partnerships also prevent the erosion and loss of knowledge. This frame contributes a sense of urgency to equity and inclusion work, and identifies the consequences of failing to support marginalized students in gaining assurance as knowers.

Moreover, the argument that epistemic confidence relates closely to intellectual courage —perseverance in one’s ideas and knowledge (Fricker, 2007)—points toward the ways in which micro-level experiences of change may contribute to broader social and cultural shifts. By becoming more confident in their knowledge, the participants in our study likewise became more willing to share and advocate for that knowledge, laying the groundwork for new relationships and conversations that may contribute to equity and inclusion on a broader scale. This analysis extends considerations of equity and inclusion that tend to focus on systemic/structural approaches, or on steps and checklists for teaching more inclusively or training inclusive educators (Lawrie et al., 2017; Marquis et al., 2016b; 2016c). Instead, both partnership and epistemic justice encourage us to think about how equity may be advanced through dynamic, relational means (Campano et al., 2016). While structural issues should not be ignored or individuals 'responsibilized' for achieving equity, these relational, confidence-building practices may be an important piece of the puzzle.

In combination, partnership and epistemic justice offer a compelling way of thinking differently about equity and inclusion in higher education. Welcoming students into broader conceptions of knowing that value the experiential, processual, relational, and affective resonates with calls by feminist, critical race, and disability/Mad studies theorists (amongst others) to work toward greater equity and justice by centring diverse knowledges (de Bie & Brown, 2017; Delgado-Bernal, 2002; Jaggar, 1989). These insights also reframe the importance of emotion to equity and inclusion efforts, suggesting that affective features like confidence are essential to epistemic and broader structural justice (Chanda-Gool & Mamas, 2017). While participants in our research regularly drew on the language of ‘confidence,’ overlapping concepts like agency, empowerment, self-efficacy, and self-worth merit further attention in the advancement of epistemic justice on campus (e.g. Habel, 2012).

Of course, partnerships in their fullest sense may not always be possible within classrooms and research contexts (Bovill, 2017), and different examples and approaches might lead to different outcomes. Even within the two programs described here, participants have most certainly had varying experiences, which our necessarily partial data set cannot speak to in full, and it is unclear how quickly confidence may develop or how long a partnership may need to last to have these effects. Partnership is also not easy to enact and maintain; the challenges of stepping meaningfully outside of traditional roles and working within institutional cultures that can feel inhospitable have been widely discussed (Bovill et al., 2016; Marquis, Black, & Healey, 2017). Some have raised concerns about the relative inclusivity of extracurricular partnership opportunities themselves as well (Bovill et al., 2016; Felten et al., 2013). These are important potential limitations or complications that should not be discounted.

Nevertheless, the findings reported here suggest the potential value of continuing to develop and refine partnership practices in higher education, and consider how these overlap with questions of epistemic justice. Drawing on this preliminary research, for instance, faculty might seek to create more equitable conceptions of knowledge in their classrooms and encourage student confidence. This could take the form of introducing students to how knowledge is created in the academy, building opportunities for students to engage in knowledge-generating conversations that matter to them, inviting embodied and affective forms of knowing (Gonzales, 2015), and varying the ways knowledge and ideas get assigned value and evaluated. Extracurricular initiatives such as the partnership programs described here offer ways of building on and extending these practices by engaging students as partners in processes of pedagogical design, conceptualization, and research. While such strategies may be especially significant for students from equity-seeking groups, they also stand to enhance the education of all students.

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Discussion

Building from the articles described above, and extending connections between them, this thesis makes contributions to three primary bodies of work: Disability Studies writing on psycho-emotional disablism, Mad Studies and service user writing on Mad epistemologies, and writing from within Survivor Research on data analysis.

Contributions to the Conceptualization of Psycho-Emotional Disablism: Who We Can *Be*

The writing on psycho-emotional disablism by Carol Thomas (1999, 2007), Donna Reeve (2002, 2004, 2006, 2009, 2012, 2014, 2015ab), and others offers a compatible home for much of this thesis. This concept helps connect the discussion of ethical/epistemic loneliness and other affective and relational harms back to Disability Studies conversations about oppression. The framework of psycho-emotional disablism avoids a tragedy /medicalized focus on the psycho*pathology* of disability (e.g. struggling to adjust to disability as a negative thing) that has been highly criticized by disability communities (Watermeyer & Görgens, 2014), and de-emphasizes the psycho-emotional effects of *impairment* (e.g. effects of being in pain, physical discomfort). Instead, it encourages us to consider the psycho-emotional dimensions of disablism and disability oppression (and we might add sanism here) within social relationships and how they undermine the wellbeing of disabled people (Thomas, 1999, 2007).

Thomas (1999) argues it is important to investigate how disability oppression affects “who we *are*” (p. 46), how we think about ourselves, and who we are prevented from being, rather than exclusively attend to restrictions on what we can *do* (for example, as a result of systemic or structural barriers). She characterizes the impacts of disability oppression as follows:

> The effects of psycho-emotional disablism are often profound: the damage inflicted works along psychological and emotional pathways, impacting negatively on self-esteem, personal confidence and ontological security. Disabled people can be made to feel worthless, useless, of lesser value, ugly, burdensome (Reeve, 2002, 2006). Moreover, impairments may themselves be affected in problematic ways by the impact of psycho-emotional disablism. (Thomas, 2007, p. 72)

Recent scholarship on ableist/sanist microaggressions, while often not explicitly connected to writing on psycho-emotional disablism, similarly describes the psychological impacts of everyday, subtle insults disabled/Mad people experience. These include: anger, embarrassment, invalidation, rejection, isolation, alienation, self-doubt, damaged self-esteem; feeling unimportant, invisible, worthless, dehumanized; and the exhaustion of having to repeatedly test and confirm one's interpretation of confusing encounters with microaggressions ("Did that happen?") and decide how to respond (Gonzales, Davidoff, Nadal, & Yanos, 2015; Goodley, 2018; Keller & Galgay, 2010). Mad Studies literature offers many other examples of sanist microaggressions (Meerai, Abdillahi, & Poole, 2016; Poole et al., 2012); however, with the exception of Liegghio's (2013) work which begins to theorize epistemic violence as a denial of Mad 'being', there is little written on the impact of everyday harm from sanism at the level of ontology or personhood.

The writing on psycho-emotional disablism has been primarily developed and advanced by sociologists (Reeve, 2002, 2004, 2006, 2009, 2012, 2014, 2015ab; Thomas, 1999, 2007), or those offering psychological/psychoanalytic perspectives (Goodley, 2011; Watermeyer, 2012). Consequently, there is a common focus on themes like identity, socialization, subjectivity, social roles, intergroup relations, the gaze/surveillance, and passing/concealment. In response to Watermeyer's (2012) observation that the phenomenon of psycho-emotional disablism could benefit from further theoretical and conceptual anchors, I elaborate on how my work and its engagement with feminist philosophy contribute to our understanding of the psychic-emotional harms of disability oppression: First, my thesis offers several interrelated conceptual anchors (epistemic injustice, ethical loneliness, predictive/normative/ideal expectations, as well as sanism as a way to name Mad-specific oppressions). In doing so, it asks us to also attend to the epistemic and moral properties of psycho-emotional disablism. Second, my work provides examples of how Mad people resist forms of psycho-emotional disablism, and how knowing/knowledge can be developed in the wake of these kinds of harm. It endeavors to avoid reproducing damage-centred research (Tuck, 2009; Tuck & Yang, 2014a) by interrogating the structures that contribute to harm, politicizing emotions rather than pathologizing them, and desiring affirmative ways of relating.[14]

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[14] While I am disinclined towards psycho-emotional disablism's emphasis on the '*psycho*-emotional', I do use this phrasing below in keeping with prior work in this area. My worry is that a focus on the '*psycho*-emotional' may inadvertently slip into reinforcing and pathologizing the 'psychic' as an individual state rather than a socially constituted and political one. This is what is happening with the *bio-psycho-social* theoretical model of 'mental illness', which has been critiqued as practically operating as a bio-bio-bio model (Read, 2005). Read (2005) argues that as opposed to meaningfully attending to the role of social factors like poverty, trauma, or oppression, alongside biological ones, in the construction and experience of distress (as is indicated by the language of bio-psycho-social), psycho-social factors are only being recognized and interpreted biologically. For example, when the consequences of poverty/trauma/oppression are narrowly understood as triggering "an underlying genetic time-bomb" (p. 597). In the context of psycho-emotional disablism, then, my preference is to avoid an inadvertent association with a (bio-bio-bio)-psycho-social model of 'mental illness' by naming embodied impacts of disablism *epistemic-affective*

Offering Additional Conceptual Anchors

Carol Thomas' (1999) introduction of the concept of psycho-emotional disablism was largely prompted by the dominant focus in Disability Studies on structural forms of oppression - those made visible through a social model of disability. Her argument, developed and supported by others in more contemporary writing, was that the psychological fallout of disability oppression was being overlooked. Whynacht (2017b) makes a companion case in the context of anti-psychiatry inflected activism, asserting that critiques of biomedicalization in mental health often ignore and fail to respond to emotional and psychological suffering. A similar rationale led Fricker (2007) to elaborate on the epistemic components of injustice - because they were not being addressed through structural approaches - and Stauffer (2015) to write on ethical loneliness, given the limits of legislative/procedural mechanisms of redress. Although orienting through different theoretical traditions, the conceptualizations of psycho-emotional disablism, epistemic injustice, and ethical loneliness come together in their efforts to notice ontological, affective, and epistemic characteristics and consequences of violence that were largely being ignored or inadequately responded to through structural remedies like the social model of disability, redistribution of material resources, human rights legislation, or reconciliation commissions. They each address the significant role that social relationships play, as does this thesis: those between Mad students and staff/faculty

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(and ontological, moral) harms, and to think of them philosophically and socio-politically, rather than psychologically.

at the university (*Loneliness* paper), service users and providers (*Resistance* paper), and students and faculty partners (*Confidence* paper).

Fricker's (2007) work helps us appreciate how the often-noted psycho-emotional harm of *lost confidence* (Reeve, 2012) and the corresponding impact on "who we *are*" (Thomas, 1999) have epistemic properties. She does this by referring to the work of Sandra Lee Bartky (1990). Bartky (1990), a feminist philosopher, develops a framework of psychological oppression drawing on Frantz Fanon's concept of "psychic alienation", "where the alienation in question consists in 'the estrangement of separating off a person from some of the essential attributes of personhood'" (Bartky, 1990, p. 30 as cited in Fricker, 2007, p. 58). Bartky (1990) further describes this as follows:

> [P]sychological oppression is dehumanizing and depersonalizing; it attacks the person in her personhood. I mean by this that the nature of psychological oppression is such that the oppressor and oppressed alike come to doubt that the oppressed have the capacity to do the sorts of things that only persons can do, to be what persons, in the fullest sense of the term, can be… Alienation in any form causes a rupture within the human person, an estrangement from self... To be a victim of alienation is to have a part of one's being stolen by another. (Bartky, 1990, p. 29, 31-32)

The essential attributes of personhood to which Fricker (2007) attends, via Bartky (1990), are those that recognize (or fail to recognize) someone as a knower and enable (or fail to enable) their participation in knowledge production and exchange. These failures can lead to a loss of *epistemic confidence* and the inability to develop the related virtue of intellectual courage - losses that can prevent someone from knowing what they might have known and being who they might have otherwise been (Fricker, 2007). When we lose or fail to gain epistemic confidence, we are less likely to persevere with our knowledge (such as our interpretations of the world /our experiences that contradict or challenge dominant interpretations) or to develop Mad/disability theories that can imagine otherwise and offer alternative interpretive resources. As a result, our possibilities for being are restricted.

One way epistemic injustice can harm the formation of our sense of self and confidence as a knower is by interfering with a needed process of "steadying the mind" (Williams, 2002, p. 192 as cited in Fricker, 2007, p. 52), which is further described as follows:

> [T]his process of settling the mind is the most basic mechanism whereby we come to be who we are. It settles not only one's mind, but thereby (some basic aspects of) one's identity too. As not only our beliefs and desires but also our opinions and value commitments settle themselves through social dialogue into more or less stable states, so an important dimension of our identity thereby takes shape. (Fricker, 2007, p. 53)

According to Fricker's (2007) interpretation of Williams, in order to steady our mind and sense of who we are, we need to be able to engage in trustful conversation with others where we honestly share our perspectives and are treated as trustworthy and legitimate knowers by those with whom we engage; a sense of self/self as knower is inherently relational.[15] Epistemic injustice excludes us from this participation in knowledge exchange through prejudice against us as speakers, and by undermining our own confidence in truthfully conveying our knowledge. We can see this reflected in the *Loneliness* paper, for example, when I describe lacking an epistemic community where

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[15] The discussion of distrust in the *Resistance* paper introduces an important complexity here: Several participants seem to develop and express a sense of who they are through their opposition to telling the truth or disclosing requested information they believe to be private. In the absence of trustworthy others to whom one can honestly share one's perspectives, Mad people/service users may be finding alternate routes to steadying a sense of self.

my interpretations of harm are confirmed. Without these others, I had no one to help steady my interpretations of myself and the world, leading me to worry that there was something wrong with me for being lonely. While Fricker's (2007) focus on "steadying the mind" may not fully work with a Mad politics (as it potentially excludes those with madness labels that are pathologized for not achieving a state of 'stability'), it is a provocative explanation of how our sense of self/personhood and our ongoing process of becoming is tangled in our relations with others. It also details a set of mechanisms through which epistemic injustice can harm who we *are*, a helpful illustration to inspire future theorizing.[16]

Stauffer (2015) similarly references how abandonment by humanity and associated ethical loneliness remove people from the human relationships that are needed

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[16] This account is in many ways incomplete and potentially inconsistent with Mad Studies in its suggestion that a "steadying of the mind" and stable sense of personhood/self is possible and desirable. There are several expressions of madness that are pathologized specifically because people do not adopt and sustain a singular or consistent sense of who they are (e.g. those labelled with Borderline Personality Disorder, Dissociative Identity Disorder, or with forms of psychoses) – and scholars are calling for us to recognize these alternate states as ways of being/knowing rather than disorder (Molloy, 2015; Redikopp, 2018). My work continues to come up against different philosophical (sociological, psychological) conceptions of the 'self'. Who *are* we as disabled people? How are our philosophies and experiences of personhood informed by violences like disablism? Stauffer (2015) elaborates a helpful logic for addressing these questions:

> In order to discern whether repair is possible, we need to know what repair is. And, in the wake of oppression and violence inflicted on human beings by other human beings, in order to understand what repair is, we need to recognize what breaks selves and worlds. In turn, in order to comprehend what breaks a self or a world, we ought to know something about what selves and worlds are – how they are formed, what sustains them. Finally, we need to understand how to make judgments about what can be repaired, what should be repaired, what cannot be repaired, and, perhaps, what should be left broken. (p. 35)

In order to understand the psychic/emotional harms caused by disablism (and how they might be redressed/repaired), we need to know what breaks selves and worlds (in general, and for disabled people). In order to comprehend what breaks a disabled person's self or a world, we ought to know something about what selves and worlds are for disabled people – how they are formed, what sustains them. We also need to make judgements about what can be done to address disabled people's experiences of harm. The above application of Fricker (2007) and Stauffer (2015) to the notion of psycho-emotional disablism begins to imagine some of these connections – how particular harms work to undermine disabled people's personhood.

to “establish that we share a world in common with others where stable meanings can be created” (p. 89). She provides the example of prisoners living in solitary confinement who lack affirmation of the sounds they hear as real or hallucinations. Their sense of their own perceptions/ knowledge is disrupted by the absence of others. Stauffer (2015) extends this further to suggest that their very identity is unraveled in this isolation because they lack confirmation from others that they live in a shared world. Since Stauffer (2015) views personhood/self/identity as relational, the absence of these relationships damages the possibility of a self. This explanation about a lack of shared meaning helps affirm *why* disablism can cause a disabled/Mad person to feel “out of place” or like “they are not part of the same social world as other people” (Reeve, 2015a, p. 61): They may lack an epistemic community where their experiences of disablism and its psycho-emotional consequences are acknowledged and understood. These examples imbue ‘confidence’ (security, certainty) with philosophical and socio-political significance: While some people are secure in their beliefs/experience of living in a world with shared meaning, others have had this certainty interrupted. While some people are confident that society will provide social conditions that enable their intelligibility (and do not recognize that this belief requires belief), others have had this confidence interrupted (p. 20). Confidence in one’s self/identity, knowledge, intelligibility to others, and existence in a world of shared meanings can be diminished or destroyed by human violence.

Negative messages about disability/madness can also lead to the hermeneutical marginalization of disabled people, and a lack of alternative interpretive resources for understanding disability differently. Although Thomas (2007) does not directly refer to epistemic injustice, she does discuss how the “creation, placement and use of denigrating images of ‘people with impairments’ in public spaces by the non-disabled (Hevey, 1992; Garland-Thomson, 1996, 1997a)” (p. 72) can undermine disabled people’s confidence and emotional wellbeing. The mental health literacy trainings, instructions, and paraphernalia (stickers, certificates, squeeze-toys, stuffies) described in the *Loneliness* paper could similarly be considered public representations of madness that contribute to psycho-emotional harm. They characterize Mad students as risky, in distress, and “out of place” (Reeve, 2015a) in the classroom/campus rather than as legitimate knowers with epistemic pursuits. A lack of hermeneutical resources for understanding disability/madness in more positive ways can lead to a loss of confidence in our knowledge, and this loss of confidence can make it even more difficult to imagine and promote alternative messages. If our capacities as disabled/Mad knowers are undermined, and the knowledge of disability communities (including positive/alternative ideas of disability) is not regarded or supported, we might come to believe or accept common negative constructions of disability (and of ourselves). Fricker (2007) describes this embodiment of external messages as “actually coming to be what one is constructed as being” (p. 166).

Additionally, living in a society full of disparaging representations of disability/madness can contribute to a loss of knowledge and the forgetting or restricting of one’s knowledge. Marks (1999) describes how bearing the ways one is hated can affect a person’s receptivity to new ideas/information and the development of their knowledge.

The example she provides is of people with learning/intellectual disabilities who are, against popular misconception, often actively alert to “society’s pity, hatred and even death wishes towards them” (p. 618). This knowledge can affect their “willingness to be open to ideas in an external world. The messages from the environment that it would be better if you did not exist can be too much to bear” (p. 619). The result is that people can restrict or dampen their development of new knowledge in an effort to not “see, hear or understand what is going on in a hostile world” (Sinason, 1992, p. 38 as cited in Marks, 1999, p. 619); as Rosenberg (2010) writes, the active refusal of “what we cannot bear to know” (p. 251) comes to structure what we do and can know. Similarly, Beresford (2003) affirms how difficult knowledge can be forgotten or too painful to develop:

> Some things that happen to us may be so awful or traumatic that we cannot even remember them (even if sometimes we know that they have happened). ...There are also experiences which have been so painful that people find thinking about them or analysing them very difficult and try to push them away. (p. 43)

These examples urge us to recognize how the psychic/emotional effects of disability oppression are interwoven with epistemic harms: The excruciating psychic/emotional difficulty of experiencing society’s hatred impacts what we can and do know and remember.

Likewise, when contemporary Mad /service user movements focus on transforming ‘lived experience’ into recognized knowledge and expertise (such as through the advancement of peer support as a profession, survivor-led/controlled research, or service user collaboration with healthcare providers), we can inadvertently contribute to psycho-emotional harms - and hermeneutical lacuna - within our own communities by focusing on Mad knowledges as ‘useful’ (Beresford, 2007; Boevink, 2007; Toikko, 2016), and neglecting how they can also emerge in the wake of harm and be difficult to bear. These questions about knowledge as difficult /not 'useful' emerge in the *Loneliness* paper, where loneliness is described /theorized as a way of knowing that arrives in the wake of harm, and as something that can be 'moved' with, as opposed to 'used'. Approaching Mad knowledges on their own terms as they surface through loneliness and other psycho-emotional harms can prompt us to develop understandings of Mad knowledges as (also) difficult (see Pitt & Britzman, 2003), as well as to recognize the significant role Mad/disabled communities can play at aggravating or addressing forms of psychic/affective/ epistemic harm.[17]

Turning to Stauffer's (2015) analysis exposes how repetitive harms can coalesce into a sense of abandonment by society, which builds on Reeve's (2009) preliminary engagement with abandonment as a psycho-emotional harm. While Reeve's (2009) work, through the theorization of Giorgio Agamben, draws attention to the political constitution of a person/citizen at the level of the state, Stauffer's (2015) focus describes

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[17] These concerns about positioning knowledge as (only) 'useful' also apply to the context of pedagogical partnerships described in the *Confidence* paper, and the ways the literature on and practice of 'Students as Partners' can similarly present the knowledge of students, and students from equity-seeking groups in particular, as 'valuable' and an important and useful contribution. That paper explores how to support students in gaining confidence in their knowledge – presumably a positive, useful kind of knowledge that has been otherwise obscured, suppressed, unnoticed. The paper positions epistemic justice as the recognition and facilitation of students' knowledge, rather than, for example, the acknowledgement of (some of) students' knowledge as other than useful - as also difficult (Pitt & Britzman, 2003), maybe even useless (Geddes, 2003).

Although not discussed in the paper, I wonder whether confidence and difficult knowledge are necessarily antithetical. Perhaps we need some level of intellectual courage to say when knowledge is difficult /not useful, and to inform identification of what is needed in response. This discussion of difficult knowledge also points to some of the limits of the notion of 'confidence'. Uncertainty, hesitation, disorientation, cautiousness (a loss of confidence) are legitimate responses to unsettling forms of knowledge, such as those produced and lost through trauma. There is more to be thought here.

abandonment as resulting from multiple ethical lapses by multiple human beings that destroy a cooperatively authored self/world. I find Stauffer’s (2015) work with abandonment a compelling addition to writing on psycho-emotional disablism because it distributes responsibility across humanity/society, understands personhood/‘selves’ as formed in relation with others, and asks us to rethink what we owe each other. Whynacht (2017b) similarly asserts the need to focus on neglect and abandonment (an absence or denial of care) as forms of violence in mental health contexts because they risk being “rendered unintelligible” (p. 59) if we only understand violence as coercive or involuntary treatment. As Stauffer (2015), Reeve (2009), Whynacht (2017b), and the *Loneliness* paper all affirm, abandonment (by multiple human actors in society, by the state, by mental health services, by critical activist groups, by the academy) is a significant form of affective violence that regularly remains hidden and unacknowledged.

Stauffer’s (2015) work, however, does not stop here. Rather than focus on abandonment as the ultimate harm, she explores the condition of ethical loneliness that is produced through abandonment. Those writing on psycho-emotional disablism similarly acknowledge how, “[l]ike any other form of emotional abuse, the effects of psycho-emotional disablism can be cumulative, with past experiences reinforcing the negative impact of current psycho-emotional disablism” (Reeve, 2014, p. 124). One characteristic of ethical loneliness is a lost capacity to trust others:

> [W]hen a human being undergoes a trauma inflicted by another human being, “the world is suddenly a malevolent one, not simply because something bad has happened to the victim but because the world of people is seriously tainted. Trust in others is seriously disturbed.” (Janoff-Bulman, 1992, p. 78 quoted in Stauffer, 2015, p. 77)

This can result in what Reeve (2009) refers to as the psychic harm of existential insecurity - “the uncertainty of not knowing how the next stranger will react” (p. 210), which is evident in the *Loneliness* paper when I describe worrying about when my request for support will next result in referral (away) rather than response. This thesis also explores at length a lost “capacity to expect just treatment or help in the absence of such treatment” (Stauffer, 2015, p. 15). Coming to believe that we only have a right to low expectations is a significant consequence of ableist violence, as is noted in writing on psycho-emotional disablism:

> Somewhere deep inside us is the almost unbearable knowledge that the way the able-bodied world regards us is as much as we have the right to expect. We are not full members of that world, and the vast majority of us can never hope to be. If we think otherwise we are deluding ourselves. (Battye, 1966, p. 8-9, as cited in Reeve, 2004, p. 88)

Oppression can also damage our sense of entitlement (including to just treatment) as disabled people:

> I have argued that social oppression **leads to** emotional invalidation. However, emotional invalidation **also** reproduces social oppression, because it prevents people with learning difficulties from developing a sense of entitlement. Without a sense of entitlement, people with learning difficulties have greater difficulty challenging social oppression. (Marks, 1999, p. 619; emphasis in original)

We might draw on Thompson and Sunol’s (1995) categorization of ‘expectations’ as predictive, normative, and ideal, as I do in the *Resistance* paper, to theorize what is happening in these excerpts. It is understandable that Mad/disabled people might lower our predictive expectations of just treatment in response to prior negative experiences of disablism. If we don’t regularly experience just treatment, then we may come to predict its possibility as low. This is a consequence of disablism – lowering /having low predictive expectations. However, another more devastating psychic/emotional harm of disablism is that we may come to lower our beliefs about what we deserve (normative/moral expectations) or desire (ideal expectations) (Thompson & Sunol, 1995). As the excerpts above indicate, we can come to believe that "the way the able-bodied world regards us is as much as we have the right to expect" (Battye, 1966, p. 8 as cited in Reeve, 2004, p. 88), or be "prevent[ed]... from developing a sense of entitlement" (Marks, 1999, p. 619). This goes beyond expectations based in the probability of them being met – to reflect psychic/moral deterioration of what we believe we are owed.

The *Resistance* paper, through its engagement with feminist philosophy, describes several psychic-emotional harms – including anger, resentment, distrust, and a lack (or lowering) of expectations for just treatment from others. One of the specific contributions of this paper is that it begins to articulate the *moral* harms of disablism, not only the psychic/emotional ones recognized through established conceptualizations of psycho-emotional disablism. While the paper itself describes how participants defend their self-respect (self-worth/dignity as people) and maintain a claim on just treatment (Tessman, 2009), we can imagine that this may not always be what happens; there may be times when psycho-emotional disablism and a resulting lowering/loss of expectations of others wears someone down to the point of losing expectations of themselves as well. When this happens, we can fail to fulfill our potential.

> The world we live in often thinks little of us, and so expects little from us. And if we unconsciously buy into those low expectations, we face the danger of frittering away our time and so failing to reach our potential. That we are pitied, and that people are amazed that we do the mundane things of everyday life, does not mean that we should live pitifully. (Clifton, 2018, p. 226)

We may also lose belief in ourselves as deserving of respect. Mason (1990), for example, offers this painful description of internalized oppression:

> Internalized oppression is not the cause of our mistreatment, it is the result of our mistreatment. It would not exist without the real external oppression that forms the social climate in which we exist. Once oppression has been internalized, little force is needed to keep us submissive. We harbour inside ourselves the pain and the memories, the fears and the confusion, the negative self-images and the low expectations, turning them into weapons with which to re-injure ourselves, every day of our lives. (n.p.)[18]

When we internalize disablism/sanism and view ourselves as inferior, flawed, incapable and lacking the ability to be anything different, we can come to distrust our own moral judgements or autonomous ability to act responsibly (Bartky, 1990; Liebow, 2016). This shows up in the *Loneliness* paper when I write about how lacking an epistemic (and, we might also infer, 'moral') community with a shared sense of meaning contributed to worry that my process of knowing was wrong - disordered, disruptive, inappropriate. I began to doubt my ability to observe, interpret, and know, including my faith in my understanding of 'just treatment' and its guidance for how to act in the world. Although I do not explicitly write about the moral effects of epistemic loneliness in that paper, losing confidence in my knowledge also applies to and erodes confidence in my ethics and normative expectations of myself and others (and losing confidence in my ability to act responsibly/ethically further undermines confidence in my capacities as a knower and in

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[18] The significance of this quote is that it attributes low expectations to internalized oppression, rather than a natural consequence of disability. This contrasts with how Farone and Pickens (2007) frame how the "onset of a mental illness can rupture the emerging sense of self and usually requires intense and painful restructuring of one's beliefs and expectations" (p. 36). They suggest that madness/disability as disorders grounded in individual embodiment and biology inevitably require a revision of one's expectations, rather than Mason's (1990) attribution of lowered expectations to external societal oppression.

knowing well). Messages about Mad people as dangerous/violent, cheating the welfare system, or otherwise depicting us as criminals can similarly lead us to believe we are morally deviant (as Liebow, 2016, describes with regard to racialized people; also see Reeve, 2015a), a perception that is well-enough recognized that mental health self-stigma scales routinely ask a question about whether Mad people perceive themselves as dangerous (Corrigan & Watson, 2002). These sorts of psychic-emotional-moral harms can prevent us from demanding entitlements, holding expectations for just treatment from others, defending our self-respect, affirming ourselves as knowers, and organizing against disablism/sanism. While psycho-emotional disablism literature often comments on disabled people coming to feel like we are worthless (Thomas, 2007), we may also come to feel like we are ‘bad’. This merits further attention. There may be a shift here between believing we do *not* deserve <u>positive</u> treatment to believing that we *do* deserve <u>negative</u> treatment.

To summarize: In this thesis I draw on a range of theoretical frameworks to extend current conceptualizations of psycho-emotional disablism. First, engaging Fricker’s (2007) work helps us attend to the epistemic properties of affective harms, especially those related to a loss of confidence in one’s knowledge/as a knower, an essential attribute of personhood. In taking up Stauffer’s (2015) work, I offer additional anchors for understanding the psychic harms of abandonment, loneliness, being out of place/not existing in the same world, loss of trust in others, and a loss of expectations of just treatment. Lastly, writing on low/loss of expectations asks us to also consider the moral harms that accompany psychic/emotional disablism.

Resistance to Psycho-Emotional Harm

This thesis affirms Thomas' (1999) observation that "disabled people are [not] simply recipients or 'victims' of this disablism. On the contrary, they exercise agency and resist" (p. 47). This exertion of agency can take the form of daily persistence and survival, as well as resistance "fuelled by a belief in the value of the self" (p. 47). Reeve (2002, 2013, 2015a) describes several forms of such resistance, including passing and concealment of difference/impairment, emotion work to manage others' reactions (e.g. labour to educate people about disability), and the creation of alternative theories and perspectives to challenge pathologizing medical perspectives on disability, among others. Each of these strategies operates at the level of the everyday, epistemic/affective, and interpersonal, and outside of dominant structural approaches to addressing injustice.

As another example of everyday resistance, the *Loneliness* paper offers 'moving with loneliness' as both a psychic/emotional effect of epistemic injustice as well as a way of knowing. Rather than treating loneliness as (only) a problem, this analysis explores the possibilities of loneliness. Related literature similarly suggests how loneliness can be restful and creative (Dahlberg, 2007); involve living in confidence and feeling free (Graneheim & Lundman, 2010); and can be a way of not having to cope with working alongside others (Lindgren, Sundbaum, Eriksson, & Graneheim, 2014). As Lindgren et al. (2014) describe it, loneliness may also play a role in working towards change:

> The participants described that loneliness could be beneficial, existentially rewarding, and a driving force in life, because the experiences of loneliness will create a reference to the experience itself, from which desires and striving for future social situations could be shaped. (p. 117)

In response to this complexity, the thesis recognizes the importance of paying attention to psycho-emotional effects of disablism/sanism and interrelated violence, while also examining how these harms can generate forms of resistance, new ways of knowing, and inspiration for justice work. If we accept its provocation, the *Loneliness* paper encourages us to dwell with other forms of psychic/affective/epistemic harms, to move with them, and to see what expressions of knowing or calls for redress emerge. We might, for example, dwell with anger, or uncertainty, and see what comes from them, rather than only identifying them as types of psychic harm.

In contrast to the above discussion of how disabled people can be deeply damaged by low expectations (using them as weapons to re-injure ourselves, believing they are all we have a right to, being blocked from developing a sense of entitlement), the participants quoted in the *Resistance* paper demonstrate how low expectations can also be a form of armour and defense, protecting Mad people from re-injury. Resentment, anger, and distrust expressed when expectations are not (or are predicted to not be) met can help us maintain the belief that we have a right and entitlement to much more. By doing so, they operate like burdened virtues – dispositions /affective states that are the consequence of injustice and difficult to live with, but simultaneously play an important role in struggles for liberation (Tessman, 2005). This suggests it may actually be very dangerous to pathologize or suppress (and cause a loss of confidence in) these so-called negative affective states among marginalized people (or to encourage gratitude, forgiveness, or trust) because this can take away important means of self-protection. We need further ways of preventing the internalization of oppression, and of understanding how low expectations can both cut and shield. We also need to recognize when resistance is not possible, and when harm imposed by other human beings is so destructive of someone's self/personhood and sense of living in a shared world that a harmed person loses hope in their own ability to resist or the possibility of assistance from others (Stauffer, 2015). Social conditions that enable revision and repair are required alongside any enactment of individual agency.

Finally, the *Confidence* paper encourages the cultivation of confidence, and explores how partnerships between students and faculty members can repair psycho-emotional harms like a loss of epistemic confidence. This echoes Reeve's (2014) work: "If psycho-emotional disablism is viewed as a form of invalidation and disrespect, then relationships with others that are validating and respectful can be very healing" (p. 124). The *Loneliness* paper also offers examples of non-clinical, reciprocal relations that helped shift my experience of loneliness, and especially emphasizes the importance of epistemic community. While the writing on psycho-emotional disablism does note the importance of peer support and meeting other disabled people who offer alternative, more positive, views of disability (Reeve, 2015a; Thomas, 1999), an important part of repair that can go unrecognized is having one's observations and interpretations of harmful encounters affirmed by others who recognize the problem and its injustice (Stauffer, 2015). We need knowledge-affirming communities where we share meanings of violence and requirements for a more adequate response, and are treated as knowers and able to engage in the knowledge exchange required for the co-operative authoring of our 'selves'. The formation and support of disability/Mad epistemic communities is thus essential to mediating affective-epistemic harms from disablism. At the same time, we cannot underestimate how difficult it can be for Mad/disabled people who have sustained repetitive forms of everyday violence to heal from these experiences or rebuild worlds in the aftermath, especially when violence continues.

Closing: Taking Emotions Seriously, Towards Desire

The work of this thesis aligns well with the writing on psycho-emotional disablism and pushes it in several different directions: toward the epistemic and moral qualities, additional forms of resistance, and to dwelling with harm to see what emerges. This approach has the potential to avoid the pitfalls of further sedimenting damage-centred research that Tuck (2009) and others encourage us to resist - “research that operates, even benevolently, from a theory of change that establishes harm or injury in order to achieve reparation” (p. 413). First, engagement with the concept of psycho-emotional disablism actively responds to calls from within disability/Mad communities to talk about psychic/emotional experiences rather than ignore them (Reeve, 2002, 2004, 2006, 2009, 2012, 2014, 2015ab; Thomas, 1999, 2007; Whynacht, 2017ab, 2018). When we don’t account for these forms of harm, we further entrench the already existing hermeneutical lacuna (which is all too happy to apply labels of ‘mental illness’ to these experiences) and fail to generate interpretive resources for disabled/Mad people to understand our lives. Whynacht’s (2018) work, for example, describes how her collaborators labelled with borderline personality disorder “have been made to feel as if their sensitivity and expressions of emotion were constantly in/appropriate. ...Emotional expression is the basis on which [her] collaborators have faced violence, exclusion, neglect, invalidation and dismissal" (p. 20).[19] To make matters worse, Whynacht's (2018) collaborators feel like "nowhere people" that are neither supported by medical systems nor activist groups that challenge those systems:

> In addition to being positioned in between diagnostic categories, they found their concerns and experiences were not reflected in scientific discourse about mental health, or in critical scholarly discourse, such as the field of Mad Studies. The former was only concerned with suffering that emerged from broken brains, whereas the latter spent so much time arguing that psychiatry was oppressive that it ignored their emotional suffering all together (Whynacht, 2017). Harm was caused by biomedical neglect and a failure of social constructionist critique to take their suffering seriously or acknowledge the painful reality of those seeking medical care who are turned away. (p. 8-9)

In response, Whynacht (2018) and her collaborators take emotion seriously and attend to the pain that forms in the space *between* us, rather than positioning emotions as housed in individuals. She argues for "emotional justice", referencing the work of Esther Armah to gain recognition of the emotional pain lived (often in silence) by Black women in the aftermath of violence (Whynacht, 2017b). While Whynacht's (2017a, 2018) characterization of Mad Studies feels inconsistent with my encounters with and creation of Mad social and intellectual community,[20] I agree that we need to continue developing

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[19] This suggests that disablist/sanist violence can produce psychic-emotional harms, while these harms can themselves also become sites of further disablist/sanist violence. Barad's (2007) agential realism, however, that informs Whynacht's (2018) analysis, would reject an emphasis on causality or on emotions only mattering when they are generated through or a site of violence. Scholarship on psycho-emotional disablism could further imagine and explore alternative ways of engaging with affective states that do not only present them as a consequence of disablism or in a cause/effect manner.

[20] In the Hamilton Mad Students' Collective group that I founded and facilitated, for example, many members identified as having received BPD labels, which came to feature in the Mad student zine that we created (Mad Pride Hamilton, 2014). In our context, 'Mad Studies' didn't already exist as a thing in our city or on our campus, and so we created Mad social and intellectual community for ourselves in the ways that we needed. Within the context of this Mad Studies space in a post-secondary environment, most of our critique has been regarding our abandonment and neglect within the university - its disability-related accommodation systems, inadequate attempt at providing mental health services, exclusionary curriculum and classrooms - as opposed to a narrow critique of psychiatry. Thus, when Whynacht (2017a) argues that

Mad theories that recognize and attend to emotional pain in nuanced ways. My thesis contributes to this area by exploring how feminist philosophy can support our recognition of psychic/emotional/epistemic/moral harm.

Second, a responsible engagement with disablism/sanism and its affective harms requires us to politicize emotions rather than contribute to their pathologization, and to critically expose the mechanisms /actions through which these harms are produced. Doing so historicizes 'damage' and how it has arrived so that it cannot be positioned as only within us (Tuck, 2009). The *Loneliness* paper, for example, challenges how loneliness has been constructed as a psychological problem and instead maps it as a consequence of societal abandonment. We need theories of change that disrupt the mechanisms of mainstream change theories (e.g. theories that say all that Mad students need is referral to mental health services) and offer an alternative vision of how things could be otherwise.[21]

"[a]s outsiders, those with a BPD diagnosis do not see their experiences reflected in the current composition of mad activism and scholarship in Canada" (p. 54), I worry that this generalization doesn't account for the ways those with BPD labels are actively creating Mad community and Mad Studies as a discipline. As well, to develop her critique, it appears like Whynacht (2017a) is primary citing scholars whose work pre-dates the creation of a discipline formally referred to as Mad Studies in academia and who do not themselves identify as Mad, which obscures a vision and practice of Mad Studies that seeks to privilege inquiry inspired by and grounded in the ways of knowing, being, and doing of members of the consumer/survivor/ex-patient/Mad movement (Menzies, LeFrançois, & Reaume, 2013).

[21] A couple of people hearing my argument that referral is a kind of abandonment have countered, "Yes, but, what about when we <u>want</u> a referral and services are so inadequate that there is nowhere to refer us?" Or, "But didn't you find some services helpful? Isn't there a need for <u>both</u> referral to mainstream services <u>and</u> epistemic support?" In my writing, I am not arguing against the existence of therapeutic services - and do agree these are needed and under-resourced - but that the practice of referral as the best/only response to Mad students and as all that we are owed is entirely inadequate. Our advocacy must expand beyond an argument for more or better clinical services. I also recognize that my ability to pursue and complete graduate studies has been greatly aided by formal supports. However, the most significant contribution of these services to my life has been to offer support when the academy failed to, and to help me process (re)traumatization caused by the university itself.

Third, taking Stauffer's (2015) lead, paying attention to harm itself, as opposed to procedural mechanisms of response (e.g. hate crime legislation, disability awareness campaigns, legal rights; the forms of reparation to which Tuck [2009] refers), can encourage alternative understandings of and responses to violence to emerge, including those that re-examine what we owe each other. When we, within our own Mad/disabled communities, dwell with harm, we can recognize and affirm how our bodyminds are not the problem (in the *Loneliness* paper - loneliness, and me as someone living loneliness, are not the problem), and that emotions that might be considered a form of damage (e.g. distrust, anger, loneliness) can be engaged with, resisted, and politicized differently. They can teach us what we want from justice and what justice would require.

Fourth, the approach to harm developed through this thesis begins to encourage an orientation towards desire, which Eve Tuck (2009) describes (in contrast to damage-focused research) as follows:

> [E]ven when communities are broken and conquered, they are so much more than that - so much more that this incomplete story is an act of aggression… Desire, yes, accounts for the loss and despair, but also the hope, the visions, the wisdom of lived lives and communities... Desire is about longing, about a present that is enriched by both the past and the future... Exponentially generative, engaged, engorged, desire is not mere wanting but our informed seeking. Desire is both the part of us that *hankers* for the desired and at the same time the part that learns to desire. It is closely tied to, or may even be, our wisdom. (p. 416-418)

Referring to Jameson's work, Tuck and Yang (2014a) also write that "desire [is] a counterlogic to the history that hurts. Desire invites the ghosts that history wants exorcised, and compels us to imagine the possible in what was written as impossible; desire is haunted" (p. 235). In this thesis, loneliness is explored as both a form of harm and, when moved with as a companion species, a kind of longing and desire that can bring about alternative relationships and possibilities for epistemic community. This is perhaps most evident in the use of the language of ‘discrepancy’ (Stein & Tuval-Mashiach, 2015) as a way to differentiate between what exists and what could exist - what I long for and seek to create - an approach that could be adopted for other forms of harm. In the *Resistance* paper, desire underlines participants’ normative and ideal expectations - what they long for and demand in terms of just treatment. The *Confidence* paper reveals how the cultivation of confidence plays an important role in facilitating desire and students’ courage to seek change. This focus on desire, however, does not mean we only tell ‘good’ or hopeful stories; we also need to be aware and responsible for how harm is represented (Fine, Weis, Weseen, & Wong, 2003). Fine, Weis, Weseen, and Wong (2003) encourage “telling many kinds of stories, attached always to history, larger structures, and social forces, offered neither to glamorize nor to pathologize, but to re-view what has been, to re-imagine what could be…” (p. 199). If we respond to knowledges we form in the wake and negotiation of harm on their own terms, they can offer visions of what could be otherwise - visions haunted by the experiences of what was not otherwise.

Contributions to Mad Epistemologies: What and How We Can Know

This section situates the contributions of the thesis within wider conversations about Mad epistemologies. Rather than a more traditional discussion that pulls together and emphasizes the contributions of the three above articles, I use the ‘egg salad’ of the thesis as a starting point for the generation and development of some new ideas, drawing in several additional sources of evidence to do so. As discussed further below, common articulations of Mad 'experience' position it as separable from, rather than constituting, who we are. In contrast, this thesis begins to draw attention to how Mad ontology/epistemology are entangled, constitutive, and generated in action/doing/living. Additionally, the thesis and discussion shift from a focus on 'mental illness'/service user experience as the basis of experiential knowledge to a focus on 'experience' constituted through harm. Understanding 'experience' in this way can encourage us to carefully and ethically recognize, affirm, and develop Mad onto-epistemologies on their own terms.

'Lived Experience' & Being/Knowing Entanglements

Mad/service user knowledge is commonly characterized through a metaphor of proximity, which has been inherited from positivist science and its privileging of neutrality/objectivity through distance (Beresford, 2003; Rose, 2009; Russo, 2012). Oftentimes, our efforts to describe how service user knowledge is different from these scientific standards, and yet equally valuable, results in characterizing Mad knowledge within traditional epistemologies instead of dismantling these exclusive foundations. This frame of proximity/distance also tends to present 'experience' as an unmediated foundation of knowledge - we 'have' an experience, and then generate meaning from it to produce knowledge. For example, Toikko's (2016) discussion of how service users becoming "experts by experience" suggests that one step involves gaining 'distance' from and reflecting on experience, and translating emotions into an abstract form:

> The distance from difficult experiences gives service users more space to think about

> their situations and allows them to reflect on their experiences. Since the majority of mental health problems are deeply emotional, it is important to translate them into an abstract form. The ability to describe one's experiences can be viewed as a precondition for becoming an expert by experience. Creating such an abstraction gives an individual the opportunity to analyze his or her experiences without emotional restrictions. ...Many of the interviewees emphasized that the passage of time was a key element in achieving emotional distance from their difficult experiences. (p. 299-300)

This analysis troublingly values rationality, diminishes the legitimacy of emotional ways of knowing, and creates a linear progress narrative, where we get 'better' at interpreting our experiences as our emotionality recedes.

Beresford's (2003) analysis, in juxtaposition to how providers/academics/experts know (through removal, third-hand rather than first-hand experience), affirms nearness/immediacy/insider relation to experience as a key component of service user knowledge. His writing suggests that service users/survivors have privileged, transparent access to the understanding and interpretation of our experiences:

> [P]eople's own interpretations of their experience can result in the most authentic knowledge because experience and its interpretation can be closest to each other. (p. 41)
>
> [P]eople's accounts of their experience are most powerful when they are most immediate. They can still have a value as knowledge later, but then they may also tell us about what such experience later came to mean for them and their lives. (p. 43)
>
> User-controlled research is working from the inside and going out whereas most research is people looking at something from the outside and going in, so the perspective is very different in user-led research because it starts from the inside. (mental health service user/survivor quoted in Beresford, 2007, p. 336)

While approaching from alternate directions, these perspectives share the following commonalities: There is an 'experience' (something that has happened to a person, something they have lived through) and there is its interpretation, which is not static, but can change over time. This interpretation is either improved by greater distance/more space/ability to view from the outside/time passing or from interpretation generated more closely to the experience itself. In either case, ‘experience’ and its ‘interpretation’ develop in a linear manner (‘experience’ occurs first, then ‘interpretation’), and exist outside of a social context. Individual people are presented as producing an authentic account of what they have lived based on their proximity to the experience, unaffected by other factors; essentially, they have a clear, and undistorted, view. This metaphorical emphasis on unobstructed vision is reinforced in writing on service user involvement in healthcare research, where our contribution is described as “enabl[ing healthcare/academic researchers] to see further and wider than the researchers had the capacity to do on their own. ...bring[ing] forward what the research fellow initially had not seen” (Mjøsund et al., 2016, p. 275).

Scott’s (1991) canonical writing on ‘experience’ offers a different take, whereby rather than a person ‘having’ an ‘experience’ and then generating meaning/interpretation, the person is constituted by experiences and their meanings. In a Mad Studies context, this would mean our Mad ‘knowledge’ is not simply created through experience, but is developed by seeking to explain why we have the experiences we do, why they are interpreted the way they are, how these experiences come to constitute us, and how our shifting interpretations change how we remember and experience an experience. As Scott (1991) elaborates:

> It is not individuals who have experiences, but subjects who are constituted through experience. Experience in this definition then becomes not the origin of our explanation, not the authoritative (because seen or felt) evidence that grounds what is known, but rather that which we seek to explain, that about which

> knowledge is produced. To think about experience in this way is to historicize it as well as to historicize the identities it produces. (p. 779-780)

Rather than taking ‘experience’ (or any other category) as a foundational ground from which knowledge is built, Scott (1991) encourages us to “tur[n] attention instead to the history of foundationalist concepts themselves” (p. 796) - such as experience, madness, identity - and how they have come to operate as foundational. Within this orientation, proximity or distance from ‘experience’ is not at issue because we do not view/interpret our experiences from elsewhere - rather, we are constituted by them; we are ‘in’ them and ‘of’ them, not ‘viewing’ them. As Madden and Speed (2017) similarly affirm in the context of patient engagement in mental health, “[n]arratives of experience are structured, performative, means of understanding, and persuasion, not an unproblematic means of transparent access to truth” (p. 5).

Scott’s (1991) orientation to ‘experience’ shows up in the *Loneliness* paper in this way: Rather than say I ‘have’ an experience of loneliness, and I am building knowledge about loneliness from these ‘experiences’, and rather than think of myself as more or less lonely - closer to or more distant from loneliness - the paper investigates how I have come to be constituted by loneliness. It seeks to explain what it might mean to have an ‘experience’ of loneliness - examining mainstream notions that present loneliness as a problem, a fault of the individual, and considering epistemic forms of loneliness that position loneliness as a condition resulting from abandonment by society. An ‘experience’ of loneliness is what I seek to explain, and about which knowledge is produced, and these different ways of coming to think about loneliness, reconstitute my ‘experiences’ of it; my affective states/embodied encounters become sites of inquiry and investigation rather than already known or knowable in simple and straightforward ways. Similarly, the *Confidence* paper emphasizes how knowledge in the academy is constructed, and how facilitating a marginalized student's capacity to participate in this production requires de-mystifying how and why these processes work the way they do. Although these were not explicit and intentional drivers in the creation of that paper, the work might be read as resisting an interpretation of 'experience' as unmediated - instead exploring how pedagogical partnerships can function within the academy in such a way that epistemic confidence is generated, and 'experienced'. Ultimately, this politicized reconstitution of my 'experiences' (of loneliness or other states) asks us to examine how we are constituted through affective-epistemic harms (and efforts to mediate and address them), and has the potential to encourage confidence in my (evolving, iterative) knowledge/knowing when the process of inquiry and re-creation mediates more disparaging interpretations.[22]

Scott's (1991) work, which challenges the dominant metaphorical conception of knowledge as visible/viewable (gained through vision and the observation of objects), helps us question the 'foundations' upon which conversations about Mad knowledge are being built - those related to experience and the proximity/distance of our perspective. Perhaps instead, Mad knowledges/knowing are formed in the ongoing reconstitution of ourselves and our relations with each other. Barad's (2007) development of a

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[22] I am not suggesting that "the only disability in life is a bad attitude", or that it is always possible or easy to reconstitute our experiences (and ourselves). I am saying this reconstitution was sweaty in the way Ahmed (2017) suggests, is ongoing, and required a 13-page acknowledgements section. In this way, reconstitution of my 'experiences' echoes Stauffer's (2015) discussion of revision after violence – how we go about rebuilding a self and world after we have been abandoned.

posthumanist, agential realist intervention moves beyond a critique of foundational categories to open up other ways of moving/knowing in the world. In particular, encouraging us to recognize how ontology-ethics-epistemology (or onto-ethico-epistemologies) are entangled rather than separable, Barad (2007) writes:

> [T]he locus of knowledge is presumed to be never too far removed from the human, and so the democratizing move is to invite nonhuman entities into our sociality. But the nature-culture dualism is not undermined by inviting everything into one category (man's, yet again). The point of challenging traditional epistemologies is not merely to welcome females, slaves, children, animals, and other dispossessed Others (exiled from the land of knowers by Aristotle more than two millennia ago) into the fold of knowers but to better account for the ontology of knowing.
>
> ...They [brittlestars - a kind of sea organism] challenge our Cartesian habits of mind, breaking down the usual visual metaphors for knowing along with its optics of mediated sight. Knowledge making is not a mediated activity, despite the common refrain to the contrary. Knowing is a direct material engagement, a practice of intra-acting with the world as part of the world in its dynamic material configuring, its ongoing articulation. The entangled practices of knowing and being are material practices. (p. 378)[23]

In this excerpt, as applied to Mad Studies and this thesis, Barad's (2007) work can explain how the point of Mad Studies/survivor research challenging traditional psychiatric epistemologies through the generation of experiential /Mad knowledge ought not be just an inclusion of Mad people into the fold of knowers, such as by legitimizing

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[23] Alongside her articulation of the inseparability of onto-epistem-ology, where "knowing is material practice of engagement as part of the world in its differential becoming" (p. 89), Barad's (2007) work describes being/knowing as inherently ethical matters (ethico-onto-epistem-ology). As she writes:

> Knowing is a specific engagement of the world where part of the world becomes differentially intelligible to another part of the world in its differential accountability to and for that of which it is a part. ...Knowing requires differential accountability to what matters and is excluded from mattering. (p. 379-380)

Barad (2007) introduces the phenomenon and methodology of "diffraction" as an "ethico-onto-epistemological matter" (p. 381). In contrast to "reflection" and its focus on visual metaphors, mirroring and sameness, and assumptions of subject/object separability, diffraction recognizes the entanglement of difference. It can analyze how boundaries come to be created, rather than presuming binaries in advance.

Mad knowledges as different from but complementary to psychiatric knowledges. To do so does not challenge mainstream foundations of epistemology – it just 'welcomes' Mad people into existing arrangements, as Scott (1991) also resists. Instead, Barad (2007) argues that "the point of challenging traditional epistemologies is... to better account for the ontology of knowing" (p. 378). Rather than argue that Mad epistemologies are legitimate by changing the criteria of validity (e.g. proximity to experience as valuable rather than evidence of bad science), her approach challenges an entire construction of epistemology as distinct from ontology; knowing occurs through intra-acting with the world (that is, not treating phenomena as separable as would be the case in '*inter*-acting') – knowing is an engagement with being. This thesis similarly describes and understands Mad knowledge as generated in action/doing/living - or intra-actions with the world. It begins to draw our attention to how Mad ontology/epistemology collapse into each other – and how this may be an important direction for future exploration.[24] One contribution this orientation makes, which may be especially significant for Mad knowledges, is that it does not reinforce a hierarchical binary between the mind/knowing/epistemology and the body/doing/ontology - one that has historically dismissed Mad and other marginalized people as 'bodies' without minds (Voronka, 2015).

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[24] It is not that this understanding is 'new' to Mad people, or other groups marginalized by the dominance of Western epistemologies. Our knowing/knowledge has always been generated through living our lives (as the feminist slogan 'the personal is political' suggests). The description of our knowledge as first hand/direct/near to 'experience', however, is increasingly prominent right now in an effort to promote its legitimacy within healthcare systems. The work of Scott (1991), Barad (2007) and others is to suggest that a demand for inclusion is a dangerous strategy. We would be much better served to inquire into our own ways of Mad being/knowing than to seek an explanatory framework that compares/contrasts our expertise against traditional psychiatric epistemological frameworks.

The emphasis on living/experimenting/trying/acting as knowing is evident in varied ways throughout the thesis. Some scholars seem to locate Mad/service user knowledge in the mind, as is expressed by Toikko (2016) above, and gestured at by Beresford (2013) when he writes: “There is a massive body of unrecorded and hidden service user knowledge, which remains alive in the memories of service users” (p. 191). The *Loneliness* and *Resistance* papers, in contrast, suggest that this knowledge is not only ‘alive’ (and lost) at the level of consciousness and cognitive ‘memory’, but also in tacit embodied memory and ways of being - our emotions, dispositions, actions, ways of relating, ethics. We can pay attention for it in the wake of harm, in our affective states and how they compel us to act and relate, in our everyday resistance and labour/work to exist, in ‘quiet’ data that we worry others will disregard, in our moral talk and the ways we dis/engage in relationships with others. Without attention to ontology/ways of being, these expressions of knowing might be missed. Embodied knowledge is not ‘only’ embodied, it is also conceptual, as Ahmed’s (2017) work emphasizes in its discussion of how thinking/action happen together:

> [I]n working to transform institutions, we generate knowledge about them. Concepts are at work in how we work, whatever it is that we do. We need to work out, sometimes, what these concepts are (what we are thinking when we are doing, or what doing is thinking) because concepts can be murky as background assumptions. But that working out is precisely not bringing a concept in from the outside (or from above): concepts are in the worlds we are in. (p. 13)

This helps confront one of the problems Voronka (2015) identifies with regard to peer-based knowledges from ‘lived experience’: recognizing peers only as contributing knowledge from embodiment, ignoring how we also develop conceptual and analytical insights from our embodied and political engagements with the world. Mad knowledge is not ‘only’ embodied or ontological – it is the entanglement of ontology-epistemology and produced by doing/working.

The thesis illustrates how Mad knowledges are intimately tied to Mad ontologies/ways of being. Jensen’s (2004) work refers to this as epistemology “*collaps[ing] into* ontology” (Jensen, 2004, p. 248; emphasis in original) - when “activities such as observing or representing [traditionally understood as epistemology] are viewed as specific *ways of* intervening and constructing [ontology]” (p. 248). That is, “[k]nowing (and thinking about knowing) are turned into *particular styles and methods* for connecting and cooperating with specific actors (human and otherwise)—thus shaping reality, or *doing* practical ontology” (p. 248; emphasis in original). In this approach, epistemology is reformulated as activities that contribute to “(re)building the world” (p. 248). We inhabit worlds - we are part of the world and it becomes part of us; we do not just occupy the world and ‘look’ at it (Muir & McGrath, 2018).

Within the context of this thesis, loneliness is conceptualized as a social condition produced through the abandonment of Mad people as knowers. It is both a form of harm /what harm is (ontology), as well as, when we ‘move with loneliness’ (epistemology), a way of knowing (about harm). Rather than affirm Toikko’s (2016) emphasis on valuing abstractions and distance from emotions for experts by experience, the *Loneliness* paper encourages us to engage with emotions as important to Mad knowing processes. When we ‘move with loneliness’ and use it as a way of knowing, we are not only thinking about and representing loneliness as it is, but also interacting with loneliness, and reconstructing what it is and what alternative ways of relating might look like in the world. Ahmed (2017) refers to this type of engagement as "think[ing] on our feet":

> When we are trying to intervene in the reproduction of power, we have to think differently; we have to think on our feet. I suspect an academic illusion (and perhaps even an academic conceit) is that theory is what we do, because we can afford to withdraw from the requirement to act quickly; time for contemplation is assumed as time away from action. ...I have learned from diversity practitioners that strategy can be not only thought in action but thought sharpened by action. (p. 93-94)

In contrast to developing knowledge through reflection on distant experiences or contemplative time 'away' from doing/living/action, 'moving' with loneliness is a way of "think[ing] on our feet". Revision is about the past echoing differently (Stauffer, 2015). It's not necessarily about the past being further away /more past - but about how I am (re)constituted by the past in the present. This type of onto-epistemological engagement and reconstitution could be further explored in relation to any other psychic/emotional/epistemic form of harm.

Similarly, the *Resistance* paper illustrates how service users are actively intervening in the world, their engagements with service providers, and their self-conceptions through lived knowledge (onto-epistemology). Knowing what is likely to occur (predictive expectations of unjust treatment) manifests in resistant styles and manners of relating to service providers that reshape those encounters (lowering expectations, self-reliance, distrust). 'Expectations' (based in embodied knowledge of probable, right, desired outcomes) are a way of connecting with others and fashioning reality - a form of self-protection, an approach to boundaries in relationships, and a method for maintaining a claim on just treatment and (re)building a more just world.

Participants are expressing knowing through doing in their encounters with service providers and within spaces of possible support, which then further sharpens their predictive expectations and affective responses. This is a different way of thinking about ethics than those typically put forward by social work professional codes, which focus on teaching ethics to students so that when they enter an encounter with a service user, they can ‘apply’ those ethics through individual decision-making and expertise. In this view, service users are minimally involved in the doing/knowing of ethics - they have ethics ‘done’ to them as a matter of so-called ‘protection’ (Doel et al., 2009; O’Leary, Tsui, & Ruch, 2012). The *Resistance* paper, on the other hand, demonstrates how service users are actively involved in negotiating their encounters with others and generating standards of good treatment.[25]

Redefining ‘Lived Experience’ as Experience of Harm

As we develop Mad onto-epistemologies, we need to critically engage with the challenges of claiming ‘experience’ as the foundation of our knowledge, which may require redefining what ‘experience’ means (Scott, 1991). As Cresswell and Spandler (2016) write:

> Mad Studies attempts to redefine the experience of ‘mental illness’ and reclaim madness as a political identity… While such social constructionism is potentially radical, it does beg the question of what constitutes the ‘madness’ – the original experience – which we then use as a basis for political action. (p. 359)

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[25] The challenge of this suggestion that Mad ontology collapses into epistemology is that it complicates our current activism strategies for legitimizing peer/Mad/service user knowledges in healthcare systems. There may still be (moments where there is) a concrete, everyday utility for arguing that our knowledges are different from but complementary to psychiatric knowledge, within traditional frames of reference that separate ontology and epistemology – even when this approach is not theoretically defensible and implicates us in the epistemic injustice these strategies endeavor to address.

We also need strategies that dismantle and/or operate outside of traditional epistemological structures rather than simply arguing for our inclusion within the frameworks that constituted us as irrational, disordered non-knowers in the first place. Attending to practical ontology and the entanglement rather than hierarchical binary of ontology-epistemology-ethics may be one promising avenue to explore. This approach may, for example, lead to honing alternative social movement strategies, where instead of tactics that are based on teaching people better 'knowledge' about madness (e.g. that madness is socially constructed, service user perspectives on madness) that try to shift our thinking, we emphasize different ways of being/relating.

This thesis moves away from describing Mad knowledge as derived from experiences of 'madness' (as a biochemical illness, as socially constructed, as a sociomaterial phenomenon) or efforts to obtain help /use services to recover from this experience, which is a commonly held definition of service user knowledge:

> Service users' knowledge alone is defined by and primarily based on direct experience of madness and distress and associated policy and provision from the receiving end. It grows out of their personal and collective experience of policy, practice and services. (Beresford & Boxall, 2013, p. 70)

There is no encounter with madness that offers an unmediated foundation upon which we build experiences. The physiological /psychic /cultural /spiritual /material existence of altered and extreme states or profound distress and suffering take place in a social context that regularly frames these experiences as abnormal, thus contributing to the 'experiences' we have. When only understood as developing from madness or interactions with service use/policy, 'experience' is more likely to be decontextualized as an individual's contemporary interpretation of something that happened (an experience they ‘had’). This can obscure how we are constituted by our experiences and have developed collective and shared (rather than only ‘personal’) meanings in intra-action with each other over generations of Mad history. A focus on madness/service use as the origin of ‘experience’ is also more likely to encourage the transformation of experience into ‘useful’ knowledge for improving psychiatric systems, and to ignore how Mad knowledges can be difficult, resist easy implementation, and call for the dismantling of traditional epistemological structures rather than a place within them.

Instead, given the widespread entrenchment and use of the notion of ‘experience’, and the futility of trying to abandon it, I am inclined to follow Scott’s (1991) encouragement to “redefine its meaning” (p. 797). Over the course of writing this thesis, I have begun thinking about Mad knowing /knowledge as generated through ‘experiences’ of harm: through the affects of epistemic injustice; ethical/epistemic loneliness produced when one has been abandoned by humanity and unheard in requests for help; through the work of survival and resistance within this context of violence; through all of the other intersections of harm that Mad people experience. This is especially present in the *Loneliness* paper’s emphasis on knowing through the harm of abandonment/loneliness, and in the *Resistance* paper, where knowing and moral talk occur in the strategies participants devise to resist forms of harm resulting from discrimination/prejudice and unmet expectations of just treatment.

Stauffer’s (2015) articulation of a double harm as described in the *Loneliness* paper (being abandoned + not being heard = a condition of ethical loneliness) is echoed in earlier writing by Cresswell (2005):

> Self-harm survivor knowledge, to sum up, may be viewed as structured in terms of a perceived double violation. In violation #1, the survivor is survivor of the gendered trauma of childhood [for example, sexual abuse/assault]; in violation #2 the survivor is survivor of those medical modes of intervention which are conventionally presented as treatments. (p. 1675)

This emphasis on harm, as opposed to a 'mental illness' per se, helps direct our attention to the forms of violence (e.g. oppression, poverty, trauma, abandonment by society) that contribute to harm and associated distress, how distress /madness become sites of violence that cause further harm, as well as the ways Mad people are not heard in our complexity, including in relation to the harms we endure, when seeking to express or receive support in difficult times.[26] A focus on harm also attends to its psycho-emotional qualities (such as loneliness, loss of confidence, loss of expectations of just treatment), and emergent Mad ways of knowing that arrive through harm. In addition to knowing through experiences of harm, Mad knowing is also generated through 'experiences' of 'diversity work' - "the work we do when we do not quite inhabit the norms of an institution" (Ahmed, 2017, p. 91). This includes the work Mad people/service users do to survive in the academy, service systems, relationships, and broader society in a context where we do not belong (due to being constructed as different and undesirable), are unintelligible, and not seen as legitimate knowers, as well as our efforts to create Mad community, Mad theory, Mad knowledge.

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[26] Mad people's experiences of violence are frequently unheard by psychiatric systems, as well as in other social relationships. This is especially the case in contexts where mental illness is understood as a form of biological disorder/pathology, rather than caused or amplified by violence or leading to greater exposure to violence. A failure to hear also occurs when Mad people tell stories of difference and discrimination, rather than the expected and apprehendable stories of illness and recovery.

This understanding of Mad experience as generated through harm encourages us to investigate how this occurs and how we come to be constituted through 'experiences' defined in this way. 'Experience' as harm "is at once always already an interpretation and something that needs to be interpreted" (Scott, 1991, p. 797). Furthermore, if Mad knowledges often develop in the wake of violence through experiences of harm, then how we conceptualize violence matters. These conceptualizations impact how we discern, comprehend, become constituted by, and revise our experiences of harm, how we come to recognize (or not) Mad forms of knowing that emerge in the wake of harm, and how we articulate our responsibilities to easing and addressing these harms. We might ask ourselves, what sorts of Mad knowledges/ways of knowing become perceptible/audible (or imperceptible/inaudible) through a particular conception of violence, and how do they call for justice? What might other understandings of violence enable us to notice about how our knowledges develop and emerge? Applied to this thesis, the conceptualizations of violence examined here (epistemic injustice, ethical loneliness, psycho-emotional disablism) contributed to specific understandings of harm (epistemic abandonment and loneliness, loss of expectations, loss of confidence), a recognition of specific forms of emergent knowing (moving with loneliness, resistance, onto-epistemologies), and specific visions for revision (alternate ways of relating, synthesis of service user ethics, bolstering of confidence, techniques for Survivor Analysis).

This revised emphasis on Mad experience as emerging through harm does not do away with our encounters with difference, suffering, emotion, or extreme states that get called 'madness', but draws on them as situated within a wider context where they are not positively received. For example, Molloy (2015), writing about Dissociative Identity Disorder, argues that “no compelling reason exists to privilege a cohesive narrative… If dissociative ways of knowing were valued differently, perhaps fewer people would land in spaces meant to heal them by ‘integrating’ them” (p. 463, 473). Framing ‘experience’ through harm would not eliminate the experience of dissociation, but would understand and re-interpret it in a context where dissociation is often actively intruded on with a goal of integration.

Voronka (2015) ends her thesis - a critical genealogy of peer support work - with a proposal that similarly encourages us to abandon the use of an experiential knowledge of pain or mental illness. Instead, she encourages us to operate as Mad informants with a politics of how we have been made Other and strategies for dismantling oppressive systems:

> I propose that to imagine otherwise requires a shift: from abandoning our participation as peer informants, towards including ourselves into the fold as ‘mad informants.’ This means politicizing rather than personalizing the informant role. We will always be informants when brought into the role of representing: yet as peer informants, we currently must check our political “guns and stones” at the door (Said, 1989, p. 210). As mad informants, we would no longer be brought in to represent others, but rather be representing critiques of the methods in which we are made Other. As an alternative, the mad informant would look otherwise: we would use our experiential knowledge to act on dismantling oppressive systemic interlocking practices of subjection rather than to speak of the pain that distress and discrimination causes us. (p. 367)

Instead of publicly telling stories of pain and damage to demand compensation for injury, we can draw on our intimate experiential knowledge of the operations of power and production of harm to expose and challenge these systems. The difference here is between a focus on decontextualized suffering (pain, damage), which risks being interpreted individually/psychologically, and ‘harm’ as produced through systems of human violence, dehumanization, and neglect. We can use our knowledge of the mechanisms that produce harm to create private and protected spaces within our own communities to develop capacities to heal from the forms of harm we regularly encounter, and to desire alternative worlds. In this thesis, my role as a Mad informant has been to describe the infrastructure that festers hermeneutical injustices and contributes to the condition of epistemic loneliness and other psychic-affective harms; instead of elaborating the personal details of my specific encounters with neglect and abandonment, I wrote about institutional failures, and saved the everyday spirals of despair for my friends. Ultimately, this thesis invites us to listen for (and otherwise perceive) Mad knowledges as they materialize, and to tend to what they need - on their own terms. This call is echoed by other Mad Studies scholars who urge us to focus on the generation and development of Mad knowledge (within and owned by survivor communities) as a primary concern (Beresford, 2016; Sweeney, 2016).

Closing: Epistemologies in the Mad Studies Classroom

This discussion accompanies us to the Mad Studies classroom. What does it look like to draw on Mad onto-epistemologies and ethics to teach Mad Studies, and to dismantle traditional epistemologies that present ontology and epistemology in hierarchical binaries? What other activities might encourage students to know through being/doing, rather than removed reflection on doing? How do we invite - in an ethical and politicized way - the sharing of ‘lived experience’ in class discussion, assignments, and through our own disclosure in a way that explores how it constitutes us and what it is without reinforcing foundationalist notions that we have unmediated, transparent access to what we have lived? How do we manage - pedagogically - engagements with Mad knowledges as based in harm? If we too easily assume that including Mad knowledge - in research, teaching, the classroom - is necessarily good, progressive, transformative, we will miss examining complexities, and what it might mean to engage with this knowledge responsibly. These questions have messed around with (my thoughts on) what I'm trying to do when I teach Mad Studies. The *Loneliness* paper offers some preliminary ideas of how we might move with loneliness as a co-instructor in our teaching, and the *Confidence* paper describes how pedagogical partnerships can mediate hierarchies between students and faculty, opening space for affective and process-based knowing that incorporates 'being' (ontology). Complex questions about Mad epistemologies also show up in our knowledge production work, such as how we develop our research questions, collect and analyze data, and report findings. I turn to some of these below.

Contributions to Survivor Analysis: Listening for Resonance, Resistance, and Quiet Data

Both the *form* in which Mad knowledge is communicated, and its *content* can be easily misinterpreted or ignored, as is elaborated in the *Loneliness* paper. Above, I also argue that Mad epistemologies are deeply entangled with Mad ontologies; we are constituted through experience rather than people who 'have' (or view, observe, reflect on) 'experiences'. Consequently, we need methodological approaches that assist us in aligning the process of analysis with its content, responding to Mad onto-epistemologies in and on their own terms, and recognizing how we are (re)constituted through our research practices and constitution of findings (rather than only scholars who ‘have’ analytical insights). This section contributes to wider work on Survivor Research (including survivor-controlled research as well as peer/service user-involved work) by making the process of analysis for the *Resistance* paper more transparent. In my efforts to take responsibility for the knowledge developed and offered by the thesis (Doucet, 2008), this writing also speaks more broadly to Survivor Ethics.

Several strategies for paying attention were used to develop the *Resistance* paper, including the techniques of “listening for resistance” (Costa et al., 2012) and “quiet data” (Voronka et al., 2014), engaging in “double reading” (Church, 1995), and moving /being moved by “resonance” (Gillard, Turner, & Neffgen, 2013, 2015; Voronka et al., 2014). These will be further elaborated below. Collectively, these practices offer different ways of analyzing data, while also providing alternative metaphors we might use when thinking about Mad knowledge - what it is and how it works. Rather than emphasizing metaphors related to vision (perspective/view/reflection/seeing as knowing), these survivor analytic techniques work with sonic and otherwise embodied metaphors related to feeling/sensing/moving (vibrations, resonance) and hearing/listening (sounds, silence, loud, quiet).

What to Listen For: Resistance and Quiet Data

In the context of the *Resistance* paper and the collaborative project it describes, I suggested to our team that we pay attention to resistance as an important theme. I had read through three transcripts and open-coded them, noting themes/patterns as I read each line, as did a subgroup of the research team. We then met to discuss and develop a coding scheme. In my initial reading, and our conversation, it became apparent that resistance was significant and particular to how I was reading the data - as these coding excerpts suggest:

- Consequence of not being supported - get seen as non-compliant; ‘noncompliance’ as resistance strategy
- Resistance to negative /unsupportive support
- Active work involved in creating support /resisting unsupportive [space] - resisting inaccurate/hurtful labels
- Resistance - trying to get support [“once I stood up and said… I don’t think this is the way things should be”]
- Protect self from the consequences of negative support - leave
- Self-pride as resistance? [“You are who you are, as long as you’re proud and happy to be who you are, that’s all that matters”]
- Didn’t need to resist - because [doctor] understood

Attention to resistance is also being encouraged in the Mad Studies literature. Costa et al. (2012), a collective of psychiatric survivor, Mad, and allied activists and academics, call us to listen for resistance in contrast to more dominant storylines:

> In our research, if we listen only for the ‘lived experience’ of individuals, and only for processes of illness and recovery – we will miss many other vital storylines. We need to complicate what we are listening for: to listen less for stories of healing and recovery and more for stories of resistance and opposition, collective action and social change. (a panelist at the *Recovering Our Stories* event described as “an academic who tries to use consumer/survivor narratives to elucidate systemic oppression”, quoted in Costa et al., 2012, p. 96)

Voronka et al. (2014), a team of peer researchers, similarly developed an analytical approach to “[speak] back to dominant notions of ‘us’ as the problem that needed to be fixed (as much research is focused on findings/outcomes that highlight symptom reductions, decreased use of emergency service use, cost-efficiencies, and a return to normalcy)” (p. 269). Instead, they focus on critical inquiry, social justice, and attention to the operations of power. This accompanies work in Disability Studies to use the construct of resistance to conceptualize individual and collective political action to effect system-wide transformation (Peters, Gabel, & Symeonidou, 2009). It also shares affinity with urging from Indigenous communities to suspend damage-centred research focused on pain, refuse ways of coding/analyzing/interpreting that contribute to damage, and to instead move towards desire-focused inquiry (Tuck, 2009; Tuck & Yang, 2014ab).

A related analytic practice adopted by Voronka et al. (2014) encourages attention to "quiet data" in interview transcripts. The authors describe 'quiet' data as follows:

> We also coded for narrative moments that were not necessarily quantifiable, the "quiet data" of experiences that detail the "knotty intimacies of violence, love, poverty, homelessness and fear" (Fine, 2012, p. 11). We focused on these moments as we worried they might not be taken up in other project findings because they were not widespread, made redundant, or worse, that they might [be] interpreted as symptomologies, as researchers have often dismissed such experiential knowledge, especially when coming in the form of critique, as "irrelevant ramblings of the uncivilized mind" (Marker, 2009, p. 28). Thus, we focused on the "messy text" of subjugated knowledges that are often overlooked in non-peer research because they are not interpreted as relevant to informing practical, procedural, or policy change (Fine, Weis, Wessen, & Wong, 2000). (Voronka et al., 2014, p. 257)

As Voronka et al. (2014) suggest, a narrow identification and application of ('loud' or 'noisy') Mad knowledge towards quality improvement of services or policy, as is common among healthcare researchers, can fail to recognize and approach these knowledges on their own terms. We also need methods that help us listen for quiet expressions of knowing (e.g. like those identified in the *Loneliness* paper - not knowing, confusion, questions, silence) so that we can hear emergent knowledges of importance to Mad theory and movement building, including Mad people's priorities for action. Listening for quiet data is akin to a psychiatric survivor reading practice that Church (1995) refers to as "double reading" – an ability, based in ongoing engagement with consumer/survivors, to read for what is written, but also for what has been (or is anticipated might be) left out so that it can be corrected:

> The other day Pat [Capponi, a significant contributor to the psychiatric survivor movement in Toronto and beyond] phoned to give me feedback on my writing. Her comments reminded me of the "correction" which her reading provides. She pointed out several places where I highlight the "outrageous" behavior of survivors without drawing out the "outrageous" situation (created by professionals) which they were outraged about. Listening to her I suddenly realized that she was reading not just what I had written but also what I had left out. The white spaces: the history of consumer/survivor pain and abuse within the mental health system. This double reading is constant practice for her. I have learned a little about it but without ongoing dialogue the practice slips away from me. (p. 126)

Collectively, these practices encourage nuanced attention to what is said and unsaid and what might be missed, and to encounters with violence and experiences of harm.

Expressions of resistance may be one form of quiet data that risks being lost or pathologized because it may not be considered useful to program/policy change, is often intuitively /unconsciously expressed, and may be perceived as evidence of individual symptomology. Resistance may also require a form of double-reading to ensure the subtle or missing context is drawn out - such as why a participant may choose quiet withdrawal rather than vocal or public outrage, or the cumulative and everyday nature of violence that leads to particular decisions. Additionally, we need to watch for forms of resistance that are themselves 'quiet' and less publicly recognized. For example, approaching Costa et al.'s (2012) call to "listen… more for stories of resistance and opposition, collective action and social change" (p. 96, quoting an academic contributor to the *Recovering Our Stories* event) through a lens of quiet data, exposes how this description of resistance emphasizes a particular form - opposition, collectivity, social change. Framed in this way, we might miss everyday forms of resistance that are not overtly intentional (are unconscious, spontaneous), are not public or collective (are private, individual), and do not have a recognizably large-scale, immediate, or long-term social change impact (Hollander & Einwohner, 2004). Consequently, when I started to read transcripts for resistance, I began to keep an ear out for quiet forms of dissent that may not otherwise be recognized as opposition and action, especially those that risk being pathologized in mental health systems (Voronka et al., 2014). This meant watching for expressions of anger, ‘aggression’, non-compliance, distrust, apathy/indifference, self-reliance, and other forms of psycho-emotional harm from disablism/sanism. It also required questioning what I was becoming aware of and what else might be hidden by these patterns of awareness.

As I reconsider it now, the resistance code was perhaps one way to attend to Mad knowledges on their own terms, rather than with an overall goal of identifying barriers/ facilitators to service and providing recommendations to service providers, which were the foundation of the rest of our coding framework. Based on our interview questions, we developed the following codes: attributes that make places and spaces supportive; attributes that make places and spaces unsupportive; pathways to supportive places and spaces; being in/connected with community; impact of supportive places and spaces; impact of unsupportive places and spaces; intimate and interpersonal relationships, systemic advocacy (services that facilitate rights and self-determination); recommendations for strategies to create supportive places and spaces. While characteristics of Mad knowledge can and certainly did show up in these categories, these codes reflect the primary focus of the research on improving service systems in support of LGBTQ people with experiences of psychosis.

On their own, these more traditional codes may not have enabled us to pay attention to more messy /quiet forms of data - especially where data blurs between ontology-epistemology-ethics, and where doing /being is a form of knowing. For example, several participants described leaving/exiting services and relationships - like Participant 14, who boycotted a nightclub in response to sanism experienced there. In the act of leaving, participants were not overtly naming why something was problematic or articulating recommendations for program or policy change - they were removing themselves from a bad situation. This is an intervention - a way of being, an ethic - based in their critical appraisal of discrimination, but would not necessarily show up in our other thematic codes. The closest option is to perhaps code ‘leaving’ as an *impact of unsupportive spaces*, which would position it in a cause/effect relationship: an ontological consequence of failed support, rather than an accumulated way of knowing/being through harm that shifts who and how one is. Similarly, participants spoke about refusing to disclose private experiences to service providers - which renders some of their knowledge quiet (and ‘non-data’) because it is not expressed. Paying attention to the moments when participants exit or elect silence is an important strategy for recognizing their knowing/being in action.

It is also significant to note that I became more aware of resistance and quiet data through my own refusal to continue writing an autobiographical dissertation, as I had initially intended. Tuck and Yang’s (2014a) argument for refusing the conditions and conduction of damage-centred research is based on three axioms: “(I) The subaltern can speak, but is only invited to speak her/our pain; (II) there are some forms of knowledge that the academy doesn’t deserve; and (III) research may not be the intervention that is needed” (p. 224). These are relevant here: I struggled to find a way to write autobiographically that did not just lead to being overwhelmed with painful experiences, or result in the documentation of these experiences. It was too damaging to write stories about the damage caused by the university - and I came to agree that the university does not deserve those forms of knowledge. Rather than write explicitly about how the violences I’ve experienced in the academy echoed against other violences, I came to focus on other things, like noticing forms of dissent/opposition as described in the *Resistance* paper.[27] I also agree that research may not be the intervention needed. Tuck and Yang (2014a) discourage us from using research “to say something that has already been said” (p. 236) (i.e. the well-known and well documented violences of academia), but this time through a different voice (i.e. a Mad student one). What is needed instead are alternative ways of relating and expanding our notions of what we owe each other, that do not demand a story of pain. Listening for the resistance of others also involved resistance to telling my own personal stories; attending to quiet data in interview transcripts required attending to the quiet data of how I came to be reading for quiet data in the first place.

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[27] These experiences of violence in the academy resulted in forms of haunting - where I came to feel like I was in a psychiatric institution when walking the halls of my department, or that I was caught in the middle of academic ‘family secrets’ that everyone knows about but doesn’t discuss (Heald 1997).

In addition to Voronka and colleagues' (2014) work with quiet data, other research teams are endeavoring to track how service user researchers approach analysis differently than academics and clinicians. The work of Gillard et al. (2010, 2012a) is one example. This pilot study empirically illustrates how service user researchers analyzed transcripts with codes related to *violence experienced while using mental health services*, and *feelings about being detained*, among other codes, more often than their academic/clinical colleagues. They were also the only team members to apply codes related to *alternatives to coercion*. Contrastingly, university researchers were more likely to code data in relation to *processes and procedures*, and were the only ones to use codes related to *patient insight* (Gillard et al., 2010). Gillard et al. (2012a) further discuss these results, pointing to how coding by the service user researchers on the team clearly emphasized participants' experiences of harm (violence, detention, coercion, forced use of medication), as opposed to health service researchers' focus on developing conceptual explanatory frameworks, and the nursing researcher's focus on staff attitudes and implementation of policy/procedures. While Gillard et al. (2010, 2012a) do not discuss researcher perspectives on why they coded data differently, or what may have informed the different ways of reading data, the service user researchers' results seem to echo an alertness to 'quiet' data and resistance through a focus on patient experiences of violence and coercion, and alternatives to these approaches. Perhaps they were haunted by those interview transcripts, and personal /community experiences or politics showed up to help them pay attention in particular ways. Perhaps they too were worried about how participant accounts, especially of resistance, might be pathologized or erased (e.g.

through a lens of patient insight or problem behaviour, codes the clinical/academic researchers did apply [Gillard et al., 2010, 2012a]), provoking them to assert alternative analyses.

In a different study, Gillard, Simons, Turner, Lucock, and Edwards (2012b) interestingly highlight how service users at an event to offer feedback on emergent findings flagged as important their ambivalence to self-care. These service users argued that it can feel like a form of abandonment to be discharged from services to self-care approaches (p. 1133), and so this ‘quiet’ piece of data was incorporated back into analysis. The authors do not explain in much detail why it was important to the service users for this point to not be lost, but I appreciate it as a form of resistance to traditional healthcare responsibilization of patients. The authors also mention significant tensions in their team regarding service user researcher perspectives on emerging data about medication use - but fall short of fully explaining why the service user researchers did not want the findings about medication to dominate the study’s conclusions. What they offer is an explanation that critiques methodology (how medication arrived as a significant theme via standardized quantitative interview questions but was not a dominant thread in qualitative conversations with participants). They do not point to a politics on medication but, I imagine, this was also at play. While the explanations provided are incomplete, these studies suggestively affirm that service user researchers are bringing a different and more critical politics to data analysis that includes attention to quiet data and forms of resistance. Future work in this area might more transparently elaborate the politics and ethics of service user researcher analysis and how these inform the themes we identify and assert.

One of the difficulties of ‘quiet’ data is that there may be very good reasons why it is quiet and needs to remain so, or at least quiet to some (while already well known and noisy to others). One of the benefits of service user involvement in research noted in the literature is that our presence can contribute to increased recruitment and retention of participants and participant openness during interviews, as well as to observations and analyses of the data that academic/clinical researchers would not otherwise notice (Happell et al., 2018). While these supposed ‘benefits’ of our involvement may bring about relevant research results and promote desired change, it also sounds like our role is to facilitate the sharing of secrets, to seduce our peers and entice stories that might otherwise remain private. These are important cautions to heed when seeking to hear quiet data. When used responsibly, this attention can further politicize our data analysis by explicitly focusing on accounts that have been historically pathologized or erased as uninteresting. Used carelessly, our attempts at amplifying subjugated knowledge may further contribute to our subjugation. In this work to identify quiet data of resistance, we may also find our way to difficult knowledges that we do not yet know how to acknowledge and that cannot be addressed properly through existing hermeneutical frameworks or modes of inquiry; attending to quiet data will not only or simply result in locating more liberatory narratives. Likewise, we must avoid suggesting that ‘quiet’ data simply exists, and only needs to be perceived through excellent hearing. We constitute data as it reconstitutes us.

The question of how to write authentically about quiet data (especially when appearing as subjugated knowledge, trauma, harm) is another important consideration. As Tamas (2009) observes, authors often tell “messy, unreasonable stories in a tidy, reasonable voice” (p. abstract):

> I am worried that there is a silence in the representational discourse that threatens to falsify it. When I tell the story I have just told… we are talking about being broken and undone. But our voices as we speak do not sound broken. We sound okay, in fact. What we’re talking about sure is awful but our narrative voice seems to have it all worked out. We know what happened and we can talk about it in full sentences that make sense... We seem to have found a way to perform an internal god trick, standing outside and above ourselves in order to speak dispassionately about passion. That’s how we turn trauma into knowledge. (para 10)

Clean and confident ways of accounting for quiet (messy, uncertain, unsettling) data, and the violences that often hide beneath that data, can compromise it. Sometimes this tidying is in a conscious effort to avoid pain and damage-centred research but, without making this explicit, writing neatly about harm has the potential to also undermine in some ways our analyses of oppression. I think in particular of the *Loneliness* paper, which cleans struggle up into a rhythm /momentum that I did not have as I was trying to figure out how to make myself intelligible. What is lost in a characterization of moving with loneliness as rhetorically smooth, rather than rough or wrinkled? How do I write with vertigo? I appreciate Ahmed’s (2017) discussion of “sweaty concepts” as a way to recognize the intellectual labour of theorizing and “trying to describe something that is difficult, that resists being fully comprehended in the present” (p. 12):

> Sweat is bodily; we might sweat more during more strenuous and muscular activity. A sweaty concept might come out of a bodily experience that is trying. The task is to stay with the difficulty, to keep exploring and exposing this difficulty. We might

> need to not eliminate the effort or labor from the writing. Not eliminating the effort or labor becomes an academic aim because we have been taught to tidy our texts, not to reveal the struggle we have in getting somewhere. Sweaty concepts are also generated by the practical experience of coming up against a world, or the practical experience of trying to transform a world. (p. 13-14)

The work to hear, understand, and describe quiet data is strenuous. My intention is that this elaborated background context of the dissertation perspires, exposing some of the scrubbing that produced the papers above.

Listening through Resonance

In addition to listening for resistance and quiet data, throughout the analytic process that generated the *Resistance* paper, I also paid attention for ‘resonances’ that I experienced with the data, drawing on the work of other service user researchers who have similarly mentioned this approach to the identification of research themes (Gillard, Turner, & Neffgen, 2013, 2015; Voronka et al., 2014). In this section, I respond to Faulkner’s (2004) recommendation that survivor research explicitly describe how it analyzes data and identifies findings. To do so, I engage with survivor/service user research and literature on resonance to further articulate my own analytical process of attuning to the data.

The theoretical and methodological investigation into resonance is wide-ranging, leading to many possible interpretations of what it might mean to refer to resonance in the context of one’s research. While emerging in physics to describe how a sound can be amplified or reverberate through reflection off a surface or neighbouring object, resonance (as well as consonance and dissonance) has been applied by scholars across disciplines to a range of sonic and social contexts, such as everyday forms of affinity, relating, and belonging (Juvonen, 2018; Kristensen, 2018; Miller, 2015; Porter, 2017). Within an interpretive tradition of qualitative research, resonance has been understood to "refer to a researcher's posture of openness and receptivity toward potential meanings embedded in a text. It serves as an important ontological and epistemological counterpoint to the postpositivist stance of objective analysis of data" (Piantanida, 2012, p. 790). Medico and Santiago-Delefosse (2014) also describe resonance as an approach to data analysis that explicitly develops interpretations by focusing on relations between researchers and participants rather than reinforcing positivist "conceptions of analysis 'emerging' from the data, as if spontaneously created" (p. 6). Resonance is used in the evaluation of rigour and quality in research or writing - referring to a form of member-checking and confirmation that the research findings resonate for study participants and with the data itself, as well as to the reverberations of the research findings on the reader/audience/social context (Burden, 2000; Finlay, 2006; Pereira, 2014; Reilly, 2013; Sweeney, Greenwood, Williams, Wykes, & Rose, 2013; Tracy, 2010).[28]

Within writing on survivor/peer research, 'resonance' appears to connote a connection between a researcher's personal experience and interview data (Gillard,

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[28] For example, Tracy (2010) defines the criteria of resonance as "[t]he research influences, affects, or moves particular readers or a variety of audiences" (p. 840); "researchers can engage in practices that will promote empathy, identification, and reverberation of the research by readers who have no direct experience with the topic discussed" (p. 844). I would argue that this particular frame of resonance as an articulation of findings that promote empathy or identification is antithetical to a Mad politics and ethics that endeavors to evade the packaging of our stories to voyeuristic audiences (see Costa et al., 2012). Instead of understanding resonance as a feeling state passed between separate individuals (like empathy, identification), I am much more compelled by notions of resonance as a "*jointly created* dynamic" (Mühlhoff, 2015, p. 1002; emphasis in original), as is described further below.

Turner, & Neffgen, 2013, 2015; Voronka et al., 2014). Voronka et al. (2014) describe their use of resonance in this way:

> Members worked individually with the transcripts, reading for emerging themes and for resonance with their own experiences of the mental health system, of mental health issues and of homelessness... A consistent theme throughout the interviews was how the expressed needs of individuals dealing with crisis were often met with responses that either sustained or further added to their issues. It is also a topic that resonated with our experiences. In particular, we worked to pay attention to participant articulations of moments wherein a clear disconnect between their needs and service systems responses were evident. (p. 256-257)

They then met as a team for a two-day working meeting where they discussed with other peer researchers emerging themes, common readings, and what they were collectively interested in coding in the transcripts. Gillard, Turner, and Neffgen (2013) explain how the service user researcher on their team (Kati Turner) "made explicit use of personal resonance with interviewees' experiences, as recounted in the data, to inform her articulation of a bifurcation of lived experience as a hostile external world and the troubled refuge of the internal world" (p. 64). Feminist researchers have also written about how being pulled into an interview and finding it emotionally difficult - and then theorizing from this reaction and going back to data through these emotions - can be essential to identifying concepts and themes (DeVault, 1990). I especially appreciate DeVault's (1990) call to more specifically understand the ways experiences can be used by researchers as a resource:

> While other feminists have noted the value of personal involvement in interviewing, even researchers who value involvement have talked of it in a mostly unanalyzed way, as experience rather than as an element of method. If feminist researchers are to move toward a more disciplined use of the personal, we need to make the process one that we can consciously adopt and teach. We need to analyze more carefully the specific ways that interviewers use personal experience as a resource for listening. (p. 104)

This is a call I take up here. While several of us as peer researchers are engaging with data in some way and calling this connection ‘resonance’, there is little published discussion about what we mean by our use of this word, how an approach through ‘resonance’ has manifested or worked, or the ways our engagement with resonance relates to other theoretical or methodological literature. Retrospectively and in conversation with a range of these descriptions, I begin to describe how ‘resonance’ came to affect my analytic work on the *Resistance* paper.

Resonance as Moving /Being-Moved

I began engaging with the data for the *Resistance* paper in the fall of 2014, which was the first significant analysis conducted for my doctoral work. Through a variety of contextual factors, commitments, and curiosities, I was moved by what I was reading in interview transcripts, a motion Mühlhoff (2015) describes as affective resonance, “a dynamical entanglement of moving and being-moved in relation, of affecting and being-affected” (p. 1016). Key to Mühlhoff’s (2015) analysis is an emphasis on resonance as a “*jointly created* dynamic” (p. 1002; emphasis in original) that emerges and unfolds through relational entanglement rather than a feeling state passed between separate individuals (or passed from transcripts to researcher).

In addition to the resonances that led to the articulation of resistance as an important theme (as described above), during the initial open-coding process, I was affected by expressions of how hard participants were working to navigate un/supportive spaces. What moved me, in part, was worry that without attending to the labour involved in navigating un/supportive spaces, this work - and the knowledge it takes to do the work

- would remain unrecognized. This attention to labour showed up in my open-coding in this way:

- If don’t get support /negative support - leave, just deal with on own
- How do people come to know whether to disclose or not?
- Work involved in maintaining supportive spaces!!; all the work involved; active work to create support
- Working as a support to others; Being around peers; Mutual support - supporting others too; Work involved in building community
- What we do for the people who support us
- Protecting home - lying [not telling peers they’re no longer homeless]
- Prepared! Having answers prepared to maintain support (I’m all prepared, I’ve got all the answers for avoiding something that I don’t want to let happen by mistake)
- Says [spaces] are the same level of supportive [over time] - earlier talks about work to make them supportive
- What to do in response to unsupportive place - boycott, don’t go back
- Active work involved in creating support /resisting unsupportive [space] - resisting inaccurate/hurtful labels
- Finding support - you have to <u>look</u> for it - used up all research resources
- Underlined words: constantly trying, I’ve tried lots of things, You just gotta like really search to find it, so tired, with them it’s <u>easier</u>

These expressions of labour resonated with my own efforts to create supportive spaces for myself and my peers /community and survive unsupportive ones - work that is often exploited, unnoticed, unfairly distributed. It felt like a lot of work (and made me tired) just to read participant accounts of how much work it was, and I became increasingly more aware of how heavy and burdensome the work is in my own life when I saw it reflected in the typed words of the transcripts. My ‘method’ of living /labouring in Mad communities produced this analysis on labour.

Attention to ‘expectations’ also showed up, quietly, in this initial open coding where I was beginning to point to what participants were saying about what ‘should’ happen when they seek support:

- Hiding - feel shouldn’t have to hide

- Don’t want to belong where can’t be myself
- Inconsistency/hypocrisy - not standing behind what they claim; can’t just claim something, have to act on it
- Don’t need to be accepted everywhere; as long as have a couple good places where can be open/have people who get it, not everywhere needs to be supportive
- [Support] Not meeting expectations
- Vision of future won’t happen - what sees as possibilities and what not (“It would be nice, it would be nice, but I don’t see it happening…”
- What community ‘should’ do; expectations (“I mean I should be accepted…”)
- Expectations for support and then not supportive; don’t expect support + are supportive
- Underlining: “I don’t think this is the way things should be”

While we did initially open-code, discuss, develop a coding framework, and code transcripts, and while I did start with the excerpts formally coded under the node of resistance, I ultimately went back to all of the transcripts with a highlighter and pen, and hid out in my parent’s basement for a week during the winter break of 2015-2016 to think and write with the data.

As I wrote and rewrote and revised, the theme of expectations came to emerge as significant and ‘moving’; it affected me in such a way that I began to recognize how I have similarly readjusted my expectations and attempted to mediate my emotional reactions to unmet expectations for just treatment - not just in mental health service use, but in education, employment, other relationships. This reading became especially prominent when I returned to working on the *Resistance* paper in the spring of 2018 to figure out how to situate it within a wider literature. I played with locating it in the LGBTQ/psychosis literature and the LGBTQ/Mad writing on resistance, neither of which quite worked. The former was predominantly focused on improving healthcare services (a focus I was increasingly unenthused by, given my desire to engage with Mad knowledges on their own terms), and the latter did not feel sufficiently grounding as a singular conceptual frame. While I found that the language of ‘resistance’ regularly appeared in Mad/Disability movement writing, it was rarely theorized as a concept in relation to resistance studies, and seemed to function like a catch-all that darn-near anything could be called resistance. Consequently, I did not find this writing on resistance particularly moving. I also came to realize that I did not personally relate to resistance as a ‘thing’, and that participants didn’t speak directly in the language of resistance either, so perhaps as a concept it wasn’t fully conducive to helping us understand our lives. Instead of these as frames, I began to bring to the analysis my thinking about expectations from the *Loneliness* paper I had just completed writing over 2017-2018. In some ways, the interview participants were expressing a lost “capacity to expect just treatment or help in the absence of such treatment” (Stauffer, 2015, p. 15), as I describe in the *Loneliness* paper; they expected very little. In other ways, their actions of resistance demonstrated a claim on just treatment, even when this treatment was not regularly received (Tessman, 2009). While lost expectations of just treatment is a significant anchor in Stauffer’s (2015) work, she does not develop this further through theory on ‘expectations’ specifically, which led me to search for other relevant material. Starting with Stauffer’s (2015) discussion of ressentiment /resentment as a way to protest unjust treatment and defend self-respect, I found my way into feminist writing on self-respect, resentment, trust, and maintaining a claim on just treatment, and Thompson and Sunol’s (1995) definitions of predictive, normative, and ideal expectations.

The very reasons why I could not engage in autobiographical writing at the time (as mentioned in the Research Questions and Methods sections above), were revealing themselves in how I was being moved /moving with the interview transcripts and my own relation to the theme of lost expectations of just treatment. According to Brinkman's (2014) abductive model of inquiry, "we do research, inquiry, analysis, for purposes of living, and theories and methods are some of the tools used in the process" (p. 722). He proposes the focus of our inquiry be "situations of breakdown, surprise, bewilderment, or wonder" (p. 722) - those instances where we encounter "stumble data" (data we stumble on), and in our stumbling, use thinking tools to regain our balance.[29] The breakdown in my understanding that propels this thesis - and that has provoked resonances with and through the data - was coming to know the academy as violent, and a site of abandonment (of students, Mad people, students/staff/faculty from equity-seeking groups, etc.) resulting in many of us losing our expectations of just treatment or help (Stauffer, 2015).[30] This theme echoed through conversations in my daily life with Mad/disabled peers, although we were not directly referring to 'low expectations'.

When I started analyzing the data in 2014, and returned to it in 2015/2016, I was in the midst of difficult relational dynamics and their reanimation of prior harms that were not fully describable in words. I was having a difficult time making these harms intelligible to others. Returning to the analysis in 2018, made space for resonances

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[29] Brinkman (2014) attributes the term "stumble data" to a conversation with colleague Lene Tanggaard.

[30] See, for example, McAlpine, Paulson, Gonsalves, and Jazvac-Martek (2012), Willimon and Naylor (1995), and Wisker and Robinson (2013) for work on abandonment/neglect in higher education. As Lynch (2010) observes, "[n]ew individualized academic capitalism breeds an organizational culture marked by increasing egocentrism, very conditional loyalties (to the university and higher education), and a declining sense of responsibility for others, particularly for students" (p. 57). She attributes much of this "carelessness" to the academy's endorsed pursuit of self-interested, autonomous, rational personhood, rather than recognition of relationality and interdependence as central to who we are.

between my own experiences and the data to emerge. The overwhelming emotions attached to modifying expectations had, by this point, moved with and reconstituted me, and I was more alert to how participants managed their low expectations and modified their emotional attachments to particular outcomes. My daily negotiations of lowering/modifying expectations had felt like unplanned responses that 'just happened', or expressions of damage ('trust issues'); however, through analysis, I began to wonder how they might also be intentional, (unconsciously) considered strategies and knowledge-based skills. This return to analysis also occurred at a time when I had become a course instructor and supervisor of students. I was surprised when students would email to thank me for (doing my job) providing feedback on their work. Their statements like "no other instructor has done this" suggested very low expectations of me and others as instructors. What did I need to do in order for students to not downgrade expectations of me and my capacities to support them? I was also overwhelmed with the number of things I was involved in and was making difficult and distressing decisions about which projects (and interrelationships) I could let slide/delay/neglect. My moving/being moved by resonances emerged through my own need to modify my expectations of others, as well as in desire to fulfill and expand the expectations others have of me.

It's unlikely the resonance of 'expectations' would have emerged from the data or affected me in the same way without these co-occurring life circumstances (or that I would have correspondingly affected the data analysis in these ways). As Mühlhoff (2015) emphasizes, resonance is a "*jointly created* dynamic" (p. 1002; emphasis in original) between myself and the participants' narratives. Resonance became a way of being moved and moving ideas across datasets, across experiences (my own as they varied over time and context, friends, participants in several projects), and across literatures. Fine, Weis, Weseen, and Wong (2003), in their writing on our social responsibilities as researchers, encourage us to deploy multiple methods in research so that different kinds of analyses can be constructed. While my colleagues and I had intended to supplement our interview data with focus groups, due to a host of factors related to human resources (staff transitions), project funding, and institutional ethics review, this became impossible. Instead, we might consider the conceptual work I was doing in the *Loneliness* paper, and the autobiographical illustrations used to make those arguments, a companion text and complementary method for the project. Figuring out ways to understand my bewilderment and stumble over knowledge about the academy's abandonment and neglect became the base of both the *Resistance* and *Lonelines*s papers and their attention to lost/low expectations. The *Confidence* paper, which illustrates just treatment cultivating epistemic confidence, and another research project on which I was simultaneously working (related to social work students from equity-seeking groups in field placements) became additional sites for the exploration of expectations of (un)just treatment. In addition to using the 'thinking tools' (Brinkman, 2014) of academic writing to regain my footing (and to move), 'relational tools' were also essential: I needed a bolstering of epistemic confidence and crafting of epistemic community before thinking tools could work. These relational tools are described in the *Loneliness* paper, and reflected in my Acknowledgements section.

Had I continued writing autobiographically as my method of inquiry, I am not sure that I would have been able to notice or label resistance in my own life/work, or to refer to my own developing ethical codes or moral talk. I would have needed someone to point these out to me. I think it would have felt too bold to claim these for myself, or strange to call parts of daily life ‘resistance’, as if they were consciously planned and enacted. I was engaged in resistance, yes, but understood these actions as living, working, defending my friends, rather than as resistance. It was easier to read/move with the transcripts and to observe what it felt like participants were coming up against, resisting, or claiming as the sort of treatment they deserve, as this is what I would do for a friend or peer, or a student when providing feedback on their work. It is often in listening and talking with others, and reading and responding to data, that I begin to imagine how those same forms of response could apply to me. By theorizing and writing about the lives of my participants, I began to also theorize my own life (St. Pierre, 1997, referring to Fay, 1987). The resonances of resistance/‘expectations’ may not have been possible with solely autobiographical writing. They required relation with others.

As Toikko (2016) and Beresford’s (2003) work above suggests, discussions of Mad knowledge tend to reinforce visual (and related directional) metaphors - such as those that emphasize the role of reflection on experience to generate knowledge, the standpoint from which one gives a perspective, as well as one’s proximity to experience (and whether it is direct /first-hand) and the resulting clarity (or distortion) of their view.[31] In contrast ‘resonance’ is a sonic metaphor that invites us out of the Cartesian dominance of the ocular where “seeing is knowing” (Vidali, 2010). This facilitates a different engagement with epistemology and ontology, blurring the boundaries between onto-epistemologies through being/knowing simultaneously: Engaging data through resonance dismantles the notion of researchers as ‘removed’ observers offering transparent interpretations (epistemology) of data as objects (ontology), and instead understands analysis dynamically as we move and are moved by our data (being/knowing together). We are “lacking earlids” (Cox, 2013, as cited in Schrimshaw, 2015, p. 162), which means that, in contrast to the rational selectivity of reason (we can close our eyes, choose what to view, critically select which thoughts to engage with), sounds can forcefully or involuntarily enter, envelop, and affect us (resonate). Analyses of lost/low expectations came to compel me, and were not provoked or sustained by conceptual curiosity alone; embodied responses to confusion and despair played a significant role. Fricker (2007) and Stauffer (2015) do, however, describe at length our failures to listen (despite “lacking earlids”) and substantial ethical problems with who and what we hear (and do not hear), which suggests ethical being/knowing through resonance is not guaranteed.

This analytic approach through resonance affirms the ways Mad researchers may be affected by and affect data as a legitimate and valuable form of knowing. It resists pathologizing embodied responses to data, such as how Mjøsund et al. (2016) comment

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[31] As Erlmann (2010) elaborates: “Just as the mirror reflects the light waves without its own substance becoming affected, the mind mimetically represents the outside world while at the same time remaining separate from it” (p. 9).

that “[i]nvolving service users in analysis of transcripts from former patients with similar experiences may give rise to affective issues” (p. 274). The authors go on to note the necessity of adequate support “for all involved [in] the research process, not only the participants”, and maintaining a focus on “interpreting the data” rather than “discussing our own feelings” (p. 274). While I appreciate their recognition of the support required to negotiate our movement by/with data, this phrasing leans towards presenting the process of affecting and being affected by our research as a potential problem rather than an essential quality of a peer/service user analytic process.

Resonance as Relating

In addition to ‘resonance’ as something that materializes through our interactions with data, we can infer that Turner’s engagement with ‘resonance’ may also involve ‘relating’ to it:

> I had some strong feelings about how I thought (and wanted) the data to be grouped and what it was telling me. I knew I had these feelings because I related very personally to the data I was dealing with.… Some people described things in a way that felt almost identical to how I might have described them if someone had asked me the same questions… I don’t attribute my response purely to having had similar experiences, but I do think my proximity to the experiences and subject matter meant that an extra ‘level’ or layer of sensibility and vulnerability was uncovered within me. (Gillard, Turner, & Neffgen, 2013, p. 63)

The role of relating to the data is reinforced by a comment about the peer researcher “identif[ying] themes which the other researchers understandably found difficult to relate to” (p. 62). It is not entirely clear what might be meant by “relate personally” or share “similar experiences”, but these phrases seem to suggest a common, individually encountered experience - perhaps of or in response to madness or service use. This is supported by others: Stevenson and Taylor (2017) write about involving people with dementia as co-researchers and how the co-researchers were “particularly interested in responses that resonated most with their own experiences” (p. 6). Similarly, Voronka et al. (2014) focus on the theme of people in crisis being met with unhelpful responses that aggravate/maintain their distress because it was “a topic that resonated with our experiences” (p. 257).

I similarly encountered situations where my analysis was informed by resonances with my individual/collective ‘experiences’ and a community politics. Two examples from our team’s discussion on open-coding are elaborated below. The first involves a participant’s fear of living in their city. They seemed to at least partially attribute this fear to their psychosis and described how, when they left the city to visit friends elsewhere, their fear disappeared, and they felt happy.

> …my schizophrenia and my ummm…. psychosis up here. It just made it really bad. Like I mean like, I’d walk in the street, that’s why I turned my music thank god. It’s a help to zone everything out. But, I was walking down the street, it was just like constantly, people were staring at me, and I was like ‘what the hell did I do?’ And it just kept bugging me, like someone else is going to attack me. It just kept going through my head. So I kept walking on the street, and looking over my shoulder, and I’d never done that. But the day I went to the appointment for two weeks after that appointment, that’s all I did every day, was look over my shoulder. I just didn’t feel comfortable or safe in my own city. I was ready to move out of [city], I just felt like I was not wanted here. Which was really weird. I had spent my whole life here, and then it just like, one day… it twisted right around, it’s like yeah, you need to move from here, you’re not welcome here, and it’s not a proper place for you to be. [page 2 of transcript]
>
> [later, on page 11] ...I’ve been in [larger city 2 hours away] partying and that with my friends... And you can walk and you can be free. You can live your life, and be proud and happy with who you are. Here [participant’s city], you have to live in fear, which I don’t think is right. I think it’s utterly wrong that you should have to live in fear in your own city, but that’s the way they are here… I have no fear when I’m down there. I’m happy, you know, I’m proud to be who I am. And I feel like I’m in the best place in the world. But when I’m at home, in my own

> home town, it’s like, I don’t want to be here. That’s what bothers me. (Participant 11)

When reading and discussing this excerpt, I was worried that this story could be interpreted as (only) a form of psychosis-related paranoia. Like Participant 11, I have felt afraid in particular geographical locations due to their association with past harm and have learned though experience that extreme fear (paranoia, psychosis) can be very concretely tied to what one has lived (e.g. the participant’s experiences of homophobic violence), rather than only irrational /biological /ungrounded. Resonance with my lived experience and related politics encouraged me to consider multiple interpretations beyond those that might be more dominant, and to recognize the participant’s survival strategies (listening to music, leaving the city). I also began to notice other examples in the transcripts where participants resisted by ‘exiting’ harmful situations, which became an entire subtheme in initial analysis on resistance. In this way, resonances with experiences and their resulting politics can invite us to pay attention for quiet data that might otherwise be missed or misinterpreted.

Another example was Participant 11’s description of being told to write their feelings down on paper. I had initially coded this section ‘wellness strategies’, and not thought much about it:

> I told straight out that I was gay, and they were fine with that. And they would help me, and they would talk to me about all my issues. They had me doing hands on things, where saying I’m dyslexic, I can’t write the best. But they start talking to me, and they start talking to me, and they start drillin’ into my diagnosis, my schizophrenia, and gettin’ certain things that come up, and instead of me gettin’ upset, they put a pad of paper in front of me and say write it out. And it would help, it helped a lot. Because I could put my feelings down on paper. And then like, this is like what you need to do. Instead of getting’ upset, or going hiding somewhere, write your feelings down on paper. So just fold it up, put it

> somewhere, nobody needs to see it. Just put it down on paper, and it would help your brain. It will help your issues. Which I learned slowly that it was helping. It was doing an amazing job. (Participant 11)

At the time of our open-coding, I had just finished a peer support worker training program. This included becoming a certified facilitator of Wellness Recovery Action Plan (WRAP) peer support groups, where there is extensive focus on identifying and using one's 'tools' to promote control (self-determination, autonomy) over one's life, especially during distress.[32] In our team discussion, a colleague commented on how being able to write privately ("nobody needs to see it") is a more self-determined form of writing than what typically happens when a patient is 'written about' in case notes or assessments. My response at the time was that while it may be true that "nobody needs to see it" - this can also mean that "nobody is around to read it either" if the participant does want their writing/feelings witnessed by another person. While I am not myself a journaler (that part was dissonant), I have been abandoned in similar ways, such as when directed to use 'coping skills' rather than heard in my expressions of harm. I was especially disturbed that the participant would be encouraged to write when dyslexia makes it difficult for them to do so, which points to how the provision of a resource or new coping strategy could also indicate a failure to hear or be in attunement. This felt familiar - being encouraged to do something that doesn't work for me, and doesn't recognize particularly important facets of who I am. Yet, in this specific situation, the participant reports coming to find writing helpful. We are invited to consider how journaling can, for some, support access to and the maintenance of autonomy and

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[32] For further info, see http://mentalhealthrecovery.com/wrap-is/.

avoidance of involuntary forms of help when distressed. The encouragement to journal or individually practice other coping strategies can be experienced by others as a form of abandonment (see Gillard et al., 2012b).

My Mad/survivor contribution to this discussion was to raise contrasting perspectives that other service users might bring to this excerpt and its interpretation, based on my own ‘experiences’, yes, but also my participation in (and thinking about) broader peer support philosophies on strategies like journaling. In my analysis, I was endeavoring to be accountable to the peer support and Mad Studies epistemic communities to which I belong, as Doucet (2008) describes in reference to the work of Lorraine Code:

> The epistemic communities within which we work, and for whom we write, exert subtle pressures on our knowing processes so that “producing knowledge is less a matter of face to face confrontation with data than of negotiation within an epistemic community...” (Code 1995, p. 28–29, as cited in Doucet, 2008, p. 81)

This journaling excerpt could easily be coded as an example of ‘attributes that make places and spaces supportive’ because the participant was provided with helpful coping resources. Instead, I was engaging in a politics of double reading (Church, 1995) - reading for what was written (the participant’s positive experience of journaling), but also for what was left out (other peer/Mad politics on wellness strategies). Perhaps I was also reading for boredom, hence my initial lackluster engagement with this excerpt in comparison to other arising themes; I was not ultimately interested in formalized wellness tools taught by service providers. In early analysis, this excerpt did become an example of a professionally instructed and endorsed ‘coping strategy’ (alongside others that were mentioned: listening to music, going on walks, mindfulness, sleep, nutrition), in contrast to the majority of strategies participants described that would not be recognized or promoted by traditional service and support systems (e.g. language with which to name their experiences as harmful/not what they deserve, anger/resentment, distrust). These pointed to a significant gap between what was offered to service users and what we might actually need in our life to deal with everyday realities.

While these and other aspects of data analysis were certainly informed by my own context, in large part my use of resonance did not involve relating individually to the data I was reading or seeing myself in the data. Many of my experiences have been told and retold and reinterpreted and recreated in Mad, disability, queer, and trauma survivor communities such that it is difficult to entangle a ‘personal’ experience from how my experiences have been shaped in relation with others. Instead, resonance provoked me to think about friends (several of the transcripts sounded like people I knew - quite likely they were people I knew), about stories I have heard and co-constructed with Mad peers, and about treating the participants as members of my community with whom I share an affinity, rather than as more removed relations. I came to care about them - especially perhaps because finding people (in-person and in writing) who both identify as LGBTQ and have experiences of psychosis is not a common-day occurrence - and I was keen to learn how they survive to inform my own survival. I was bringing an everyday-ness to data analysis.

My embeddedness in everyday relations with members of a project’s participant group may be especially relevant and impactful in team approaches to research where data risks becoming decontextualized; for example, when there’s a division between those who do the field work and those who write the results, or when researchers only engage with written transcripts - a research design that can lead to “break[ing] knowledge down into its constituent parts, and hav[ing] one set of researchers collect these parts while another set puts them together again” (Mauthner & Doucet, 2008, p. 976). This increasingly common context applied to the project described in the *Resistance* paper, where a research assistant conducted the majority of the interviews (I facilitated one as well), and the research team engaged with written transcripts. In these forms of research design, we might think about peer researcher ‘resonance’ as a re-embodiment of decontextualized data.

This is perhaps especially the case when listening for the quiet data of resistance. None of our research questions asked about resistance, and participants rarely used language explicitly connoting resistance, so examples could not be easily identified discursively. If only conducting a thematic analysis of major or common patterns or directly observable data, we likely would have missed the underlying, subtle, short, scattered, affective illustrations of what resistance looked like. Paying attention for resistance involved noticing how participants were feeling or acting, such as through expressions of anger that are more perceptible to a researcher when attached to embodied experiences and relationships rather than only reading words on a page. A peer researcher’s contribution to analysis through resonance may reflect the depth /immediacy of our daily connection to people sharing affinity with the study population, in contrast to those conducting analysis who have not met with participants or engaged in field work themselves, and are engaged in “textually mediated over embodied research relationships” (Mauthner & Doucet, 2008, p. 978).

In his writing on the ways through which we gain insights, Klein (2013) draws attention to how our experiences can sensitize and attune us:

> Experience isn’t just about having the necessary knowledge. Experience is about how we use our knowledge to tune our attention. Our background can sensitize us to cues or patterns that others might miss… This notion of being attuned, of being sensitized, fits with the concept of a generally prepared mind. People with a generally prepared mind haven’t done specific homework to get ready for their insight.[33] Rather, their efforts and their interests have prepared them to notice things others miss. (p. 126)

Using this framework, and Turner’s similar recognition of experiences providing “an extra ‘level’ or layer of sensibility and vulnerability” (Gillard, Turner, & Neffgen, 2013, p. 63), we might understand resonance through relating as the unique ways Mad/psychiatric survivor researchers are prepared to notice things in data that others

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[33] Ahmed (2017) would likely object to this suggestion that homework hasn’t occurred or is not needed. She writes:

> Feminism is homework. ...Homework is quite simply the work you are asked to do when you are at home, usually assigned by those with authority outside the home. ...If feminism is an assignment, it is a self-assignment. We give ourselves this task. By homework, I am not suggesting we all feel at home in feminism in the sense of feeling safe or secure. ...Rather, I am suggesting feminism is homework because we have much to work out from not being at home in a world. (p. 7)

We might similarly suggest that Mad Studies and Survivor Analysis require homework - a self-assignment of working out we need to do as a result of not being at home in our world. We engage in extensive homework (and housework - building, transforming the master’s residence) to prepare ourselves for noticing things others routinely miss (Ahmed, 2017). Much of this labour remains unacknowledged and uncompensated by service user involvement schemes that, at best, pay us for our participation in meetings, not all of the work we do ‘at home’. The artificially imagined gap between ‘the university’ and ‘the community’ commonly promoted through the academy’s ‘community-engagement’ initiatives also ignores all of the living/working (‘homework’) we do in the community; Mad Studies are not only completed at the university, but also at ‘home’.

might miss.[34] This might include both the circumstantial conditions of our lives, as well as intentional efforts to learn, unlearn, practice, and affiliate, such as through care labour of other Mad people, Mad/disability politics and activism, and accountabilities to Mad epistemic communities. Additionally, Stauffer's (2015) work would suggest that one of the reasons Mad/survivor/peer researchers may be more sensitized to hearing quiet data is that we have been "disarmed" (p. 110); we know that we are not autonomously self-sufficient, and that worlds and selves can be destroyed through human violence and unresponsiveness. Thus, it may be that we become more attuned to how we and others are impacted by those around us and expansive in our views of what we collectively owe each other. Stauffer (2015) also argues that "[i]f hearing is meaningful, it has to be embedded in an openness where what is said might be heard even if it threatens to break the order of the known world for those who listen" (p. 80). For those of us who have had our known worlds already broken, and have experienced epistemic injustices that disrupt our certainty /confidence in our own knowledge, perhaps our bodyminds have been 'prepared' in such a way that we become more open to disruptive insights. Perhaps we also "acknowledge that [we] may not have already at hand the tools to understand what [we] will encounter" (p. 104), and thus are less inclined to enter story listening or data analysis with predeterminations of which stories will be heard and treated as relevant.

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[34] While Mad people/survivors may be especially attuned to forms of data that others might miss, Church's (1995) method of "double reading" (p. 126) suggests that would-be allies can learn (some of) these practices too, so long as they remain in ongoing dialogue with survivors.

Resonance as Resource for Hearing Quiet Data

As DeVault (1990) articulates, resonance through embodied experiences is a "resource for listening" (p. 104), and, in particular, a way to "focus on attention to the unsaid, in order to produce it as topic and make it speakable" (p. 104). This echoes writing on resonance as "refer[ing] to processes of vibration well above and below the range of human hearing and in a range of nonaudible mediums" (Porter, 2016, p. 458, referring to Goodman, 2010), such as the somatic and intuitive (Gershon, 2015). Resonance can play a role in helping us listen for resistance and for quiet data that might otherwise be missed, especially when it is vibrating in an alternative, non-dominant, routinely misinterpreted or delegitimized hermeneutical context (e.g. telling a story of resistance rather than a culturally expected illness, medication, recovery story). As described above, the sorts of quiet data that my particular engagement with resonances amplified were those related to labour/work (of resistance) and moral/ethical dimensions of service user relations with service providers (expectations), especially those manifesting at sites that may be pathologized (anger, resentment, distrust).

Kati Turner similarly argues for her service user perspective on data that she does not want to be lost:

> I remember being very vocal in the group meetings and quite insistent at times. It wasn't that I disagreed with what Steve and Marion were saying, more that I felt I had a perspective which they could not share and that it was incredibly important that this perspective did not get submerged or absorbed so much into our joint perspective that it lost its uniqueness. (Gillard, Turner, & Neffgen, 2013, p. 63)

What is missing from Turner's account is *why* it was important for a particular perspective to not be submerged, what that perspective was, and what the risks were of it being submerged by non-peer researchers on the team. To what extent was Turner contending for a quiet perspective grounded in a collective Mad politics? This information is commonly absent from writing on service user contributions to analysis, which tends to substantiate that service user researchers do identify and argue for unique themes (Happell et al., 2018) without clarifying why or how these themes emerge as important. In future writing, it is these components of the Mad/peer researcher role in data analysis that need further articulation. Perhaps the pertinent question is not, “Does service user involvement in mental health research produce different knowledge, and if so, how?” (Gillard et al., 2012a, p. 240), but “What politics/ethics/experiences do service user researchers bring to data analysis? How and why do these politics/ethics/experiences appear and inform what service user researchers attend to, interpret, and advocate for as important?”

Summary and Limitations

If, rather than slip it into our writing, we explicitly engaged with and wrote about resonance, we might find a friendly tool for generating Mad knowledge - discerning subtle, tacit ways of being/knowing that are not readily perceptible at the level of language or consciousness, especially not within our current hermeneutical frames and how they direct us to listen. This labour to recognize knowledge/knowing differently is inherently ethical work, calling us into different forms of responsiveness and accountability: As we develop and refine approaches for recognizing harm and resistance to harm (including unideal forms of resistance that may themselves cause/aggravate harm as they simultaneously redress it) these ways of Mad knowing come to made demands on us.

There are several limitations and risks to an analytic approach through resonance: First, it has been argued that “resonance is not an analytic technique. Rather, it stems from our very existence, our way of being and relating in the world” (Piantanida, 2012, p. 790, drawing on Gadamer, 1976). In many ways, this is how resonance feels to me as well - it just happens. My interest in writing about resonance as a process/approach is to make more transparent the provenance of the *Resistance* paper, and to inquire into what other service user researchers might mean when they refer to resonance with experience in their research. As it stands, survivor research appears to be adopting a social science-informed approach to inquiry with specific articulations of methods and processes. It may be worth further developing an argument against methods altogether, and to propose other approaches to recognizing and affirming knowledge through existing/living. Or, alternately, as St. Pierre (1997) models, to redefine all of the signifiers that are used within qualitative research, and through this redefinition, to explore other emergent possibilities. St. Pierre (1997), for example, explores how “think[ing] about different kinds of *data*… might produce different knowledge” (p. 177; emphasis added), and theorizes how emotional, dream, sensual, and response data inform her thinking/research. Mad /survivor research might engage in a similar project with the signifier ‘analysis’, to trouble what it means. Perhaps living/being is analysis. If so, what does this mean for how and what we know and notice knowers and knowledge?

It may be that, for a range of reasons, Mad analysis is impossible to describe. Especially when conceived as a sound wave, resonance may provoke affective responses that cannot be easily translated into language. As well, it is often difficult to thoroughly trace how and why certain themes resonate (or not) in the ways they do and to excavate underlying contexts (politics, ethics, 'experiences'), which encourages caution in our claims to comprehension. Doucet (2008) admits that "we may not always fully know what motivates our research" (p. 76), and it may be partway through our research or many years later (or never) when we realize underlying influences. Holbrook similarly describes the difficulty of tracing research analysis within the arts-based method of collage:

> When I think about breaking down the practices that went into the construction of a collage to provide a methods section that somehow conveys the rigor of that work, I literally shrug. I couldn't begin. Even if I had set out to somehow capture the practices, put up cameras turned on 24 hrs a day in every corner of my house, in my car, attached to my lapel, or even more directly, somehow affixed inside my eyeball or in the deepest part of my gut, I couldn't record all the places where my practices unfolded. (Holbrook & Pourchier, 2014, p. 757)

These challenges of tracing, finding words, and articulating resonances out loud to others (or in our writing) may be significantly more difficult for service user researchers who have had our epistemic confidence undermined. Kati Turner, for example, describes needing to "be very vocal… and quite insistent at times" (Gillard, Turner, & Neffgen, 2013, p. 63) regarding her analytic perspectives as a service user. In order for service user researchers to confidently express our knowledge, we need social contexts in which this knowledge is recognized; however, in order for our knowledge to be recognized, we need to assert what it is. To support the possibility of Survivor Analysis, we must cultivate conditions where Mad people can gain confidence in our knowledge/knowing processes.

Another complexity is that the themes that resonate through data analysis may - based on who we are, our contexts - vibrate through and reinforce existing hermeneutical infrastructure rather than amplify subjugated perspectives. This is especially likely if resonance in research analysis is contained to and quieted by one's personal experiences rather than reverberated through a broader /collective politics, making it more difficult for us to notice and seek to understand experiences to which we do not relate. This concern might be at least partly addressed by drawing on resonance as one technique in combination with others, such as collaborative discussion with peers or other colleagues (Gillard, Turner, & Neffgen, 2013; Voronka et al., 2014). My account is also constrained by attending to quiet data primarily at the stage of analysis, rather than earlier on in the research process, and by no longer having contact with participants at the time I was engaging with their interview transcripts.[35] Without an ability to reconnect with them and seek their input on developing analyses, I came to experience greater accountability to the Mad epistemic communities who will read and engage with the writing, and to theorizing in a way that contributes to our collective work.

A concluding worry is that we will present analyses developed through resonance with lived experience as innocent, shared, and automatically more ethical. At the end of

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[35] Although the project did, from the outset, focus on un/supportive spaces/relationships broadly defined rather than restricted to service settings - which did enable attention to quiet forms of support.

their paper, Gillard, Turner, and Neffgen (2015) frame resonance through lived experience as a strength of the research:

> Our collaborative, interpretive approach, described at the beginning of the paper, was a strength of the research. Throughout the analysis process the service user researcher on the team argued strongly that a lived experience perspective should guide and shape our analysis. We made explicit use of the service user researcher's personal resonance with interviewees' accounts to inform our descriptions of internal and external worlds experienced in conflict. (p. 11)

Resonance with lived experience may very well be a strength of an analysis, but this frame also risks positioning the contributions of people with lived experience and the arguments we gain confidence in through our data as outside of scrutiny (and may in some ways suggest a loosening of 'expectations' of us as scholars/knowers). As Russo (2016) observes, "a commitment to *giving a voice* to psychiatric patients makes any further reflection about ethics superfluous… mere interest in people's lives described in their own words is seen to guarantee a better and more ethical approach" (p. 220, emphasis in original). An unquestioning acceptance of a 'lived experience' perspective on analysis may also universalize what this experience is. A researcher quoted in Garfield et al. (2016), for example, expresses worry that if lay people receive too much training on data analysis or participate in too many research projects, "they may start 'coming to the data with a researcher's hat on'" (p. 8). This suggests the value of a lay person's involvement is to provide an uninformed/blank/neutral 'user' perspective (and 'only' a user perspective), as opposed to a skillfully honed and deeply contextualized political perspective, responsibility, or ethics. Voronka (2016), who seriously questions the possibility of change through peer participation in research, argues that an essentializing of ‘lived experience’ can erase very significant differences across Mad people’s research politics and how they inform our work:

> By positioning ourselves, and being positioned, as ‘experts by experience,’ we are hailed into leading and co-producing research that has the opportunity to solidify, retrench, revision, or radically disrupt dominant ways of doing mental health research. Some of us as ‘experts by experience’ want more of the same; some of us want to transform systems; some of us want to tear them down. Lived experience in and of itself does not dictate our approach to the topic at hand. (p. 198)

What is clear is that data analysis is political, and we could all benefit from further discussion on what a politics/ethics of analysis that recognizes and responds to quiet Mad knowledges on their own terms might require.

Closing: Multisensory Methodologies

This focus on sonic forms of analysis (listening for resistance, quiet data, resonance) is well-aligned with Fricker (2007) and Stauffer’s (2015) work to address injustices that occur when people are unheard in their testimony of harm or efforts to develop and exchange knowledge. Given the general agreement that Mad knowledges are embodied, we may want to explore the potential of multisensory methodologies - such as those related to sound - for Survivor Research and the theorization of Mad onto-epistemologies and epistemic justice. Daza and Gershon (2015) explain the opportunities of sonic inquiry as follows:

> Sounds are present in the tone and tenor of talk, the dissonance and consonance of relationships, the echoes of the past reverberating ever forward, resonances of possibilities and power, and in the embodied, imbricated now. Sonic methodologies avoid ocular binaries of framing or an Othering gaze. Sounds provide a means for spaces, people, and objects to resound and articulate that the impossibility of closing an earlid is a possibility for more socially just, ecological methodologies. (p. 639)

By drawing on other multisensory methodologies and the range of sensory experiences for being/knowing madly, we will be able to further articulate what Mad knowing looks/feels/tastes/smells/sounds like, and to address the ableist limitations of an exclusive focus on hearing or vision/sight.

Further Questions and Future Work

The articles in this thesis call for future work in a range of directions, which are briefly elaborated here.

Epistemic Injustices and (Loneliness) in Mad Communities

A critique that Mad Studies and other activist/critical engagements with madness have failed to engage with emotion/feelings/pain (see Whynacht, 2017ab, 2018), could be theorized as a form of epistemic injustice in Mad communities - especially a hermeneutical form where we have inadequate interpretive resources for understanding these experiences due to the privileging of other areas of scholarship/thinking/activism. Not being able to hear these expressions of harm is also a characteristic of ethical loneliness. Another example might be the erasure or misrecognition of difficult knowledge through contemporary struggle to make the knowledge gained through 'lived experience [of madness]' 'useful'. As Voronka (2015) affirms, "the recent turn to value and validate the lived experiences of madness is a markedly new development and holds many possibilities. Yet, what does this move us towards?" (p. 306). Of utmost concern in this thesis, as further developed in the *Loneliness* paper, is that a focus on Mad knowledges as only useful /positive can contribute to the disavowal of knowledges emerging in the wake of harm. Consequently, when we advocate for the formation of roles for service users in mental health service systems (e.g. as peer workers, educators, service user researchers), we risk entrenching forms of epistemic injustice /epistemic loneliness if and when we come to value, promote, and encourage certain ‘productive’ Mad knowledges, and fail to grapple with knowledges that are difficult to bear or that we should not know. Future research might further investigate these dilemmas and more expansive ways of recognizing and critically evaluating and engaging with forms of Mad knowledge - and what they make perceptible and further obscure.

Mad Mourning and Remembrance

In the *Loneliness* paper, I indicate that the condition of epistemic loneliness is attached to experiences of loss and bereavement. While there has been some initial writing on Mad grief (Poole & Ward, 2013), further theorizing loss and mourning in Mad Studies might help to articulate other compounding forms of (epistemic, ethical) loneliness produced by the harms of sanism. No doubt the erasure of Mad people’s histories and testimonial accounts - including a lack of witnessing of violent treatment and death that occurs, in part, because we are deemed not to be valuable knowers /persons - has an impact on our experiences of epistemic loneliness. For some of us, especially Mad activists/community organizers, our loneliness may also be related to our proximity to the death of those we organize with and for, and in our efforts to bear and be responsible for knowledges that are difficult. If we paid further attention to the links between loss and loneliness and between ‘moving with loneliness’ and Mad mourning, this may call us to particular responses. For example, supporting Mad folks with our epistemic pursuits may mean creating spaces for us to grieve and build knowledge of mourning without being seen as ‘at risk’, interpreted with alarm, and referred away.

While Stauffer (2015) convincingly outlines the limitations of Truth and Reconciliation Commissions and other institutionalized procedures and mechanisms of redress, these forms of formal recognition do not generally exist (yet) in the context of Mad Studies, leading scholars like Spandler and McKeown (2017) and activist groups like Our Voice/Notre Voix (LeBlanc, 2016) to ask whether a Truth and Reconciliation process or apology is needed to address psychiatric forms of violence. Future scholarship could explore the range of writing and thinking on remembrance, memorialization, apology, and other forms of envisioned or demanded response within Mad/Disability communities; what these analyses tell us about epistemic/ethical loneliness and repair; and implications for Mad ethics, epistemologies, and pedagogies.

Mad Ethics

The *Resistance* paper makes a case for the further generation and synthesis of Mad/service user ethics as forms of knowing and relating, and their implications for social work. These could be developed through both theoretical engagement with other writing on disability bioethics, narrative ethics, and research ethics; patient ethics; service user perspectives on ethical issues like boundaries, disclosure, and trust; and disability studies, feminist, and other liberation-focused engagements with moral philosophy and virtue ethics. Given the current state of service user ethics, which are largely intuitively lived rather than formally synthesized through systematic ethical frameworks (Brodwin, 2016), a sociomaterial approach to inquiry in this area may help in elaborating Mad onto-ethico-epistemologies and the workings of ‘matter’ in Mad moral talk and service user intra-actions with service providers (see Fenwick, 2016; Fenwick & Nerland, 2014). The *Resistance* paper, for example, quotes participants speaking about tea and slippers (Participant 4), marijuana and prescribed medication (Participant 7), money/pay for work (Participant 16), and the feared possibility of being physically beaten up (Participant 2), as well as concepts of truth, boundaries, care, help, listening, acceptance, belonging, fear, safety, claims. How do these and other phenomena come to matter in service user enactments of moral norms /ethics? As we can see in the *Loneliness* paper, materials like suicide alertness stickers, certificates of mental health training completion, anti-stigma elephants, and referral instructions play a significant role in the creation of epistemic loneliness. Further work could more fully examine how matter matters, especially in the identification and practice of more ethical forms of relating and response.

With a sparse body of empirical literature, there is much more that could be done by engaging disabled and Mad people and service users directly with regard to the development of disabled/Mad moral norms. A particular area that service user ethics may be able to make a needed contribution is what I have been referring to as Mad (d)e(a)thics - the ethics of how we mourn and tell stories about members of Mad communities who die by suicide. I have attended several memorials that aggravated rather than eased epistemic forms of loneliness; they erased my loved one’s Mad knowledge and participation in Mad communities by posthumously reinforcing psychiatric mental illness paradigms. While our movement has importantly encouraged the creation of crisis plans and psychiatric advanced directives, we have fewer public conversations about instructions for after we have died. Ethical knowledge related to Mad death and bereavement is of great importance to Mad communities. It could also start to inform social work practice by, for example, influencing how we think about, teach, and monitor adherence to professional codes of ethics (such as ‘ethical’ requirements of ‘referral’).

Mad Resistance

While there appears to be little writing in Mad/Disability Studies that explicitly theorizes resistance and/or connects these theorizations to the wider tradition of resistance studies (e.g. Andersen et al., 2017; Gabel & Peters, 2004; Peters, Gabel, & Symeonidou, 2009; Swerdfager, 2016), nearly every piece of Mad/disability scholarship I have read casually references resistance in some way. Given the wide use, with differential meanings, and little intentional theorization of what we mean by this term/action or the function it plays in our scholarship, it could use further theorization. How is this word/term used, with what effect? What does it make visible? What is further obscured?[36] What moral norms are Mad/disabled people enacting through varied expressions of resistance?

Survivor Perspectives on Partnership

Considering the *Confidence* paper in relation to this thesis as a whole, we might think more broadly about what Mad Studies can offer pedagogical partnership approaches and literature, beyond the framework of epistemic justice. For example, psychiatric

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[36] Orr’s (2012) writing from within Women’s and Gender Studies on the prevalence, use, and lack of definition of the keyword ‘activism’ may be especially helpful here as an example of what a word comes to do within a discipline.

survivor communities have a long and contentious history with the notion of 'partnership' - with service providers, primarily - and question whether we should be collaborating with academics or mental health professionals (Costa, 2015; McKeown, Cresswell, & Spandler, 2014; Roper, 2016). What might these particular histories, analyses, troubles, complexities offer the relatively new focus on student-faculty/staff partnership in higher education? What might service user ethics offer the values and principles that pedagogical partnerships promote? The *Resistance* paper, for instance, complicates a simple emphasis in service settings on 'trust' and explores service user ways of orienting to dis/trust, which may provoke alternative avenues for thinking about collaboration in higher education. Conversations between pedagogical partnership in academia, university efforts at 'community-engagement', service user involvement in mental health systems and health professions education, and Mad Studies/ethics and psychiatric survivor organizing, might enrich both the sorts of partnerships we undertake and how they work, as well as Mad ethics for rejecting/refusing partnership, choosing separatism or more conflict-based rather than consensus-driven methods of creating change.

A significant dilemma arises here: service users regularly indicate that their confidence is bolstered by participating on research teams, such as with clinical /academic researchers (Beresford, 2007; Russo, 2012; Stevenson & Taylor, 2017). Yet these types of projects, which are not typically survivor-directed or controlled, can get us into troublesome territory when they use Mad knowledges to comment on or improve services, rather than prioritize the development of our knowledges on their own terms. Within the narrow scope of these collaborations, we may also feel forced to draw on individualized accounts of our experiential knowledge (of madness, service use), and to suppress difficult and politicized knowledges formed through harm and Mad epistemic communities. Consequently, it is entirely possible for us to be empowered or to gain confidence from politically questionable initiatives. As a participant in Kalathil (2008) comments, “It’s a bit of a trade off really – we’ll provide you with confidence building skills and you provide us with stuff that we can say we’re doing user involvement and we’ll be both happy and we won’t cause too many waves” (p. 19). In light of this critique, we need to remain skeptical of opportunities for confidence building when they are not also accompanied by systemic change; confidence-building cannot become “an exercise in itself” (p. 19).

If epistemic/psychic confidence is something we do indeed want to foster in an effort to redress forms of psycho-emotional-epistemic disablism, then what partnerships/projects enable these relational and affective potentialities, without compromising our politics and responsibilities to Mad epistemologies? What are the wider change possibilities of initiatives focused on altering the relations between us, or fostering the epistemic confidence of Mad/disabled people? Hollomotz (2013), for example, referring to the work of Hingsburger (1995), comments on how “only those who practice decision-making in respect to mundane issues will feel confident enough to speak up about ‘big’ decisions, such as deciding whether they should speak up against derogatory treatment” (p. 56). Just as mundane forms of oppression underlie and can accumulate into egregious and overt forms of mistreatment and bodily violence

(Hollomotz, 2013), the cultivation of everyday confidence and practices of resistance may have a significant role to play in struggles for justice.

Revisiting Structural Approaches to Justice

While I have taken the critiques of legislative/human rights approaches to justice seriously in this thesis, and explored alternative frames, I am not proposing that these institutional mechanisms are not worth participating in, whether as community-engagement staff in the university, accessibility compliance officers, disability accommodation workers, mental health service providers, or employment equity specialists. What I think these positions can specifically offer is a capacity to de-mystify the university for students, staff, and faculty from equity-seeking groups, as is explored in the *Confidence* paper. By working within the institution, these staff can become very good at understanding how the institution works - information that can be used to support Mad/disabled/marginalized students (and staff) in their negotiations of campus. When I have been in these roles, they are essentially a kind of academic peer work bridging the institution and the people I care about. Being more explicit about how things work and why, and about the specific strategic importance of particular activities and their limitations - and pushing back at these - can stop us from simply following instructions. We can use our insider positions to figure out and question (navigate, manipulate, feign integration in) academic conventions, becoming more aware of our own rights and entitlements in the process that can help sustain our work. We can interfere with the directions to refer Mad students to counselling and/or the accommodation office as all that's expected and institutionally endorsed, seeking instead to imagine and offer other types of support. We need wider understandings of what we owe each other beyond the technicalities of our roles - recognizing how there are those of us already taking on wider responsibilities, and that the labour involved in this has never been equitably distributed (Ahmed, 2017). We must continue building alternatives to legislative compliance and service provision approaches to distress and inaccessibility. This might involve further theorizing the psychic-affective-epistemic harms experienced on post-secondary campuses, and developing relational approaches to address them.

Conclusion

As a whole, this work explores what it might mean to live a Mad politics. Central to this politics, and to the overall contribution of the thesis, is its focus on (1) the recognition and redress of affective-epistemic harms that are often ignored by legislative/social welfare approaches to in/justice; and (2) the generation and refinement of Mad knowledge/ways of knowing that respond to our own priorities as Mad people, rather than those of mental health systems. It contributes to these areas of Mad Studies theory in several ways: First, by recognizing and politicizing the often ignored affective-epistemic effects of abandonment and neglect Mad people experience from society, including loneliness, anger, resentment, distrust, low expectations of others and lack of confidence. Second, by seeking new conceptualizations (such as epistemic loneliness), and contributing to existing ones (like expectations of just treatment, psycho-emotional disablism) in order to more adequately interpret and attest to these harms and call for their redress. Third, by affirming emergent Mad moral and epistemological frameworks, especially those that manifest in the aftermath of harm and account for ontologies of knowing. Fourth, by developing Survivor/Service User Research approaches to analysis (listening for resonance, everyday forms of service user resistance, and ‘quiet’ data) that value affective engagements with data and perceive and respond to Mad onto-ethico-epistemologies in and on their own terms.

This thesis ultimately calls for greater relational justice, an expansion of what we owe each other, and alternate ways of relating. It focuses on “the spaces between us” (Whynacht, 2017b, p. 57), rather than developing or improving structural mechanisms for addressing injustice. Seeking relational justice is one strategy for challenging sanism and associated privileging of law, reason, independence, and unemotional, objective knowledge. A focus on relational justice encourages us to instead revalue emotions, relationships, and interdependence (Poole, 2014). I began my doctoral work and this thesis with questions about how to live a sustainable and responsible Mad politics. The conversation above - while full of holes, of stories I cannot tell - is my preliminary attempt at thinking/working/living this through. Rather than be useful, used, put to use, I hope it offers a form of company, accompaniment, and that it moves. It has moved me.

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