Title: Deep Experiential Knowledge: Reflections from Mutual Aid Groups for Evidence-

Based Practice

Authors:

Tehseen Noorani

Durham University

tehseen.n.noorani@durham.ac.uk

Magnus Karlsson

Ersta Sköndal Bräcke University College

magnus.karlsson@esh.se

Thomasina Borkman

George Mason University

tborkman@gmu.edu

Corresponding author:

Tehseen Noorani

Durham University

c/o Department of Anthropology, South Road Durham DH1 3LE

tehseen.n.noorani@durham.ac.uk

Abstract

Background

This article charts the relationships between the model of evidence-based practice (EBP), healthcare markets where providers are increasingly competing through the adoption of EBP-certified interventions, and the cultivation of experiential knowledge within self-help and mutual aid groups (MAGs). After 35 years of neoliberal reform, service user involvement in research, service provision and evaluation, and patient-centered care has been operationalized in increasingly measurable ways. In seeking to value and incorporate service user experiences, current models of EBP do not unpack the heterogeneity within experiential knowledge.

Aims

This article explores a more meaningful use of experiential knowledge than the cursory and tokenistic treatment it is often given.

Objectives

- Propose, illustrate and theorize the concept of 'deep experiential knowledge' (DEK)
- Identify ways that the acknowledgement of DEK are useful in healthcare policy, governance and the clinical encounter.

Methods

Drawing upon case study vignettes, we analyze MAGs as epistemic communities of problem-solvers.

Findings

Deep experiential knowledge is a robust and collective form of knowledge, generated over time in the long- term members ('old-timers') and collective knowledge of MAGs. Five characteristics of deep experiential knowledge are proposed.

Discussion

By rendering DEK amenable to the logic of EBP, we outline potential benefits of foregrounding DEK in the conduct of healthcare research, policy and governance, and the clinical encounter.

Conclusions

DEK constitutes an authority that distinguishes different degrees of experiential knowledge of healthcare problems. Attending to DEK helps untangle some of the challenges posed by evidence-based practice for and to successful service user involvement.

Keywords

Deep experiential knowledge; mutual aid groups; self-help; evidence-based practice

Wordcount

8372

Key messages

- 'Deep experiential knowledge' (DEK) is produced through self-help/mutual aid group (MAG) practices
- DEK is narrative-based, collectively-produced, polyvocal and develops over time
- Measures of DEK that would benefit evidence-based practice can be advanced by analyzing its genesis in MAGs

- Acknowledging DEK paves the way for participatory approaches to healthcare research, governance and treatment

Introduction - Experiential Knowledge in the Context of Evidence-Based Practice

Recent healthcare reform to increase participation can be traced through the changing ways in which the experiences of clients, service users and patients have been operationalized. One cornerstone for these reforms is evidence-based medicine, introduced by Sackett and colleagues (Sackett *et al.* 1996), and later adapted beyond the medical sphere as evidence-based practice (EBP; Gambrill 2003). The EBP model is comprised of three components: the best available evidence from systematic research, clinical expertise based on professionals' shared experiences, and patients' "values and preferences" (Sackett *et al.* 2000). Sackett and colleagues emphasized the need for objective measurement in only the research component. However, the model's abstract presentation belies the neoliberalization of healthcare provision across all three components. Contemporary healthcare systems often predicate funding on the outcome of monitoring and evaluation metrics, while client values and preferences are increasingly measured in order to assess the efficacy and efficiency of services provided them (Dudhwala *et al.* 2017; Gambrill 2006).

Beginning with the anti-authoritarian social movements of the 1960s, experience has gained salience as a source of political representation, often under the banners of 'public', 'patient' or 'user' involvement (Beresford 2002, Fredriksson and Tritter 2017). Today service users are commonly invited to sit on boards, committees and steering groups, help evaluate health and social services, act as media-liaison representatives and train professionals from the vantage point of their experiences receiving the services. Critiques of the operationalization of service user involvement highlight the tokenism, professionalization and assumptions about representativeness involved (Madden and Speed 2017; Meriluoto 2017).

In seeking to join with movements to meaningfully incorporate clients' values, views and knowledges in healthcare research and service provision, this article draws upon studies of self-help and mutual aid groups (MAGs) as distinct sites for the documentation of *experiential knowledge*. By offering researchers of self-help and mutual aid, policy-makers and healthcare providers a more nuanced account of the epistemic attributes of experiential knowledge, our objective is to show how recognizing its variety and complexity alters our understanding of relationship between service user involvement and EBP, thereby responding to key challenges posed by the ongoing implementation of EBP.

Our argument is that there has been a failure to grasp the depth dimension of experiential knowledge, wherein the value generated takes narrative rather than numeric form. Our interest in depth is connected to wider debates concerning the loss of authority under modernity (Arendt 1993[1954]), proposing that MAGs might offer instructive counter-examples. As such our argument is consistent with postcolonial warnings about the flattening of all voices (Stengers 2012) and feminist critiques of objectivity (Harding 1986), while troubling the individualism often implied by terms such as 'recovery' and 'person-centered care'.

The literature on MAGs is primarily available in the disciplines of sociology, anthropology, social work, and community psychology. All authors have conducted research on MAGs as primary scholarly interests. One of the authors (XXX) has devoted her career to the investigation of self-help and mutual aid practices, and was the final editor of the only journal dedicated to their study.[i] Two of the authors (XXX and XXX) have been Chairs of the self-help and mutual aid interest group of Division 27 of the American Psychological

Association. This article draws on the authors' extensive engagements with MAGs, as well as the wider research and literature on the subject.

We begin by introducing models that seek to improve upon Sackett's model of EBM by acknowledging the experiential knowledge of the service user in the healthcare encounter. Such models open the door to analysing this way of knowing. We describe the epistemic productions of MAGs, placing particular attention upon the difference between new and established group members. We introduce the term *deep experiential knowledge* (DEK), describing both it and ways of knowing it, and end with reflections on operationalizing DEK in our contemporary, measurement-oriented policy climate.

1. From Patients' Values to their Experiential Knowledge

The literature that has most closely sought to take forward Sackett *et al*.'s evidence-based medicine model focuses upon the direct encounter between service users and healthcare professionals. Charles *et al*. (1997), Légaré and Thompson-Leduc (2014), and Durand *et al*. (2014) have offered models of shared decision-making, most often identifying the professionals as generating the possible options from which a choice must be made. Karlsson and Oscarsson's professional-user dialogue (PUD) model responds to these, suggesting the third source of information in the EBP model - the client component - remains undertheorized (Karlsson, 2016). Drawing on Borkman's (1999) theorization of experiential knowledge, Karlsson and Oscarsson insist clients' input not be limited to their values and preferences, but also their knowledge of the specific problem/situation.

Consequently, in the PUD model shared decision-making must be negotiated between

professional and client, where each party relies upon distinctive kinds of knowledge and the patient's experiential knowledge is understood as analogous to the professional's clinical expertise, and both together draw upon the best available research. Consistent with Habermasian modes of deliberation, both the space of the negotiation and the capacity for both patient and professional to draw on collectivized knowledges are considered essential.

However the account of experiential knowledge in the PUD model itself does not allow for distinctions in the quality of experiential knowledge. We identify here a need to acknowledge heterogeneity within experiential knowledge itself. Certainly, the term has come to denote many things: for instance, sanctioned institutional research into service users' recovery narratives, the literary genre of self-help, celebrity testimonials and illness narratives have been used to mobilize social movements in what has been described as 'evidence-based activism', activism that engages the politics of knowledge and evidence-making to win resources and improve healthcare outcomes (Rabeharisoa *et al.* 2014, Brown *et al.* 2010). In contrast with these, we draw on literatures that approach experiential knowledge as the knowledge generated within MAGs, to consider how this particular kind of epistemic production can speak back to the demands of EBP. Examples we draw upon in what follows include the 12 steps/12 traditions, weight-loss, mental health, stuttering and parent MAGs.

2. MAGs as Spaces for the Cultivation of Experiential Knowledge

In 1976, Borkman introduced the term 'experiential knowledge' to characterize the knowledge produced in MAGs, describing it as "truth based on personal experience with a phenomenon" (1976: 445). Soon thereafter, Borkman (1990) described experiential

knowledge as holistic rather than either piecemeal (like folk/lay knowledge) or specialized

(like professional knowledge), emerging from the continuous and layered experiences of

living with a problem. It included knowledge of experiences of stigma, interpersonal

relationships, emotions at different points over the course of having the problem including

the key existential-spiritual question of why this is happening to oneself, practical aspects of

living with the problem such as taking transportation or the paperwork involved in dealing

with service providers, financial costs and, inevitably, coping with well-meaning others who

give poor advice.

MAGs are defined as voluntary associations under self-directed leadership and with little or

no financial costs, to share a problem or status which they seek to change through

reciprocal helping and the generation of experiential knowledge (Humphreys 2004). Self-

directed or 'user-led' leadership refers to groups neither led by professionals nor beholden

to any framework outside of that which has been collectively produced by group members.

The idea of reciprocal helping evokes the aphoristic principle attributed to MAGs, 'you alone

can do it but you cannot do it alone', together with Riessman's (1965) 'helper' therapy

principle, wherein one is helped by helping others.

We distinguish MAGs from more generalized support groups, which offer connection,

friendship, information-sharing and an increase in confidence (Cope 1995), but are not

necessarily focused on the epistemic project of knowledge production. Following histories

of neoliberal reform and deinstitutionalization, hybrid forms of mutual aid that do not

conform to all of Humphreys' criteria can easily be found - for example, support groups set

up in hospitals that are run by professional staff and espouse a particular approach to the

shared problems, or online groups run by a combination of peers and professionals. In what

follows, we risk an overly-clear cut distinction between user-led MAGs and professional-led support groups in order to highlight and further refine our understanding of experiential knowledge.

MAGs can also be distinguished from the health consumer groups studied by Baggott *et al.* (2005) and the embodied health movements documented by Brown *et al.* (2004). While both MAGs and embodied health movements share practices of refining direct experience of their bodies and problems into experiential knowledge, unlike embodied health movements and health consumer groups, MAGs are primarily focused neither on challenging mainstream healthcare, nor politically-oriented activism in collaboration with professionals, but on mutual aid practices that enable a deeper understanding of individuals' own problems through sharing experiences.

Limited research has been conducted on who does and does not join MAGs. As Kurtz (2015) summarizes, chronic progressive disease groups rarely appeal to early sufferers who neither want to see nor be involved with later-stage sufferers. Negative stereotypes of occupying a 'sick role' also deter some people from joining MAGs, though this can be a misperception as most MAGs normalize and de-stigmatize the condition for their members. For example, outsiders may consider AA members to be adopting a stigmatizing label when they call themselves alcoholic within an AA meeting but the reverse is true: AA redefines the 'alcoholic' member in a positive way as one who is likely abstinent and actively and constructively confronting their alcohol problem. The seriousness of the problem, level of psychological distress, degree of extroversion, need for affiliation and lack of an adequately supportive social network have been associated with joining MAGs (*ibid.*), while people

whose beliefs, viewpoints or demographic characteristics are sufficiently different from that of a specific MAG are unlikely to join or continue to participate.

MAG-based experiential knowledge is vetted through group protocols and 'groundrules' that mark off the space - centered upon sharing circles, respect for one another's interpretive frames and minimal or no judgement or 'cross-talk' (Karlsson 2002; Munn-Giddings and Borkman 2018). Other technologies for structuring experience are specific to groups and emerge over time, for example, role-plays that structure experience and generate insight.

Experiential knowledge by definition is based upon the individual's lived experience, that is, learning through the reactions and habituations of the body. While MAG members may bring information from outside of their own experimentation - for example, from academic and media sources - it becomes experiential knowledge by being worked through embodied practices of experimentation, whose results are shared amongst other group members. At the same time, once it moves far from its source of its embodied production, experiential knowledge becomes codified and ossified.

In understanding MAGs as sites of shared problem-solving practices, the question of whether any particular group promotes health and wellbeing or not is transformed into the question of whether and how groups produce knowledge and meaning. Of course in any instance for any particular person, these could be evaluated by given criteria as improving or damaging one's health, but it is the knowledge and meaningfulness produced in the groups that is of sustained value. The generation of knowledge through practices of sharing and listening to stories at little or no financial cost suggests that MAGs can be considered

sites of epistemic *commoning*, pertinent at a time of reduced funding for healthcare services. MAGs entail resource sharing, community formation and emphasis on the doing - on common*ing* – the same three aspects to the commons identified by de Angelis (2017).

3. Meaning Perspectives: Structures of collective experiential knowledge

The term *meaning perspective* has been used in the self-help literature to refer to the collective knowledge about the focal issue, the challenges therein presented, potential workable and unworkable resolutions, and members' resulting shared identities. Meaning perspectives can be distinguished from paradigms or worldviews, because they are limited to issues surrounding the negative impacts of the focal issue rather than entire philosophies of living (Suler 1984; Borkman 1999). The co-construction of a developed meaning perspective evolves as many members share their stories of living with the focal problem(s) and their various attempts to deal with its negative consequences and sequelae. Failures and near-failure stories are as important as success stories, as members learn from each other. Individuals' stories are informed and shaped by the group meaning perspective, whose evolving narrative is tested by the dialogue across many members (Jensen 2000; O'Halloran 2008).

In studies of MAGs, statements of meaning perspective appear in official books, pamphlets and websites. The major texts in the most famous 12 Steps/12 Traditions group, Alcoholics Anonymous (AA), are its book *Alcoholics Anonymous* (1939), and the *Twelve Steps and Twelve Traditions* (1952). Official materials for which there is consensus among members are labeled "conference approved materials," referring to the national decision-making body of elected regional representatives that meets yearly to discuss and approve

documents and other resolutions. Other types of MAGs have different decision-making processes to produce official materials. An official document portraying a MAG's meaning perspective can only convey part of the experiential knowledge of its members. An AA proverb is that 'old-timers' (a group's long-term members, contrasted with group 'newcomers') are important role models as there are no pictures in the Big Book.

A group member's narrative of their health issue develops within and in relation to the MAG's meaning perspective. Alcoholics Anonymous has been well-studied in these terms (Cain 1991; O'Halloran 2008). For example, people with severe alcohol problems often refuse to think they have a problem with alcohol, attributing their heavy drinking to other factors such as being victimized at work or having an uncaring spouse. AA regards this as part of the syndrome - denying that one has a problem. Cain (1991) studied how people attending AA learned about their alcoholism and developed their identities as alcoholics by attending AA and listening to other people's stories. Over time 'the AA story' arc came to shape their own, unfolding alongside their successful abstinence.

The codified experiential knowledge of a MAG found in official materials can be subject to serious misinterpretation by outsiders (Walters 2002; Winegar *et al.* 1987), especially professionals with specialist knowledge of the same problem who often interpret the materials in their own frameworks. The casual misinterpretation of a MAG's meaning perspective offers a historical indicator of the lack of respect for the group's experiential knowledge. Outsiders often interpret AA's first step as if it comprised the entire program of AA. It reads, "We admitted we were powerless over alcohol, that our life was unmanageable." (AA 1939). On this basis, AA and MAGs in general have been denigrated as leaving their members powerless (Miller and Kurtz 1994), rather than appreciating that

this is the first step towards empowerment and takes time and attention to be 'worked' before moving onto the second step. Thus, in providing methodological frameworks of action, meaning perspectives have been judged in terms of providing 'answers', when in fact they are also instructional, providing the schema by which experiential knowledge can deepen.

MAGs with different meaning perspectives for the same health problem(s) generate a range of bodies of experiential knowledge. For example, Overeaters Anonymous (OA) and Weight Watchers (WW) seek similar goals but have different meaning perspectives: OA, a 12 step/12 tradition group, has a spiritual component which enables it to speak to hope, motivation, and the will to continue, while WW, a commercial enterprise but with peer components, is based on research studies that view excessive eating as bad habits that require changes in one's environment. In WW, for example, group members are encouraged not to buy or bring 'trigger foods' home, and to go grocery shopping sated. WW deals less successfully with situations where a person is determined to overeat, whereas OA's spiritual components offer techniques to tackle this issue. MAGs with opposing meaning perspectives also arise - in contrast with WW and OA, Fat is Beautiful is a MAG that rejects weight norms and advocates for changed values (Borkman, 1999: 7).

In cases where the instructional aspects of meaning perspectives dominate, group members may develop competing frameworks of understanding their shared problems. The success of the Hearing Voices Network (HVN) can be explained to a large degree by the meaning perspective it offers, to treat voices as meaningful and to decode the messages that they contain (Dillon 2011). Where psychiatry has sought to suppress voice-hearing, considered a first rank symptom of the diagnostic category of schizophrenia, HVN groups experiment

with transforming voice-hearers' relationships to their voices, and ways of living with them. Adopting an ecumenical stance towards explanations for voice-hearing, established group members will likely have come across narratives that rely upon a range of mutually exclusive explanatory frames. Rather than overcoming contradictory frames, members use the tensions between frames to generate ideas for further experimentation. The instructional aspects of meaning perspectives distinguish them from collective belief structures afford HVN members a degree of skepticism as they are encouraged to experiment with group knowledge.

Meaning perspectives in the form of shared techniques for structuring experience belong to the group level, repeated and refined through their use in and around group meetings. Examples include techniques for learning what is *knowable* in the first place, learning how to cope with - and transform - difficult experiences, and for learning how to communicate difficult experiences through roleplay to those who have never experienced them (for example, Noorani 2013; Borkman 1999). Borkman has suggested that most groups that thrive for any length of time develop a "liberating meaning perspective" - one that is stigma-reducing, life-enhancing, and constructive (1999: 115-138). A key reason MAGs restrict professionals from leading or controlling their group is that professionals' meaning perspectives are usually so dominating that it dampens attempts to create a more suitable one to the members' shared situation.

4. Deepening Experiential Knowledge

With the term *deep experiential knowledge* (DEK), we aim to signal both the meaningfulness and the nuance of experiential knowledge. We also use the term to convey

an expansiveness, as the different narratives of others' experiences are interwoven through one's own embodied knowing over time, in dynamic relation with the MAG's overall meaning perspective.[ii] While other types of collectives with mutual aid features, such as Brown *et al.*'s (2004) embodied health movements (Brown *et al.* 2004; Britten *et al.* 2015) are likely to have developed DEK among long-term adherents, in what follows we seek to excavate ethnographically the emergence of DEK in MAGs. We argue that MAGs include many favourable conditions for the creation of DEK. These include recurrent interactions between individuals sharing similar problems who seek to gain deeper understanding of the problems, relevant knowledge and potential solutions, without direct concern for appealing to, or challenging, the views of political adversaries.

Within MAGs, DEK accumulates over time and can be identified most readily in old-timers, who have enhanced, extensive and enriched experiential knowledge. Newcomers to a MAG may come with rudimentary experiential knowledge of living with the group's focal problem(s); however, their experiential knowledge increases and deepens as they continue participating, hearing more narratives and seeing peers with somewhat different experiences, reflecting upon others' stories, and trying out new ideas and practices in their daily lives which they have learned from the group. By absorbing the collective stories of the group, the old-timers come to embody the collective in the singular, interpreting the multiplicity through their own lens (*cf.* Bartlett 1995). DEK is thus shared in three senses - it is generated through sharing stories, it is a living knowledge that only operates through processes of sharing, and people with DEK of a particular issue share a broadly overlapping body of (instructional and substantive) knowledge, manifest in the MAG's meaning perspective.

As a layered knowledge, of many stories of similar experiences shared over time and knitted through one another, DEK turns a single-voiced 'monoglossia' into a multi-voiced 'polyglossia' (see Jensen 2000). The acquisition of DEK requires unstitching the judgmentalism entailed in the narratives newcomers share within groups, as similar stories suggest new interpretations and perspectives. Newcomers thus undergo an unlearning that betrays their overconfidence in not yet knowing what they do not know. At the same time, polyglossia lends old-timers a certain richness of understanding, such that details in a newcomer's story might lead an old-timer to a very nuanced comprehension of the newcomer's plight, through the warp and weft of the old-timer's accumulating knowledge base.

The shared problems or preferred resolutions that emerge at the center of groups may not map onto professionally-defined problems (such as medical diagnoses or treatments). While pre-existing the members' involvement in MAGs, their problems get reformulated and refined through involvement in group meetings. Over time, narratives interweave, and DEK detaches problems from particular individuals' biographies, and rearticulates them as multifaceted and experienced differently depending on life situation and demographic specificity. The problems that emerge are therefore not multiple but *manifolded* (*cf.* Mol 2002: 53-85), and the way that old-timers' DEK draws on this variety is interpolative rather than extrapolative.

If the variation of experiences of the central problem or workable resolutions in a MAG tend towards distinct clusters, MAGs may split. The US-based Caring MAG for people who stutter split into two MAGs thirteen years after its founding due to emerging differences in values about type of speaking and new technologies: the Caring group emphasized spontaneous

expressive speaking with stuttering, while a new technology – the Hollins College precision fluency shaping therapy – emphasized fluency with a cadence and monotone (Borkman 1999: 124).

A key empirical question when attempting to draw upon the DEK of a group is how much a group member's experiential knowledge is bound up with the sociocultural idiosyncrasies of a particular group. As stated, within MAGs, the diversity of people and their narratives can work over time to reveal different aspects of the problem(s) that groups are centered around. If the demographic constitution of a MAG widens, it may shift the way that the problem is articulated and the most salient manifestations it presents. Similarly, changes in technology and available interventions can modify DEK. DEKs are nonetheless knowledges borne of particular point of view, and an acknowledgement of their meaning perspectives and demographic constitution allows them to claim a strong objectivity as 'situated knowledges' (Harding 1986) capable of incorporating reflexivity into their claims and practices. Valuing DEK then signals a systematic pluralism rather than an anything-goes relativism in knowledge acquisition.

5. The Challenge of Synthesizing Narratives

The imperatives of EBP are to provide healthcare services in accordance with the best research available concerning safety, efficacy and efficiency. In the instances that EBP seeks to synthesize such research with experiential knowledge, the latter is configured as a kind of immediate knowledge that any experiencing subject can report at any moment, available for feeding back into larger governance systems. This suggests that those who seek feedback may be unaware of, or uninterested in, the heterogeneity of the experiential

knowledges they are soliciting. Yet demands to assess the depth of any particular instance of experiential knowledge risk questioning the inherent value of the experience, perspective or intelligence of the service user, and thereby problematize the democratization of knowledge enabled by the concept of 'experiential knowledge' in the first place.

Mindful of these dangers, there may be good reasons to consider whether it is possible to assess the depth of experiential knowledge. Firstly, without being able to make such distinctions, those with the confidence generated by not knowing what they do not know are easily be conflated with those who have DEK, despite being at very different stages of understanding of their problem and workable resolutions. Secondly, treating all experiential knowledge as equivalent enables a tokenism in service user involvement. Thirdly, people who are selected by policy-making bodies and advocacy groups as representatives may be sought for the social, cultural and/or celebrity capital they bring rather than the depth of their experiential knowledge regarding a given issue.

While celebrities can bring attention to problems, they can also oversimplify problems in ways that undermine the goals of those they are asked to represent in the first place (Munn-Giddings 2003; see also Borzekowski et al. 2014). Those with superficial experiential knowledge can be quite ineffectual mediators or 'brokers' in the politics of experience as a result (Boyce 2016), failing to retain nuance regarding recovery journeys throughout their negotiations with publics and funding bodies. For instance, celebrities who advocate that mental illness is "an illness like any other" often end up increasing rather than decreasing stigma by reflecting back the very same discourses of individualism and biogenetic causality that underlie prejudice against those diagnosed with mental illnesses (Read *et al.* 2013).

The collectivizing of stories in MAGs into DEK offers an analogical process to what in EBP has been described as the need to synthesize different kinds of evidence (Mays *et al.* 2005). The 'evidence' of EBP aspires to be based on the epistemic virtue of objectivity. In relation to contemporary healthcare research this is identifiable in clinical trials and epidemiological studies which attempt to sidestep subjectivity through instituting replicable protocols.[iii] While the elimination of the subjective may not be applicable to the MAG context, there is nevertheless a rigorous mode of collectivization at play – what may be more similar to Daston and Galison's (2007) epistemic virtue of trained judgment, where patterns, and indicative deviations from patterns, are developed over time.

The compatibility of DEK with EBP is further complicated because the deep experiential knowledge of MAGs is not numeric in nature and therefore does not easily travel, while EBP has favored numerical standardization capable of easily traveling across contexts. As Han (2015) has pointed out regarding societies that value transparency, "addition is more transparent than narration" (2015: 29). While one might hope that the synthesis of numeric evidence is as efficient and fast as possible, the synthesis of narrative knowledge demands its own temporality, dependent as it is upon the unfolding of the narratives themselves (*ibid.*). We can expect both complementarities and tensions to emerge from these differences in knowledge synthesis.

6. Ways of Identifying Deep Experiential Knowledge

Ethnographic portraits of MAGs as active epistemic communities may prefigure measurable 'indicators' of the depth of an individual's experiential knowledge. Firstly, the duration of time working with a problem as a member of a MAG is suggestive of one's level of DEK only

when combined with an active principle of problem-solving, requiring experimenting with the stories of others in addition to rehearsing one's own (Borkman 1999). Old-timers with DEK will know many people's narratives, both those similar to and different from their own, and move seamlessly between them and their own. This depth enables MAG old-timers to be able to relate to the many permutations and combinations of what is essentially the same narrative arc. It differentiates DEK from the experiential knowledge that one learns simply by reflecting upon one's own experiences. The newcomer who only knows her own story can overgeneralize from it, while DEK integrates many narratives, producing patterns of repetition and difference.

Secondly, DEK can pinpoint the relevant questions to ask. In not at first knowing what one doesn't know, the newcomer can ask questions the old-timer recognizes as irrelevant to the problem at hand. Conversely, the old-timer may ask of a newcomer questions that appear unrelated, sharing a deeper connection that itself may not be explicitly articulated in a theory of health and illness. DEK acquisition thereby contrasts with the tendency to narrow the paths of inquiry when led by clinical and epidemiological methodologies.

Thirdly, DEK recognizes the false narratives of individuals faking a problem or a solution. For example, participants who have attended AA meetings for months but are vague or unwilling to talk about their preferred drink, quantity of alcohol, drinking situations, and kinds of trouble from drinking are suspected by veterans as non-alcoholics since alcoholics usually enjoy recounting their 'drunkalogues' to peers (Maxwell 1984).

Fourthly, DEK understands a particular humor about the problem(s) that is not immediately apparent to outsiders. When studying members of an early stage dementia

group in Sweden who recounted their cooking failures in frying pancakes, where one jokingly said (to widespread laughter) that she blames her new stove, and a second chimed in that she blamed her pancake spatula (to more laughter); Orulu interpreted this as the "laughter of recognition" (2012: 25).

Fifthly, DEK cannot be obsolete - it must be an up-to-date, living, knowledge that continues to prompt experimentation through one's self and sharing with others. Oka (2003: 194-196) describes conflict within Japanese MAGs for parents of children with intractable diseases, where current leaders with grown-up children have now-obsolescent knowledge of the treatment of the diseases but seek to retain control over younger MAG parents with young children who have up-to-date knowledge of treatment.

DEK as conceptualized here concerns patterns of similarity and difference across a multiplicity of personal journeys. Over time, the possibility that some MAGs may develop more dogmatic positions on what a recovery journey *should* look like must be recognised. We suggest that these situations indicate a restriction in the DEK of the group, and possibly also in group old-timers who assimilate new experiences to preconceived narrative arcs without adding complexity to the latter or working the new experiences back through their own embodied experiences. This both illustrates how DEK cannot be assumed to exist, and points to the inevitability of debate surrounding the existence of DEK in any particular instance.

7. Bringing DEK to Bear on the EBP Context

While MAGs may not cover the whole range of problems that EBP aims to address, in instances where relevant MAGs do exist, how can the collectivization of knowledges in MAGs, and the DEK of old timers in particular, contribute to EBP? The original models of EBP cursorily describe the value of what the client brings to the table, clearly contrasting it with professional clinical experience and research evidence components. Most times, this client component gets the least attention, and in practice claims to having experiential knowledge can be dismissed as anecdotal or ungeneralizable. Treating DEK as valuable opens up new opportunities. It may be fruitful to follow the implications of situating DEK within a history of attempts to collectivize experiential knowledge that can be traced back through the anti-authoritarian social movements of the 1960s. In this final section we instead reflect upon how service user involvement practices in research and service provision might draw upon the opportunities rendered visible through the recognition of DEK. We focus on three key areas of user involvement - research, policy and the structuring of the clinical encounter.

7.1. In research

In seeking to produce objective research, as is often requested in EBP, one poorly-conceived strategy has been to try to evaluate MAGs "from outside", without adequate understanding of how such groups work. For instance, MAGs have been evaluated for their efficacy as narrowly-construed therapeutic interventions using randomized controlled trials (Humphreys and Rappaport 1994: 220-223), rather than as broader democratic epistemic cultures of experimentation. This kind of approach fails to grasp the value MAGs produce in reframing problems and inventing new modes of engagement.

A more appropriate use of experiential knowledge has been through myriad forms of participatory research. Much has been written on participatory research[iv] and related traditions such as user controlled research (Beresford and Croft 2012), survivor research (Rose 2009), and recently, coproduction (Durose *et al.* 2011). Epistemologically, these traditions are all consistent with standpoint approaches that celebrate the unique insights available through personal experience. In recent years, participatory systematic review (Rees and Oliver 2012), narrative review (Greenhalgh *et al.* 2018) and realist evaluation (Pawson 2013) have risen to prominence as ways of combining rigour with experiential knowledge. In articulating DEK in this article, we add to these compelling calls for involving users in research by arguing that those with DEK would contribute more representative and nuanced knowledge to the research process than those with superficial experiential knowledge.

In one example, six researchers, half of whom had DEK as recovering substance abusers, designed and implemented participatory research into how persons with substance use disorders define recovery (Borkman 2016). Findings included novel measures of inner-focused and reflective elements of recovery. When tested with an online sample of over 9,000 self-identified persons in recovery, these measures were endorsed by those with over 20 years of involvement in 12 Step MAGs while not by relative group newcomers. In these forms of participatory research, researchers with experiential knowledge may not have what we have outlined here as DEK at the outset, but by devising methodologies where they share stories with participants, may come to develop DEK through the research process itself (*cf.* Rose 2018).[v] In a second example, long-term members of the HVN have been pivotal in reorienting the study of psychosis, driving attention towards the phenomenological variety and complexity of voice hearing and related unusual perceptual

phenomena, while bringing nuance to the construction of measuring apparatuses (for example, Jones *et al.* 2016; McCarthy-Jones and Longdon 2015, Woods *et al.* 2015).

7.2. In policy and governance

Hasty attempts to draw upon the benefit of MAGs in service provision can negatively affect their functioning. For instance, Schneider (2006: 122) calls for "clinical supervision for group facilitators" in order to govern the activity and discourses of groups that are funded. These attempts often fail to grasp the epistemic inventiveness of MAGs in producing new meaning perspectives rather than inheriting and propagating professionally-established ones.

Within an EBP paradigm, the peer assessment that undergirds the clinical expertise component serves as a model for identifying DEK in regulation and governance structures. For instance, physician specialties develop associations to develop best practice guidelines and assess peers' levels of clinical expertise. Analogical models exist in other professional and tradesperson occupations, including the ideal of academic peer review. The ways of identifying DEK described in section 6 may help to understand how MAG members can and do differentiate between the depth of one another's experiential knowledge.

One example of an institutionalized attempt to have MAG peers evaluate and select patient representatives is in Germany's statutory health insurance-funded infrastructure. Since 2004, Germany has legally required the funding and consultation of MAGs, and including patient representatives on governmental boards and committees (Matzat 2006-2007). The law states that patient representatives must be knowledgeable and active (i.e. non-

obsolete) within their patient organization (Haefner and Danner 2017: 303) and are selected by the relevant patient organization. According to Matzat, director of a self-help center in Giessen, Germany, who was at one time a patient representative,

> "the idea was that these persons bring together not only their own experiential
> knowledge, but the experience of their respective organizations in its totality"
> (2006-2007: 291).

This context appears to mandate that patient representatives are elected by their organizations and are expected to bring the wider experience of their organization with them. Outside of this example, user, patient and public involvement in healthcare rarely considers the depth of experiential knowledge of those invited to participate, focusing on important but distinct attributes such as the diversity of representatives (for example, Wilson *et al*. 2015). This can lead to individuals with limited experiential knowledge being involved. Enabling tokenism and the professionalization of a small base of service users, we suggest a reason for this is that DEK is hard to identify by those who do not have it. Consequently, it is difficult for outsiders such as professionals without a depth of personal experience to tell who has collectivized knowledge and who is largely speaking from their own individual experience.

In order to ensure spokespersons have DEK, policy might seek to invest in infrastructures inspired by peer assessment models such as the German example outlined above. Those with DEK who sit on boards and/or have influence through media platforms may still be coerced by the logics of the market, the soundbite or bureaucracy, but they will have a better chance than those without DEK to offer creative suggestions that trouble the

polarized options put forth, and/or to use their timeslot to destabilize overly-dominant monovocal narratives of what the 'right' way forward is. The fact that spokespersons are demanded in the first place signals a far wider problem of participatory democracy, but recognizing DEK will help illuminate what is at stake in the choice of representative.

<u>7.3. In clinical encounters</u>

To return to the PUD model presented by Karlsson and Oscarsson (Karlsson 2016), there are ways to draw on the collective knowledge generated in MAGs in the patient-professional encounter. Granted, professionals often have a limited time in their encounters with patients and clients. Moreover, as those with recently-acquired experiential knowledge do not know what they do not know, they may possess a temporarily over-inflated degree of confidence in understanding their problem, raising the stakes in establishing the patient or service user's level of experiential knowledge.

Each MAG has its own decision-making structures which produce collective forms of knowledge. Established MAGs have various mechanisms for codifying and packaging their DEK. In most 12 step/12 tradition groups such as Alcoholics Anonymous, knowledge is recorded through official books, pamphlets, audiotapes, CDs, films or other media officially endorsed by group. In the Hearing Voices Network, lists of what voice hearers have come to know about their voices encourage new voice-hearers to inquire further into their own voices. These meaning perspectives have been developed by groups over time. Where relevant to the presenting issues, these could be made ready-to-hand to primary care physicians looking to show patients how others have made headway with their problems. Healthcare providers might consider other ways of drawing upon DEK, including through

ongoing and systematized collaboration with local MAG groups.

In healthcare contexts where peer support roles have been institutionalized, peer support workers need to be aware of the plurality of meaning perspectives that could inspire new patients and service users into epistemic self-experimental projects, which may or may not be a stepping stone to joining a MAG. Similarly, ensuring that a range of meaning perspectives are available through statutory-funded websites[vi] and resources in primary care facilities, presenting distinct-if-overlapping frameworks for understanding a problem and moving forward with it, would allow new patients entry-points into their self-guided recovery.

<u>Conclusion</u>

This article argues that experiential knowledge can deepen over time, and that MAGs are exemplary sites for witnessing this. We propose that DEK is a generative concept for ongoing debates concerning service user involvement and the role of experiential knowledge in healthcare research, policy and service provision. In contrast with understanding experiential knowledge as a pre-existing attribute of any moment of time whose characteristics can be fed back into the governance systems in which it is produced, conceptualizing experiential knowledge as a deepening fabric distinct from patients or service users' values and preferences does not easily fit into the codification logics of EBP, where emphasis on values and preferences presumes patients or service users' experiences are devoid of deeper epistemic content. Instead, treating DEK as inherently valuable leads down a provocative path, implying that some people do in fact know better than others - even when it comes to others' problems, illnesses, health and wellbeing. Additionally, as

dynamic knowledge structures, experiential knowledge may be inherently incompatible with mechanisms that seek to judge, using pre-existing yardsticks, whether MAGs are interventions producing positive or negative effects.

Granting authority to figures, groups and networks that hold DEK suggests ways forward that unsettle the compacts between service user, client and patient on the one hand and service provider on the other. In contrast to consumerist or democratic rights discourses, we have attempted to follow the implications of the epistemic virtues of DEK without constraining it by the tripartite structure of the EBP model. Indeed, in situations where clinical research is recent, minimally replicated and under-funded, we might expect DEK to carry more weight. This opens up the possibility of developing robust indicators of clinical and professional *ignorance* (contra knowledge), as a complementary strategy to seeking indicators of DEK. More broadly, acknowledging DEK supports efforts to react affirmatively to the lack of objective knowledge, evident for instance in research funding calls, with more attention to what theories, hypotheses and ideas are being put forward by MAGs and people with DEK on the same topic.

It may be impossible to square the kind of wisdom-oriented knowledge described here with an individualism that endorses recovery as whatever a person wants. Rather, the experiential knowledge whose indicators we have attempted to expound here constitute an authority – that is, as advice that one would do well to heed but by no means should, or could, be mandated to follow (Arendt 1993[1954]). The authority of the experiential knower may be generated in self-help and mutual aid spaces, but does not necessarily extend beyond them. If it were mandated universally, it would be inconsistent with person-centered principles of healthcare, which in turn presuppose that new meaning perspectives

and paths to recovery are always possible. However, the autonomy of person-centered care comes at a price. This is not a tension that can be resolved theoretically, but one that must be worked out agonistically in each case. As has long been noted, authority's jurisdiction has become fragmented in modernity (*ibid.*) - and as with the newcomer to the group who speaks from one and not many, we must learn to feel its force.

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[i] *International Journal of Self-Help and Self-Care*, published by Baywood Publishing Company from 1999-2015.

[ii] It may be helpful to recall that etymologically 'text' comes from 'textile': to make a weave.

[iii] This can lead 'self-help' to become quite a wide label, including for example online courses and 'bibliotherapy' (Watkins and Clum 2008), leading public health and service delivery researchers to overlook what is particular to the MAG context.

[iv] For instance, see http://methods.sagepub.com/methods-map/participatory-research

[v] As with the demographic particularity of those attending MAGs, the diversity (or lack thereof) of research participants will limit how generalizable the DEK that is produced through participatory research by researchers with personal experience is.

[vi] To some extent this is what the Health Experiences Research Group in Oxford, UK, aims to do via the website, www.healthtalk.org, but the sheer number of personal stories here may obscure a relatively small number of meaning perspectives, that is, family resemblances between individuals' ways of making sense of their problems.