



ORIGINAL ARTICLE

Power *of Self* as the Resource and the North Star: A Discursive Analysis of Lived Experience Leaders' Constructions of Lived Experience Leadership

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Abstract

Lived experience leadership represents a means to effect much-needed systems transformations across the mental health sector, and yet remains largely underutilised. One barrier to the recognition and resourcing of lived experience leadership as such may be a lack of clarity regarding its nature. To redress this barrier, the current study aimed to produce an account of the defining features of lived experience leadership, as understood by those engaging in its practice. Interviews were conducted with 19 people defined by their peers as lived experience leaders, in which they were asked to discuss lived experience leadership and related concepts such as authority, power and influence.

Discursive analysis of interview data produced an understanding of lived experience leadership as defined by people with lived experience's use of a certain type of power: an experience-based and systems-informed knowledge of and fidelity to themselves as both individuals and as a collective. Results suggest that lived experience leadership is distinct from other forms of mental health leadership and offer influential figures a means to identify and thus appropriately support lived experience leadership in its own right.

Keywords

Mental health, consumer leadership, survivor leadership, service user leadership, lived experience perspective, lived experience involvement, experts by experience

History

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Since the 1970s, recipients of psychiatric diagnoses have mobilised to articulate and oppose the discrimination and oppression they experience as people constructed as having a "mental illness" (see Chamberlain, 1990; LeFrancois, Menzies & Reaume, 2013; Russo & Sweeney, 2016). As part of this movement, people traditionally cast as "patients" within the mental health system have actively pursued political change and the development of

alternative ways of understanding and responding to distress (Chamberlain, 1990). More recently, there has been increasing recognition of the need to develop and promote lived experience leadership as a means to effectively realise such change (Byrne, Stratford & Davidson, 2018).

The phrase “consumer leadership” was introduced into the academic lexicon by service user academic Sarah Gordon in 2005 to challenge the presumption that the involvement of people with lived experience (people with LE) in the mental health sector ought to depend on the benevolence and leadership of non-lived experience professionals (Gordon, 2005). Upon its introduction, this phrase was recognised by advocates as a rhetorical device with which to both signify the existence of lived experience leadership and shift the focus from people with LE’s ‘participation’ in services to their control over or meaningful involvement in decision-making at individual and systemic levels of the mental health system (Gordon, 2005; Happell & Roper, 2006). Academics and advocates have since continued to use the rhetoric of lived experience leadership; such phrasing has also begun to appear in mental health policy documents and mainstream mental health vernacular (e. g. National Mental Health Commission, 2019; Stewart, Scholz, Gordon, & Happell, 2018). Nevertheless, lived experience leadership remains largely underdeveloped or underutilised in practice (Byrne et al., 2018).

A lack of clarity regarding the nature of lived experience leadership has been identified as a barrier to its realisation (Stewart et al., 2018; Storey, 2011). Since its advent, lived experience academics and advocates have argued that lived experience leadership is distinct from their experiences of conventional leadership and so ought not to be conflated with such practices (see Carr, 2010; O’Hagan, 2009). However, few empirical studies have been conducted to explore what people with LE use the phrase “lived experience leadership” to represent, if not conventional leadership. Without such an understanding, lived experience leadership remains vulnerable to co-optation and unchecked misappropriation, with consequences for its resourcing and meaningful development. For instance, research has identified that stakeholders including mental health clinicians, executives and policymakers may apply the term to practices tantamount to tokenism, thus failing to recognise and redirecting resources away from lived experience leadership as it is understood by people with LE (El Enany, Currie, & Lockett, 2013; Storey, 2011). Research also suggests that stakeholders may define lived experience leadership in ways that are internally inconsistent, rendering it impossible for people with LE to demonstrate lived experience leadership to satisfaction or otherwise garner support for its practice (Stewart et al., 2018).

There is thus an imperative to substantiate the concept of lived experience leadership, as understood by people with LE themselves. To contribute to this effort, the authors of the current study sought to explore how lived experience leadership is constructed by people with LE.

A Note on Language

People with experience of distress and psychiatric diagnosis self-identify by various terms, including ex-patients, consumers, survivors, or people with lived experience of trauma, neurodiversity, or mental health challenges (Daya, Hamilton, & Roper, 2020; VMIAC, 2019). These terms are used differently across contexts or for different strategic purposes, and can indicate political affiliation or refer to distinct identities (Speed, 2006). While acknowledging this complexity, the authors of this article will use one term-‘people with LE’- to refer to people with experience of distress and psychiatric diagnosis, mirroring the language used by Byrne and colleagues (2018).

Method

Philosophical Paradigm

Study design was grounded within a critical-ideological paradigm (Ponterotto, 2005). Within this paradigm, realities are considered socially constructed and thus subjective and context-dependent (Kemmis & McTaggart, 2000); values, positionality and ideologies are therefore implicated in the production of knowledge (Kincheloe & McLaren, 1994) and are acknowledged as informing study design. Consistent with both the aims of the lived experience movement, with which the researchers are aligned, and the principles of critical-ideological research, this study was designed to disrupt and challenge rather than reproduce the status quo, and so support the emancipation of people with LE.

Participants and Recruitment

People considered lived experience leaders by their peers were sought for inclusion in this study. Inclusion criteria and recruitment methods were designed to identify people considered lived experience leaders by people with LE without predefining the nature of lived experience leadership. Construction of inclusion criteria was informed by previous research on lived experience leadership and statements made by people with LE regarding lived experience leadership. Per these criteria, participants necessarily:

- a) Identified as a person with LE or by another similar term (see Byrne, Roper & Happell, 2012).
- b) Held a decision-making role within the mental health sector, as a person with LE (see Stewart et al., 2018).
- c) Were identified as lived experience leaders by their peers.

Recruitment was initiated via Australian lived experience organisations, whose members were asked to nominate people they considered to be lived experience leaders for potential inclusion in the study. Nominees were contacted to confirm they met all inclusion criteria and

offered the opportunity to take part in a semi-structured interview. At the end of each interview, participants were asked to nominate people they considered lived experience leaders for inclusion in the study.

The final sample consisted of 19 people identified by their peers as lived experience leaders. All participants provided written informed consent.

Data Collection

Interviews were 56-174 minutes in duration. The interview guide allowed participants to reflect upon their conceptualisations of lived experience leadership and related concepts such as authority, power and influence. Participants are identified by their name or pseudonym of choice, per their preference.

Data Analysis

Data were analysed using thematic discourse analysis (Braun & Clarke, 2013) and multiple approaches to discourse analysis including critical discourse analysis (Fairclough, 1995; Fairclough & Wodak, 1997), discursive psychology (Potter & Wetherell, 1987), and discourse theory (Laclau & Mouffe, 1985).

Analysis was initiated via transcription of audio files and familiarisation with the data corpus; transcripts were reviewed and approved by participants. The data set was then defined as extracts in which lived experience leadership was discussed. Extracts in which lived experience leadership was explicitly mentioned were analysed initially; extracts in which participants discussed their own practices (arguably demonstrable of lived experience leadership given their nomination by peers as lived experience leaders) were coded and collated in later stages of analysis, as a means to check the credibility of the themes developed and increase the breadth and depth of analysis.

Analysis proceeded via open, inductive coding of the dataset; codes were reviewed so as to identify key words or concepts around which meaning pertaining to lived experience leadership was organised ("key signifiers"; Laclau & Mouffe, 1985). These key signifiers were treated as categories of a coding schema, which was applied to recode and collate data extracts for further analysis. Collated codes were then developed into themes, a process involving consideration of the meanings attributed to each key signifier, the relationships between each key signifier and lived experience leadership, and the relationships between different key signifiers. Participants were invited to review analysis as it occurred, and to review drafts of this article prior to publication; analysis was informed by participant feedback.

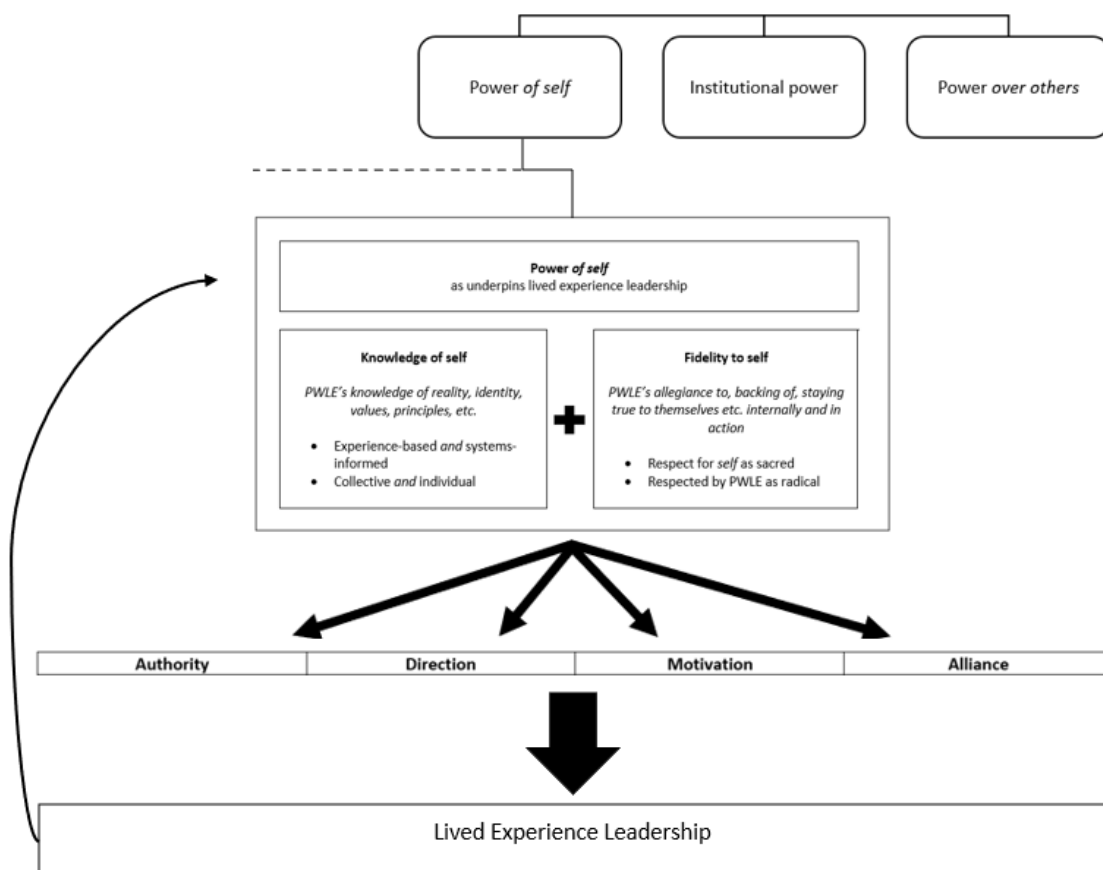
Findings

Participants differentiated between lived experience leaders who embodied their conceptualisations of lived experience leadership, and lived experience leaders who they

felt would be categorised by others as such by virtue of their role or title, but who did not exemplify lived experience leadership as participants understood it. As summarised by Andrea: “the altruistic [people with LE] are the genuine leaders... the other people tend to be quite effective at getting on boards”.

Lived experience leadership, in the sense endorsed by participants, did not merely denote mainstream leadership practices performed by people with LE or their engagement in traditional leadership roles. Rather, analysis of participants’ constructions produced an understanding of lived experience leadership as defined by people with LE’s use and expression of a particular kind of power. This power, and its role in the realisation of lived experience leadership, is explored below.

Figure 1. *Overview of Analysis*



Note. This diagram depicts analytic findings positioning *power of self* as the foundation of lived experience leadership. Specifically, this diagram indicates that among many possible iterations of *power of self* (indicated by the dashed line), lived experience leadership is grounded in an iteration of *power of self* comprised of experience-based and systems-informed, collectively- and individually-constituted self-knowledge that is respected as sacred and radical. Furthermore, this diagram depicts this *power of self* as a source of authority, direction, motivation and alliance and thus as realising lived experience leadership; in turn (as depicted by the upward arrow on the left) acts of lived experience are depicted as reconstituting PWLE’s *power of self*.

The following analysis is complex, warranting orientation to its structure. We begin by deconstructing the different ways participants discursively constituted power- as power *over*, as institutional power, and as power *of self*. We then identify power *of self* as the form of power foundational to lived experience leadership- specifically, an iteration of power *of self* distinguished by a) the context in which it is experienced, and b) the composition of the “self” in which it is grounded. Having established its nature, we then explore *how* this power eventuates lived experience leadership as a source of authority, direction, motivation and alliance. A summary of our analysis is depicted in Figure 1.

A Complex Relationship with Power

Participants’ discourse positioned power as simultaneously incompatible with and fundamental to the realisation of lived experience leadership. This section will explore the relationship between lived experience leadership and key conceptualisations of power: power *over others*, institutional power, and power *of self* (summarised in Figure 2).

Rejection of Power Over Others

Participants roundly rejected any desire for power *over others*, attributing this rejection to their own personal and people with LE’s collective experiences of disempowerment in their interactions with the mental health system:

“If you’ve been very powerless- sectioned, held down, injected... if you’ve been subject to that kind of power, where people actually have power over your body and consciousness, how then do you navigate to a position where you want that power to be used positively?” (Avery)

As in this extract, power *over others* was positioned as incompatible with participants’ identities and ethics as shaped by their lived experience of mental health service use.

Consequently, participants rejected an affiliation with leadership insofar as they considered leadership to be associated with such power: “the word leadership... will bring up stuff about authority and people don’t want to be seen to be hierarchical or in authority when they’re kind of fighting that in the system as well” (Tracy). Like Sarah, participants embraced the concept of leadership *only* where they considered it distinct from holding power *over others*:

“Power [over others] for me is something that is often associated with abuse of process, abuse generally... I don’t really like to consider having power... I like to think about being collaborative. Rather than having power, leadership would be a concept that would sit better with me [because] you can lead *with* or produce *with*”.

By virtue of their experiences, power *over others* was rendered incompatible with participants' constructions of lived experience leadership.

Lack of Institutional Power

Many participants constructed themselves as lacking institutional power. For instance, Hannah contended "I've autonomy over myself and control of myself and what I do... but in terms of the service itself, no, I wouldn't say [I have power]". Similarly, Rowan reflected:

"I'm aware of power and how it works... but I don't often go round thinking I've got power. I've built up a reputation and respect and knowledge over many years as a [lived experience] leader... that can get me entre into some things, but it can also get me marginalised".

As suggested by Rowan's reflection, access to institutional power was not necessary for the realisation of lived experience leadership.

Nevertheless, institutional power was positioned as far from incompatible with lived experience leadership. For instance, Jay stated:

"The game has always been around resource allocation, the power dynamics in services... shifting the balance of power in order to address that... paternalistic platform... where the service user was a passive recipient of a service. When I talk about leadership, it's about having that active role in the... design of services using my experience, good and bad".

Like Jay, participants positioned access to institutional power as compatible with lived experience leadership and conducive to its aims.

Ownership of Power of Self

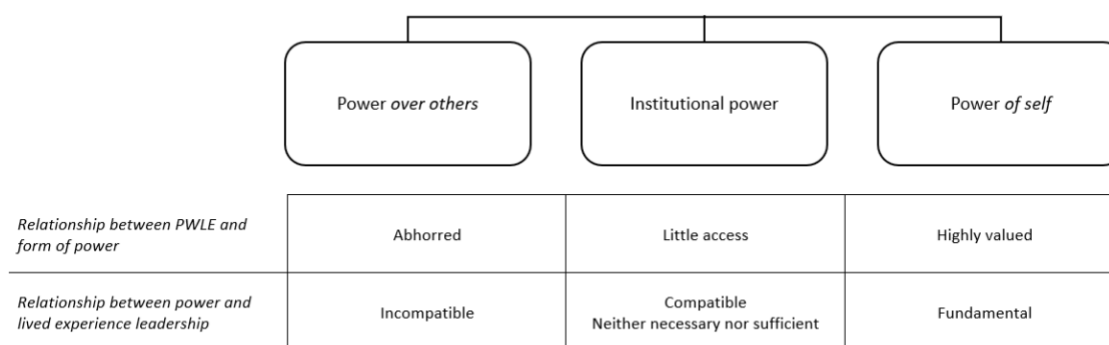
In contrast to their rejection of power *over others*, participants unanimously owned exercising power in another sense, described variously as "internal authority" (Cameron), "agency" (Avery), "autonomy and control over [self]" (Sarah), "strong spirit" (Taylor) and "personal power" (Hannah), among other identifiers. This sense of power was constructed as a *knowledge of* and *fidelity to* self. That is, participants constructed their power as grounded in experience-based self-knowledge, and realised via their acknowledgement of and allegiance to this sense of self, as exemplified in this quote by Bailey: "you have an innate authority based on the experiences you have, and that authority is meaningful... [we] start from there". Like Bailey, participants claimed this power *of self* as the foundation of their work.

Participants constructed power *of self* as expressed via acts of agency grounded in self-knowledge: "it's taking our own values and giving voice to what we think and we believe" (Alex). Simultaneously, acts of agency were constructed as enabled by people with LE's power

of self. In Cameron's estimation, "[this power] is about... feeling authorised in yourself to stand for something, to stand up for something". Across the dataset, participants identified acts of agency inclusive of knowledge production, decision-making, active involvement and adherence to principles as expressive of and enabled by power *of self*.

People with LE's power *of self* and its expression via acts of agency were constructed as inherent to lived experience leadership: "being in your own authority, being able to hold your own position against power, is another thing that's about [lived experience] leadership" (Cameron). For instance, while grappling with her identification as a leader Avery noted "I have agency, I'm doing this- and maybe that's what leadership means"; in so doing, Avery positioned ownership and exercise of power *of self* as definitional of her leadership. Indeed, regardless of their comfort in identifying as a leader, participants identified their engagement in acts of agency- acts expressive of and enabled by power *of self*- as constitutive of leadership: "I'm quite resolute in the things that I believe and stand for, so I put them out there- maybe that's a way of trying to lead" (Alex). Unlike power *over others*, people with LE's power *of self* was constructed as fundamental to the realisation of lived experience leadership.

Figure 2. Participants' conceptualisations of power



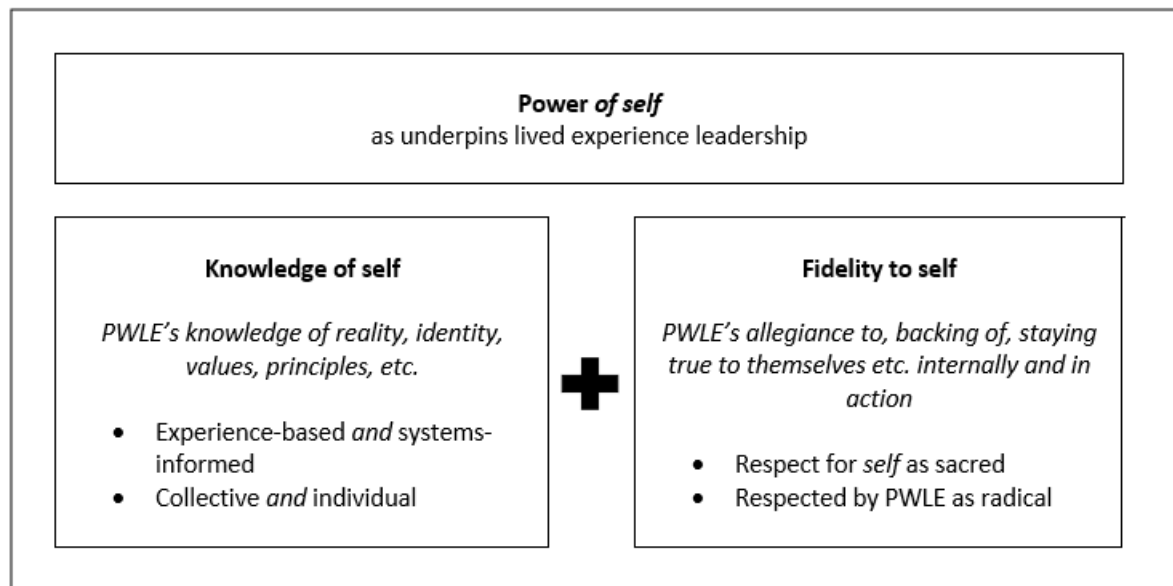
The Power Foundational to Lived Experience Leadership

Participants constructed the power fundamental to the realisation of consumer leadership as a specific iteration of power *of self*- one experienced in relation to a particular context, and oriented to a particular sense of self. This section will explore these particulars in turn (summarised in Figure 3).

Experienced in a Particular Context

Participants positioned people with LE as relating to power *of self* within a particular context. As experienced by participants, societal and psychiatric norms positioned people with LE as lesser- of less worth, credibility or capability: "the service user is at the bottom" (Hannah). Consequently, people with LE's contexts were characterised as systematically disempowering: "all [clinicians] have to do to disempower and discriminate is to follow the bloody rules...

Figure 3. Components of the specific iteration of power of self eventuating lived experience leadership



we're dealing with people who are acculturated by the design of the service into disempowering the people that they work with" (Jay). Participants identified the discrimination and oppression they experienced within these contexts as impacting on both people with LE's sense of self: "what the psychiatric system is able to do to people... it's not only the explicit coercion, its more subtle ways in which if you didn't start off hating yourself, you do by the end" (Avery) and their expression of agency:

"If you've had 10, 15, 20 years of a doctor saying 'you don't have the capacity to make a decision for yourself', to then be in a space to be making decisions... [there's] complexity around finding [your] own authority in that space" (Cameron).

Ultimately, participants framed people with LE as existing within contexts characterised by ongoing disempowerment as service users, lived experience workers, and within society generally.

Just as participants' abhorrence for power *over others* was attributable to their personal and people with LE's collective experiences of discrimination and oppression, so too was their valuation of power *of self*:

"Most of [what] happens, the one thing that gets crushed is that strength, that inbuilt strength that we have as humans and I feel that the mental health system, if it killed anything nearly in me, it was that... that's what the damage is, that's what I fight for. I say no, this system should be about cultivating people's strength" (Jay)

As this quote illustrates, power *of self* was afforded greater importance to participants by virtue of the backdrop against which they experienced it: people with LE's power *of self* could not be taken for granted in light of its active destruction via the mental health system. Having experienced its deficit, participants afforded power *of self* great respect, refusing to sacrifice their own: "I hold really strongly to my sense of integrity" (Cameron) or encroach on others': "it just doesn't feel morally right to be directing another service user because they've been directed all their life just like I have" (Avery). Viewing society broadly and the mental health system specifically as having constructed a subject position for people with LE that denies them access to power *of self*, and in recognition of its importance, participants positioned realisation of consumers' access to power *of self* as central to their advocacy efforts:

"Society defines us and we have to then collectively organise to say 'hang on, we've got the same needs to live full contributing lives as anybody else, so don't label us or discriminate against us in ways that make that harder'" (Rowan).

Rather than presupposed, participants positioned power *of self* as sacred, and of central importance to their work.

By virtue of its contrast with societal norms and expectations, people with LE's reclaiming and maintenance of power *of self* was rendered not only important but *radical*. That is, power *of self* was considered intrinsically human, unexceptional in its own right: "[it's] a given... not entitlement" (Hannah). However, in relation to people with LE's active disempowerment within the mental health system and broader society, power *of self* was made remarkable, maintained against the odds: "it's having this kind of really strong spirit... people are actively containing you, physically and chemically and... legally and every way, but you just don't let yourself get tamped down" (Taylor). Thus, people with LE's ownership and exercise of power *of self* was constructed as radical not in its own right, but because people with LE were positioned as though they shouldn't have any such power.

So contextualised, participants constructed people with LE's claims to personhood, knowledge production, adherence to principles and decision-making as acts of resistance: "we're saying you have to share that space with somebody who can equally make a decision... somebody you traditionally looked down on as a passive recipient... our leadership style as survivors is challenging that very belief" (Jay). Ultimately, the meaning of the power *of self* underpinning lived experience leadership was informed in part by people with LE's specific experiences of disempowerment.

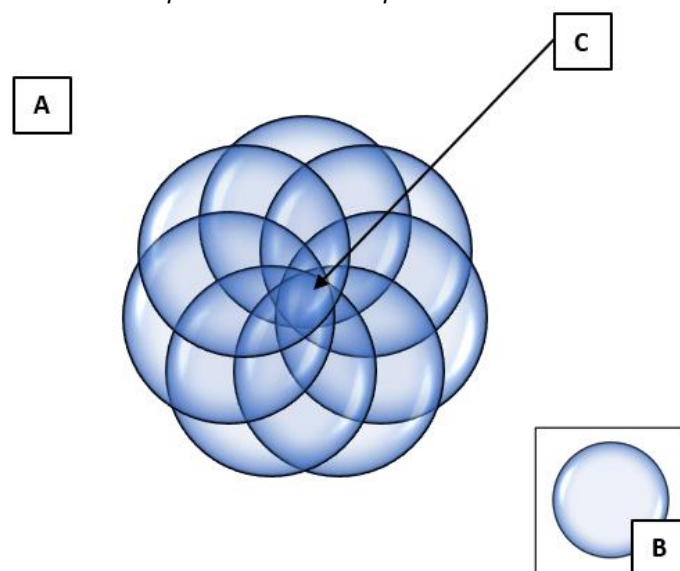
Oriented to a Particular "Self"

While participants constructed lived experience leadership as constituted of acts of agency grounded in self-knowledge- acts expressive of power *of self*- not all such acts were recognised as lived experience leadership. For instance, Andrea distinguished between lived experience leadership and people with LE's performance of a leadership oriented to "self-

interest”, describing the latter as “no different to the status quo”. Thus, lived experience leadership was not determined solely by people with LE’s expression of power *of self*.

Instead, lived experience leadership was further determined by the nature of the “self” being expressed. Rather than orienting to an isolated, singular concept of “self”, Rowan contended that lived experience leadership “is not just about individuals, as important as that is, but actually trying to make something collective and shared out of those many diverse voices”. In Bailey’s view, lived experience leadership stands in opposition to the “very strong neoliberal view that health care is an individual responsibility... it says... ‘systems and structures exist, there are structural inequalities that are in place, and they can only be addressed from a collective position’”. Thus, participants identified lived experience leadership as manifest exclusively in those acts of agency reflecting people with LE’s knowledge of and fidelity to themselves not only as individuals, but as a collective.

Figure 4. *The self central to lived experience leadership*



Note. This figure depicts the *self* central to lived experience leadership as constituted by and in relation to (A) context, inclusive of systems and structural elements, (B) PWLE’s experiences, of which there are overlapping and unique elements, and are positioned both differently in relation to context and are clustered together, and (C) shared experiences and collectivised understandings of PWLE in relation to context. Note that (A) has been placed in the space surrounding and permeating through the bubbles, while (B) has been placed on a bubble artificially separated out from the rest so as to clearly show these aspects of the composition of the more complex *self* underpinning lived experience leadership.

Furthermore, participants constructed the self-knowledge grounding lived experience leadership as derived of both experiential knowledge and the application of a systemic perspective. For instance, Drew reflected that lived experience leadership connoted a knowledge base informed by both “policy and practice [and] what people experience, how it actually feels to use a service”. Similarly, Charlie contended that lived experience leadership is based on experience and “an understanding of issues of power... an understanding of the

whole legacy of the mental health system and the consumer movement, that historical thing... [and] an understanding of how the whole system works- a critical understanding, not just a descriptive understanding". In sum:

"What [lived experience] leadership can mean in its broader sense is that there's a collective knowledge... a combination of knowledge from your lived experience and what's happened in our lives, about what we've learned from the collective knowledge of the [lived experience] movement, and also going to meetings and learning about the system and finding out about how policy works and legislation and funding and... community development as a discipline". (Drew)

Lived experience leadership was thus defined not only by people with LE's exercise of power *of self*, but by the constitution of the "self" in which this exercise of power was grounded (summarised in Figure 4).

The Role of Power *of Self* in Realising Lived Experience Leadership

This hard-won and complex iteration of power *of self* was constructed as resource integral to the realisation of lived experience leadership. This section will explore the role of power *of self* in realising lived experience as a source of authority, direction, motivation and alliance (summarised in Figure 5).

Figure 5. *Roles of power of self in realising lived experience leadership*

Power of self operates as a source of...

Authority	Direction	Motivation	Alliance
<p><i>Enables PWLE to act</i></p> <ul style="list-style-type: none"> The basis of action Reconstituted via its own use 	<p><i>Informs how PWLE act</i></p> <ul style="list-style-type: none"> Influences the processes and products of action Distinguishes lived experience leadership from similar practices 	<p><i>Drives action</i></p> <ul style="list-style-type: none"> Actions motivated by recognition of the importance of power <i>of self</i> Actions for-purpose, intended to increase PWLE's access to power <i>of self</i> 	<p><i>Inspires respect for actions</i></p> <ul style="list-style-type: none"> Actions rendered leadership by others' recognition of it as such Actions grounded in power <i>of self</i> recognised by PWLE's peers as leadership

... so as to realise lived experience leadership

Power of Self as a Source of Authority

Participants constructed power *of self* as a source of authority enabling people with LE's performance of lived experience leadership, as explicitly acknowledged by Jay: "to be able to have that dare, that daring... I recognise the importance of that. I try to nurture that in the way that I approach my work" and Bailey: "[our innate authority] can be used to change things". Per participants, acts of lived experience leadership were founded upon people with LE's complex self-knowledge. For instance, Tracy reflected that understanding "what works best for you and your own strengths and weaknesses" underpinned lived experience leadership practices. Simultaneously, Sarah contended that lived experience leadership is

“based on the principles of the [lived experience] movement, on recovery, on human rights principles”.

Critically, lived experience leadership was characterised not by people with LE’s use of the components of their self-knowledge in isolation, but rather by people with LE’s integration of these components of self-knowledge for consideration in tandem:

“You see the systemic through the glasses of the personal lived experience, but also the lived experience of those around you through collective processes and then you look at those through the eyes of the system as well and how the system then is a big factor in how people’s personal stories are determined... it’s like the eagle-helicopter view, but also the micro-personal view, and the two have to go in tandem all the time, so it is almost a bi-focal way of looking at the world” (Rowan)

Similarly, Rick described lived experience leadership as “[speaking] up... from a knowledge base, both self, about your own [lived] experiences, but also a knowledge base about what’s happening and the ability to sort of analyse it all”, while Avery reflected that lived experience-led research “is shaped not just by academic or intellectual concerns, but it’s also shaped by a kind of abstracting from experiential knowledge”. For participants, power *of self* constituted a resource actively drawn upon to propel their work.

Participants constructed people with LE’s use of their power *of self* as an inherently reflexive process: an active use of a dynamic self-knowledge, itself shaped via ongoing self-reflection. That is, lived experience leadership was constructed as underpinned by processes of integration, in which people with LE drew on individual and collective, experientially-based and systems-informed self-reflections to develop their complex self-knowledge:

“Real [lived experience] leadership... comes out of a collective dialogue, a shared dialogue... having those conversation spaces to allow people to contribute and build up a body of knowledge and a process of actually being able to collectively build on each other’s experience that becomes something bigger than the sum of its parts” (Rowan)

Additionally, lived experience leadership was constructed as underpinned by processes of translation, in which people with LE used this self-knowledge to ground their engagement in acts of agency such as speaking up, producing knowledge, or decision-making:

“[lived experience] leaders... harness that shared knowledge of not just their own knowledge- their own lived experiences- [but] also a systems way of thinking. So it’s not just about the personal story. It’s about how that personal story is then translated into decision-making

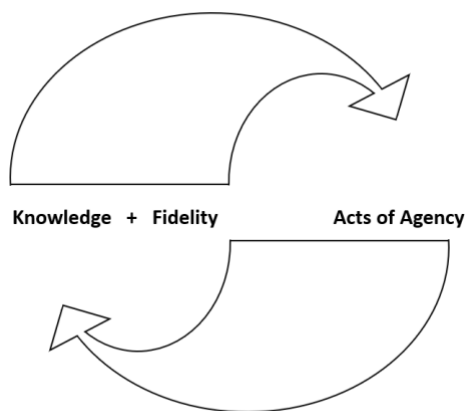
fora and papers and... communicated to other [lived experience] leaders and how we communicate with each other.” (Rowan)

Rather than distinct or linear, these processes were constructed as inherently iterative: “it’s critical to the [lived experience] movement that we constantly, through that shared grassroots sort of thing... have a self-critical reflection” (Rowan). For Jay, ongoing self-reflection constituted “the unwritten rule” of his leadership:

“I need to stand up to scrutiny: am I operating with integrity? Do... I have peers that help me to reflect? Am I doing the right thing? And if I’m not, how easy is it to challenge me and when I’m challenged, how do I respond? Do I embrace it?”

Owing to the reflexive nature of people with LE’s use of power *of self*, acts of lived experience leadership were constructed as not only founded upon but generative of their self-knowledge: “looking through the lens of your own lived experience, but also of others [and] connecting the dots so that you’re seeing the bigger picture... that’s where the real power lies”. As captured by Rowan, power *of self* was constructed as not only enabling lived experience leadership, but as reconstituting itself in doing so (see Figure 6).

Figure 6. The relationship between power *of self* and acts recognised as lived experience leadership



Note: This picture represents power *of self*- PWLE’s knowledge of and fidelity to self- as a source of authority, direction and action enabling its expression as acts of agency recognised by peers as lived experience leadership, inspiring and increasing PWLE’s access to their power *of self* in turn and reconstituted via critical reflexivity.

Power of Self as a Source of Direction

Participants constructed people with LE as using their power *of self* not only as a source of authority to enact lived experience leadership, but as a source of direction informing the way they enacted this leadership. In this respect, participants highlighted people with LE’s principles and values as integral to the performance of lived experience leadership: “it comes

down to... your values, so being quite inclusive... making sure everyone gets a turn and valuing everyone's views equally" (Taylor). Principles and values were constructed as components of people with LE's complex self-knowledge, to which people with LE maintained fidelity: "I do not sell out on my principles" (Taylor). As explained by Drew:

"[Lived experience leadership is] based on human values- the actual worth of the human being irrespective of their circumstance, [their] inherent worth... I think that's partly because we're a movement that's based on shared suffering and injustice... I think many of us would be very reluctant to hurt another person emotionally or in any other way because we know how terrible it is to be hurt or misjudged or mistreated or underestimated"

Broadly speaking, people with LE's use of their power *of self*- inclusive of their knowledge of and fidelity to their principles and values- was positioned as influencing both the *processes* of lived experience leadership (e. g. the way decisions are made) and its *products* (e. g. the decision itself).

People with LE's fidelity to their self-knowledge was positioned as the foundation of identified differences between lived experience leadership and other forms of leadership: "there's difference... based on different drivers, different value systems, different agendas" (Jay). As articulated by Bailey:

"[lived experience] movements or [lived experience]-led organisations are driven by principle, more than anything else... we see this in the difference between say us and a service provider advocacy organisation, where they talk about principles like human rights, but in a lot of ways they're representing the interests of people who are trying to make money... that changes the priorities, that changes the way they do things... there's that fundamental conflict in the way that they do what they do, and what they are actually trying to do."

People with LE's use of power *of self* as a source of direction was therefore constructed as both informing the manner in which lived experience leadership was realised, and as distinguishing this leadership from forms of leadership primarily oriented to interests other than those shared by the people with LE collective.

Power of Self as a Source of Motivation

Participants positioned lived experience leadership as realised in the face of considerable adversity, including people with LE's positioning within society: "from a societal point of view, we are stigmatized and particularly within a clinical environment we are particularly at risk of

a lot of unequal power relations and persecution” (Penny) and incompatibilities between lived experience leadership and the systems within or in opposition to which it operates:

“People that do stand up and do hold their authority, often get kicked out of work... bullied... pushed over to the side until they give up and leave... [then] the service ‘learns’ from that a hires people that are going to toe the line” (Cameron)

Nevertheless, participants constructed lived experience leadership as sustained by people with LE’s use of their individual and collective self-knowledge as a source of motivation: “I’m laden, believe me, with emotional charge because of some of the unfairness that I’ve seen over the years, but I want that to be rocket fuel for me to lever the change that I want to see” (Jay). In Cameron’s estimation, “[lived experience leadership] works [when] people... have a sense of the long-term goal of what they’re trying to do, and an ability to hold firm to an idea”. That is, participants constructed people with LE’s understanding of themselves as individuals and as a collective, inclusive of their aims and principles, as resourcing people with LE with the motivation to engage in lived experience leadership.

People with LE’s respect for their own and other’s power *of self* was constructed as a principle of particular importance to the realisation of lived experience leadership. In addition to informing the ways lived experience leadership is enacted, participants also positioned people with LE’s valuation of power *of self* as its driving force. Consider Alex’s reflection on their relationship with leadership:

“I don’t want to lead other people... I don’t want any authority or power [*over others*]... I just want [people] to be autonomous... with the ability to engage and be equal, which is not currently possible and hopefully I can lead a way where it’s more possible”.

Consistent with Bailey’s assertion “we don’t do leadership for the sake of leadership... we’re doing it for a broader reason”, Alex constructed their leadership as for-purpose, intended to increase people with LE’s access to power *of self*. Furthermore, Alex rejected affiliation with leadership associated with other motivations, aligning themselves only with a leadership motivated by respect for people with LE’s power *of self*. In so doing, Alex exemplified how people with LE’s respect for their own and others’ power *of self* constituted a source of motivation driving their engagement in lived experience leadership.

Taken together, participants’ discourses positioned their power *of self*- inclusive of their knowledge of and fidelity to their principles, values and aims- as motivating people with LE to enact and sustain lived experience leadership. Per Bailey:

“the struggle for us is to legitimise [our] form of authority and then try and change structures that have persisted for centuries... we’re fighting an uphill battle, but I think we also know that we’re fighting

the right battle and this is important work and I think that's what sustains us even though sometimes being a leader in the lived experience movement can be kind of disheartening, kind of difficult".

Power of *self* was thus constructed as not only authorising and directing, but motivating the realisation of lived experience leadership.

Power of Self as a Source of Alliance

Participants contended that lived experience leadership could not be realised in the absence of its recognition as such by others: "can a hermit be a leader?" (Charlie). However, participants differentiated lived experience leadership from forms of leadership predicated upon followership: "they need to have people that are willing to work with them- it's not necessarily about following" (Cameron). Furthermore, participants constructed attempts to cultivate followership as dehumanising, coercive, controlling, or otherwise violating others' people with LE's power of *self*. For instance, Bailey distinguished between lived experience leadership and "styles of leadership that... see people as functional... [that say] 'here's this potential asset that we could deploy in this way'... that allow people to be dehumanised. From a lived experience leadership perspective... you wouldn't say "come do stuff for us", you wouldn't sort of pitch yourself". Like Bailey, participants constructed lived experience leadership as characterised by people with LE's refusal to encroach on others' power of *self* in seeking followership: "we [don't] say 'you all should follow me, this is the right way' - [it's] more like 'this is my right way'" (Alex); people with LE were constructed as equally unwilling to cede their power of *self* and thus accept others' attempts to confer followership on them: "leadership in the [lived experience] movement is slightly different... any sort of illusions of power or trying to boss people around... is not tolerated because people have had negative experiences of power being exerted on them" (Taylor). Ultimately, people with LE's respect for their own and others' power of *self* as sacred rendered seeking followership an eschewed and ineffective means of realising lived experience leadership.

Consistent with people with LE's respect for others' power of *self*, lived experience leadership was constructed as a product of people with LE's decisions to align themselves with peers they hold in esteem, made independently of those peers' intentions: "people may... aspire to be like me, not intentionally from my perspective" (Alex). However, Charlie noted that "[while] it's others who confer leadership... you do stuff that puts you in a position where other people put a cloak on you". Specifically, participants constructed people with LE's alignment with their peers as predicated on their respect for their peers' ownership and expression of power of *self*. For instance, Jay recalled recognising a peers' leadership on the basis of his respect for her critical thinking and self-expression: "I heard her speak [and] thought 'that's a leader'... she set that example for me to hopefully want to share something that might inspire somebody else". Similarly, Taylor considered her leadership as established via people with LE's regard for her adherence to principles: "I think part of [my] leadership... where I feel that I have respect... is that the [lived experience] movement know that I will not

sell out and I will not compromise what is important". Notably, this respect was constructed as a consequence of people with LE's appreciation for their peers' power *of self* as remarkable, maintained despite adversity: "[being] so bold... there is some sort of respect. I mean it's not showing off or anything... just not letting yourself be squashed down... not letting the negative messages and cruel treatment... dampen your spirit" (Taylor). Thus, by virtue of people with LE's respect for power *of self* as radical, their peers' expressions of this power were rendered central to the realisation of lived experience leadership as the basis on which people with LE aligned themselves with each other.

Power of Self as the Resource and the North Star

Participants positioned people with LE's power *of self* as eventuating lived experience leadership in multiple ways. As summarised by Cameron, lived experience leadership was enabled by "[people with LE's] integrity. Their willingness to stand up. [Having] people that are willing to work with them... and authorising other people to do things and to become leaders in their area as well". Correspondingly, people with LE's power *of self* was constructed as resourcing people with LE with a moral compass, the authority to stand up and maintain their ground, the inspiration to align themselves with their peers, and the impetus to support people with LE's empowerment.

Discussion

This study was conducted to contribute to the theorisation of lived experience leadership, as understood by people with LE themselves. Per our analysis, lived experience leadership was constructed as founded upon people with LE's use of power *of self*; specifically, a version of this power grounded in people with LE's reflexive orientation to themselves as individuals and as a collective, from both experiential and systems-informed perspectives. Our analysis deconstructed the nature of this power and its role in realising lived experience leadership.

Our findings contrast with depictions of lived experience leadership as defined by the occupation of certain roles, or as existentially dependent on power-sharing by mental health professionals (Salzar, 1997; Wituk, Vu, Brown & Meissen, 2008). Access to institutional power, while acknowledged as conducive to realising its aims, was not constructed as definitional to lived experience leadership nor necessary for its existence. Instead, lived experience leadership was constructed as defined by and realised via people with LE's exercise of power *of self*, a resource that can be developed and utilised within the lived experience community alone. Our findings thus support calls for the redistribution of power and resources so as to support the development of lived experience leadership. At the same time, our findings are consistent with research indicating that lived experience leadership can occur regardless of role, position or access to institutional power, and develop independently within lived experience communities (Piat, Sabetti, & Padgett, 2018; Stewart et al., 2018). Indeed, in her critical exploration of "experiential authority"- a concept with which our notion of "power *of self*" corresponds- Noorani (2013) argues that the development of such authority represents

perhaps *the* commonality uniting factions of the lived experience community that collaborate with the mental health system and more radical factions. Our findings also characterise this power as underpinned by multi-perspectival, contingent, reflexive, and thus inherently unsettled self-knowledge, and therefore largely preclude the essentialisation of lived experience leadership (see Voronka, 2016). Therefore, while the phrase “lived experience leadership” has traditionally been associated with lived experience involvement within the mental health system, our findings suggest this phrase denotes a phenomena realised by people with LE across a wide variety of contexts and in many different ways.

Findings nevertheless provide empirical support for the contention that lived experience leadership is distinct from traditional or mainstream mental health leadership. In contrast to mainstream mental health leadership, lived experience leadership was positioned as incompatible with power *over others*, founded instead on people with LE’s respect for their power *of self*. Consistent with previous literature (e. g. Carr, 2010; O’Hagan, 2009), these divergent relationships with power, and corresponding differences in practice, were attributed to people with LE’s experiences of discrimination and oppression within and outside of the mental health system. Findings particularly highlighted the role of people with LE’s experiences of epistemic injustice- or unjust diminishment of people in their capacity as knowers, on the basis of prejudice (Fricker, 2007; LeBlanc & Kinsella, 2016)- in informing their recognition of power *of self* as both important and radical. Findings also emphasised the role of lived experience leadership in redressing this injustice: realising people with LE’s power *of self*- producing knowledge, participating in discourse, or otherwise expressing oneself as a knower- was positioned as both inherent to the performance of lived experience leadership and central to its aims. Overall, findings indicate it is people with LE’s reflexive use of their self-knowledge to inform their actions that may unite disparate practices as lived experience leadership, and distinguish lived experience leadership from other forms of mental health leadership.

The inconsistencies between lived experience leadership and other forms of mental health leadership may account for some of the difficulties in realising lived experience leadership within the mental health system. Due to the differences between lived experience leadership and mainstream mental health leadership, instances of lived experience leadership may go unrecognised as legitimate leadership practice. As an example, people with LE’s refusal to exercise power *over others* may manifest in their refusal to speak for others or identify themselves as a leader. As a consequence, people with traditional conceptualisations of leadership may under-recognise or fail to support people with LE’s performances of leadership as such. Incompatibilities between mental health system infrastructure and lived experience leadership may also pose barriers to its realisation. For instance, whereas hierarchies may complement mainstream mental health leadership practices, requiring people with LE to adhere to such hierarchies represents a lose-lose dilemma for people with LE with respect to lived experience leadership. On the one hand, people with LE may refuse to adhere to such hierarchies and thus lose their job or access to resources enabling effective expression of lived experience leadership within the system. On the other, choosing to uphold

such hierarchies would fail to constitute leadership in the eyes of their peers. Thus, the realisation of lived experience leadership may be constrained within mental health system infrastructures, regardless of people with LE's navigation of such contexts.

This analysis carries implications for practice. First, to realise lived experience leadership within the mental health system- and for lived experience leadership exercised outside the mental health system to exercise greater influence- lived experience leadership practices must be recognised as such, rather than delegitimised on the basis of their differences to mainstream leadership practices. We therefore suggest that figures within the mental health system seek out lived experience voices to learn more about what constitutes lived experience leadership. Second, resources ought to be directed to support lived experience leadership practice and development as envisioned by people with LE, rather than in the image of traditional conceptualisations of leadership. Third, mental health infrastructures ought to be examined to identify and eliminate incompatibilities with lived experience leadership, and so reduce instances in which people with LE find themselves in catch-22 scenarios regarding lived experience leadership. Finally, as mainstream mental health leadership is associated with epistemic injustice and other forms of oppression experienced by people with LE, and lived experience leadership represents a form of leadership developed so as not to perpetuate- and indeed to redress- such harms, influential figures within the mental health system may consider incorporating lessons from lived experience perspectives on leadership into mainstream mental health leadership development.

This analysis may inform the development of a theoretical framework for lived experience leadership. As leadership theorists have identified, the qualities and practices that constitute effective leadership are variable, dependent on the context and social group in question (Haslam, Reicher, & Platow, 2011). Therefore, decisions regarding the application of existing leadership models or the development of a novel model of lived experience leadership *must* be predicated upon an understanding of people with LE and their conceptualisations of lived experience leadership. This analysis has contributed to the development of such an understanding, and thus may inform the identification of theories appropriate for incorporation into a theoretical framework for lived experience leadership, such as theories that position power as a productive rather than repressive force (e. g. Arendt 1958, 1965, 1972; Foucault 1980), theories that position leadership as relational rather than a quality possessed by individuals (e. g. Edmonstone, 2011), or indeed theories that integrate analyses of domination with those of empowerment and solidarity (e. g. Allen, 1998). This analysis may also serve to connect the concept of lived experience leadership with other lived experience concepts. For example, the multifaceted self-knowledge grounding the power *of self* inherent to lived experience leadership may correspond with the notion of lived experience expertise increasingly utilised by people with LE.

This study has certain limitations. For instance, all contact with study participants occurred via the first author, who does not professionally identify as a people with LE. That recruitment and interviewing was conducted by an “outsider researcher” may have deterred some people

from taking part in this study, and influenced what participants shared during their interviews. Similarly, the term “consumer” was used in recruitment materials. This term carries particular connotations, including a willingness to collaborate with the mental health system; its use may have deterred people who reject this term or adopt a more radical political stance with respect to mental health reform or abolition from taking part in the study.

Conclusion

Analysis of people with LE’s discourse produced an understanding of lived experience leadership as defined by people with LE’s use of a certain type of power, power *of self*. This power was constructed as people with LE’s *knowledge of* and *fidelity to* themselves as individuals and as a collective, from experiential and systems-informed perspectives. Lived experience leadership was framed as realised via people with LE’s use of this power as a source of authority enabling agentic action, a source of direction and motivation both guiding and driving such action, and as the basis on which they recognised their peers as enacting leadership. Per our discussion, that lived experience leadership was constructed as defined by people with LE’s use of power *of self* may account for noted difficulties in realising lived experience leadership within the mental health system, with implications for practice.

Future research may wish to investigate how the foundational elements of lived experience leadership explored in this paper- namely, power *of self* and people with LE’s reflexive development and use of this power- influence the manifestation of lived experience leadership in action. For instance, lived experience values and principles were identified as a component of people with LE’s self-knowledge integral to the practice of lived experience leadership. These principles, their connection to lived experience, and their implications for lived experience leadership in action warrant further exploration.

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