

SELF-HELP SUPPORT GROUPS AND ISSUES IN RESEARCH

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ABSTRACT

Despite the potential benefits of research, Self-Help Support Groups (SHSGs) pose an interesting challenge to researchers. There can be ethical dilemmas in examining a particular research question, while attempting to work within a self-help ethos that endorses particular practices. These challenges can be found in research involving group participants who experience mental health issues. This is explored in the following article, with reference to a recent study into the group experiences of young people with mental health issues. The article does not offer concrete solutions to these difficulties, lest the discussion be prematurely closed. Rather, it encourages debate on ethical matters in SHSG research so as to improve future investigations.

SELF-HELP SUPPORT GROUPS

Research into Self-Help Support Groups (SHSGs) is a relatively new phenomenon, taking flight in the United States in the mid 1970s. Within this period, research has proliferated making use of various epistemological and methodological approaches (see Kurtz, 1997; Kyrouz & Humphreys, 2000). Collectively the research has enhanced our understanding about how these groups operate (Levy, 1976; Rootes & Aanes, 1992), why some people find them beneficial (Bolzan, Smith, Mears, & Ansiewicz, 2001), why others terminate their involvement (Heller, Roccoforte, & Cook, 1997), and how they figure into conventional healthcare systems (Humphreys, 1999; Kaufmann, Schulberg, & Schooler, 1994).

Their proliferation alone could indicate the value of SHSGs among group participants (Davison, Pennebaker, & Dickerson, 2000). Yet, further support can be derived from academic research (see Kyrouz & Humphreys, 2000). However, Levy (2000) warns that the lack of a common definition of SHSGs has diluted the impact of positive research findings. So as not to add to this problem, the term *SHSG* is here used to refer to:

a nonprofit support group run by and for people who join together on the basis of common experience to help one another. It is not professionally run, although professionals are frequently found in supportive ancillary roles (Madara, 1999, p. 171).

THE SELF-HELP ETHOS

Riessman (1982, 1997) explains that the value of these groups might be understood through the *self-help ethos*—an inherent philosophy found in most SHSGs, guiding their *modus operandi*. The ethos values supportive relationships that function on *reciprocity* (Gartner & Riessman, 1984; Medvene & Teal, 1997; Riessman, 1990), particularly among individuals with a shared experience.

It also includes several other properties. The *helper-therapy principle* for instance suggests that individuals who support fellow group participants reap the most benefit. Among the many advantages outlined by Riessman (1976), he suggests that helping individuals are exposed to learning opportunities in which their own advice is self-reinforced.

Another property is that of the *aprofessional dimension*. Relative to professional orthodoxy, this dimension values non-elitist and non-bureaucratic approaches, and situates support in a user-friendly context (Borkman, 1999). This is most explicit through the indigenous leadership of SHSGs.

Consumer intensivity is yet another important feature of the self-help ethos. It bestows power on the individual group participant by suggesting that greater benefit will be experienced by those who exercise greater involvement. This feature thus encourages self-initiative.

Further to this, the self-help ethos also values *self-determination*. At an individual level, it is for group participants to decide whether they belong to the group and the degree of their involvement. At a group level, the group participants collectively drive the direction of the group (Riessman, 1976).

In concert, these properties speak of empowerment:

In essence, one of the most significant characteristics of mutual-aid groups is the fact that they are *empowering* and thus dealienating. They enable their members to feel and use their own strengths, their own power, to have control over their own lives. This empowering dimension is extremely important for people's health and mental health; it also enhances human service productivity and contributes to effective, integrated service practice (Riessman, 1976, p. 41).

The self-help ethos is thus an integral part of SHSGs and is thought to account for the benefits experienced by group participants. This is particularly highlighted among people who participate in these groups to address the mental health issues they experience (Bolzan et al., 2001; Finn & Bishop, 2001).

RESEARCH DIFFICULTIES

Despite its liberating effects, the ethos can pose epistemological, methodological, and ethical dilemmas for researchers hoping to explore these groups. It can place them in a bind, caught between their passion for research, and their passion for SHSGs and the philosophies they represent. Although research into these groups welcomes various approaches, it would be paradoxical if such research were not situated within the self-help ethos.

What does this mean for researchers who are keen to better understand SHSGs? Although I cannot (and should not) direct the investigative endeavors of others, personal experience in a recent study is drawn upon to illustrate my attempts to explore group experiences, while being (in my view) respectful of the self-help ethos.

A CASE IN POINT

The project examined the experiences of young people (aged 15 to 31 years) in SHSGs. The young people all identified as having experienced a mental health issue, and had participated in a SHSG to address this issue. The overarching question that directed the study was what these groups could offer young people with mental health issues. Its rationale was born out of three factors. Namely, the mounting evidence suggesting that mental health issues among young people are a growing concern (Sawyer et al., 2000; WHO (World Health Organization), 2001); the benefits derived from participating in SHSGs (Davidson et al., 1999; Humphreys, 1998; Young, 1990); and the lack of literature examining the experiences of young people in these groups.

Despite my eagerness, the study did not commence without careful consideration of how I could work ethically and respectfully within the self-help ethos. Particular attention was given to epistemological orientation; theoretical perspective; research method; and ethical considerations. The order in which these issues are presented should not suggest that the (perceived) resolution of one issue led to consideration of the next. In reality, there was much to-ing and fro-ing, from one issue to the next, and back again—analogous to a four-way tennis match.

EPISTEMOLOGICAL ORIENTATION

a framework or theory for specifying the constitution and generation of knowledge about the social world; that is, it concerns how to understand the

nature of “reality.” A given epistemological framework specifies not only what “knowledge” is and how to recognize it, but who are the “knowers” and by what means someone becomes one, and also the means by which competing knowledge-claims are adjudicated and some rejected in favour of another/others (Stanley & Wise, 1993, p. 188).

Hindsight has allowed for much reflection on past research concerning SHSGs. Problems have been identified, paving the way for improved future endeavors. There are several papers offering such reflection (e.g., Humphreys & Rappaport, 1994; Kurtz, 1997; Levy, 2000). A key issue has been the epistemological approach applied by past researchers—particularly those who viewed SHSGs as somewhat akin to therapeutic interventions.

Kurtz (1997) explains that early research in the area was marked by controlled studies of outcome. Attempts were made to assess the *effectiveness* of SHSGs by interfering with group processes—for instance, contriving group conditions, and removing the self-determined nature of group involvement. This was consequent to pressure from research funding bodies, as well as the skepticism of human service providers toward the effectiveness of peer support. However, the objectivist approach (Crotty, 1998) adopted by some of these researchers did little to encapsulate the group experience. Its imposition tended to thwart the very phenomenon under study:

In contrast to any other intervention, a SHG [Self-Help Group] does not exist as an intervention apart from its members who are both the instrumentality and the objects of the intervention; change the characteristics of its membership and the intervention is changed as well (Levy, 2000, p. 595, original italics).

This led me to explore other epistemologies and their relation to the self-help ethos—particularly constructionism and subjectivism (Crotty, 1998; Neuman, 2000). Given the nature of SHSGs, it became more apparent that a constructionist approach might be most suitable for the project I was to embark upon. This approach argues that individuals construct social meaning(s) of the world through interaction with others and the environment in which they find themselves. This is reminiscent of SHSGs.

These groups bring together individuals who share a similar experience. Through engagement with the group dynamic, these individuals often come to construct different understandings—of themselves (Bolzan et al., 2001; Kloos, 2001); the issue(s) that brought them to the group (Davison et al., 2000); their relationships with others; and their place in society and/or the universe (Kennedy & Humphreys, 1994).

Given the (apparent) fit between constructionism and SHSGs, I question the value of other epistemological approaches in research concerning these groups, particularly those approaches that impose rigid principles, much to the neglect of the phenomenon under study. Research concerning SHSGs is still in its infancy

and requires further exploratory work. Without careful epistemic consideration, we risk a return to research whereby the self-help philosophies were thwarted by the epistemology of the day.

THEORETICAL PERSPECTIVE

the philosophical stance informing the methodology and thus providing a context for the process and grounding its logic and criteria (Crotty, 1998, p. 3).

Constructionism implies a myriad of understandings of the same situation. How then is it possible to understand the experience of young people in SHSGs? As social researchers, we can only capture one angle of this experience, for the reality we create is the result of interaction and interpretation:

Our world is something we make, not something we discover (Rorty, 1989) (Saratakos, 1993, p. 20).

This quote speaks of SHSGs. The ethos of self-determination encourages group participants to engage with their environment and embrace change—whether it be a cognitive shift in the self, or involvement in social politics.

It is this apparent fit which led me to adopt an *interpretive* approach for the present study. Furthermore, the approach is said to be useful in explorative research that is interested in understanding others (Saratakos, 1993).

RESEARCH METHOD

Interpretive research implies the use of qualitative research methods. Within an interpretive framework, they open opportunities for detailed insight into personal experiences; they also offer a degree of sensitivity when personal issues (like mental health) are being addressed (Flick, 1998). Yet, there is an array of methods available. These include (but are not limited to) observation, focus groups, and face-to-face interviewing—each of which has their own variations (Minichiello, Sullivan, Greenwood, & Axford, 1999).

Consideration of these (and other) qualitative methods for the present study gave rise to several ethical concerns. For instance, if I were to *observe* young people's involvement in SHSGs, would I thwart the very interactions I was attempting to understand? Some warn that the presence of *outsiders* has a negative effect on SHSG dynamics (Nichols & Jenkinson, 1992; Toro et al., 1988). This is particularly the case when observers behave inappropriately in the group context. Describing her own research efforts, Davidson (2001) explains:

one is sometimes unsure whether or not it is appropriate to laugh. This is especially true when someone seems to be making a joke at their own expense

and/or when that joke relies upon drawing attention to some aspect of their lives in which we apparently do not or cannot share (p. 170).

If I were to disregard these findings and proceed with a method of observation, what of the ethics of impeding a *potentially* positive group experience—particularly for individuals who might be emotionally fragile?

Further to this, would I attend to select features of a group, and consequently neglect those of greater importance to the young participants? Would I misinterpret observed group interactions as helpful or unhelpful to the young participants? As Davidson (2001) suggests:

group members partially share an outlook on the world . . . whose meaning would be lost . . . [by an] outsider (p. 169).

In his review of research issues, Levy (1984) asserts that the observation of SHSGs can be particularly insightful, furthering our understanding of natural “psychotherapeutic processes of everyday life” (p. 159). He also believes that this method can serve to test the perspectives offered by group participants:

The Twelve Steps of A.A. . . . as well as what group members tell us they believe about their afflictions and the means by which their groups help them, are all instances of espoused theories. . . . These theories may be gleaned from their literature as well as from interviews with their members. . . . But it would be a mistake to use them as the sole basis for inferring the processes that actually operate in these groups or the procedures used by them. Without direct observations of self-help groups, we may learn only what they believe, but not what they do or what processes account for their effectiveness (p. 160).

In one respect, I agree with Levy’s (1984) assertion that sole reliance on one research method can limit a comprehensive understanding of the phenomenon under study. Yet, his statement appears to question the validity of beliefs espoused by group participants. In this respect, the self-help ethos may be contravened, for there is potential to minimize the important element of self-determination by disregarding the perceptions of group participants, and giving precedence to the researcher’s somewhat detached interpretation.

This method also minimizes the opportunity for young people to make explicit contributions to the project. Not only does this somewhat under value their involvement, but also reduces the potential for personal empowerment. Maynard (1994) argues that individuals may experience a sense of empowerment by their involvement in a study, through:

1. “their contribution to making visible a social issue”;
2. “the therapeutic effect of being able to reflect on and re-evaluate their experience as part of the process of being interviewed”;
- and
3. “the generally subversive outcome that these first two consequences may generate” (Davidson, 2001, p. 17).

In relation to research concerning SHSGs, failure to maximize opportunities for empowerment may also contravene the self-help ethos.

An additional concern with the use of observation is that of bias. This method would obviously preclude the involvement of young people who had terminated their involvement, thus minimizing the variety of perceptions and opinions. For these reasons, the method of observation was not chosen for the current project.

What of focus groups? At first glance, this method appears to demonstrate respect for SHSGs, situating research participants in a context they are familiar with. Furthermore, like SHSGs that encourage group discussion, this method allows for the cross-pollination of ideas.

To aid my decision-making process, I took my ideas to several young people currently involved in SHSGs. Some warned that focus groups might give rise to *group think* (Janis, 1971) and limit variety of opinion. This is a particular concern when focus groups are comprised of dominating and passive personalities (however, there is literature to help researchers avoid group think in focus groups; see MacDougall & Baum, 1997). Furthermore, it would *not* be safe to assume that young people feel comfortable in a group context, given the sensitivity of mental health issues and the fact that I had met young people who terminated their involvement in a SHSG after participating *once*.

Consequently, I decided that interviews—more specifically, semi-structured, open-ended interviews (Wengraf, 2001), would be the most appropriate research method for the project. This method would provide direct answers to the research question by embracing the experiential knowledge of the young people. Furthermore, it offers the flexibility to be sensitive when discussing mental health issues. Although the project was not about *mental health issues* per se, these issues could arise through the course of the interview, given the experiences of the young people that brought them to their respective groups.

Akin to the thoughts of Davidson (2001) in justifying the use of unstructured, open-ended interviews:

the data collected for this project should largely consist of contributions from . . . [those] with personal (embodied) knowledge . . . rather than for example, the (secondary) testimony of . . . health care professionals or other (merely) interested parties (p. 164).

Merely interested parties could also include myself as researcher. Thus, semi-structured, open-ended interviews have the ability to award primacy to the young person. They can also incorporate the use of personal narratives. This lies in accordance with the practices of many SHSGs, for individuals typically share their personal experiences within the group context.

However, this is not to suggest that the interview process was problem-free. Although I was keen to demonstrate my respect for the self-help ethos, several ethical issues required attention.

ETHICS

An “ethic” is a framework of thought concerned with morality and with moral choices between things and actions seen as good or bad (Stanley & Wise, 1993, p. 200).

Prior to the study, clearance from the relevant university ethics committee demanded the careful consideration of possible ethical issues—particularly because the study included individuals with mental health issues, some of who were minors under the age of 18 years. People with psychiatric disorders and young people under 18 years of age are of prime interest to ethics committees, for they are potentially vulnerable to any exploitative research practices (Michels, 1999; Stuart, 2001).

However, ethics committees in research concerning SHSGs create a tension between a standard view of ethical practice and the self-help ethos under study. Despite their efforts toward self-determination and empowerment, participants of SHSGs may find themselves excluded from opportunities to participate in research endeavors:

in many cases, IRBs [Institutional Review Boards], and not subjects, determine whether the subject will even have the option of participating or declining to participate in a study (Berg, 2001, p. 48).

Potentially, this can limit opportunities that might expand the growing body of academic support for these groups. This is not to suggest a complete abolition of ethics committees, but rather, collaboration between these committees and SHSGs when proposed studies are reviewed.

As outlined in my submission to the relevant ethics committee, the study required voluntary participation (at all stages of the project) and maintained the confidential involvement of the young people. Confidentiality was ensured through the secure storage of taped interviews; the removal of identifying details from all interview material; and typing the interview transcripts myself. The young people were also fully informed about the nature of the study and how the findings would be used. In practice, this often led to a discussion with the young person about my interest in these groups and the passion I had for them—after all, if I was not interested in SHSGs, why would I bother with the study? More often than not, the young person also shared this passion and was aware that these groups received little recognition—from the public, as well as human service providers. I then wondered whether they recognized the study as an opportunity to change public perception, thereby inflating their positive group experiences and minimizing negative effects.

The research findings collectively suggest that young people view their involvement in these groups favorably. This then begs the question:

What should participating individuals be told about the nature of the research project? (Minichiello, Aroni, Timewell, & Alexander, 1995, p. 205).

Some interesting ethical questions are raised from the belief that responses from those with limited information about the purpose of a study are more valuable than the responses from those who are fully informed. It assumes that people do not second-guess the purpose of the research if not fully informed. It also assumes that people do not speak frankly, and that they tailor their answers to the nature of the research. Such assumptions deny the possibility for fully informed consent.

For the present study, I would not endorse a covert research approach. Nor do I regret my personal disclosures to the young people, for I believe that they served to build rapport and a communicative atmosphere before the interview commenced. Hence, in this project, I believe that honesty was the best policy.

However, there were two additional concerns that warranted serious deliberation. These included the possible inclusion of young people under 18 years of age, and the possible inclusion of individuals who might be psychologically vulnerable.

AGE

Research involving those under the age of 18 years, typically necessitates the consent of legal guardians (NH & MRC (National Health and Medical Research Council), 1999). This is despite the fact that those over 14 years can legally consent to their own general medical or dental treatment (*Minors (Property and Contracts) Act s.49*) (Redfern Legal Centre, 1999). This discrepancy creates ambiguity about the cognitive capabilities of young people. Yet, this matter is further confounded in the case of research involving SHSGs.

Involvement in these groups is typically anonymous. Few if any records on group participants are maintained. This is particularly the case in groups that address stigmatized issues, like those surrounding mental health. In effect, this means that young participants of these groups do *not* have to seek the consent of legal guardians. In accordance with the self-help ethos, *they* determine their affiliation with the group and their degree of involvement.

Given the sensitive nature of mental health issues, particularly during adolescence when self-identity and image are paramount (Garrod, Smulyan, Powers, & Kilkenny, 1999), this anonymity is quite significant. It can potentially influence the continued involvement of young people in SHSGs. This concern was raised with the relevant university ethics committee. I proposed that the consent of legal guardians be sought *only* if the young person had informed their legal guardian of their involvement in a SHSG. This proposal was approved.

According to most ethics committees, a signature typically signifies consent to participate in a study (Berg, 2001). However, I was concerned that some of the young people might be particularly sensitive about their mental health issues, and perhaps distrustful of those affiliated with research institutions. Consequently, written consent may be perceived as permanent, explicit evidence of their contact with a SHSG for mental health issue—this may be perceived despite efforts to affirm confidentiality. This issue was also raised with the university ethics

committee and I proposed that participants who feel threatened by the need for written consent, be given the option to verbalise their consent and have this recorded on audiotape. This was also approved.

PSYCHOLOGICAL STATUS

Given the project involved young people with mental health issues, it was important to consider how those that were psychologically vulnerable might be protected from any untoward effects of the interview. Any interview process, regardless of subject matter, may elicit negative affect. As Walker (1989) explains:

Anyone who has been interviewed, even on trivial topics . . . will know that the interview is a rare enough event for it to leave a mark on the interviewee. You will find yourself rethinking what you said, aware of the gaps between what you wanted to say and what you were able to say. When interviewed on deeper topics . . . the effect is more marked (p. 37).

Among those with psychological diagnoses, capacity to consent to research is typically assessed by human service providers (Michels, 1999). However, in keeping with the ethos of self-determination, I believed it was for the young people to decide on their psychological capability to participate in the study. As this might not have been appreciated by the ethics committee, I offered the young people a list of reasons that might preclude or *delay* their involvement in the study. They could not be involved if they were:

- under the direction of the New South Wales (NSW) Mental Health Act or the Guardianship Board;
- currently experiencing a personal crisis or currently ill with a mental illness; or
- recently recovered from an episode of mental illness.

Notwithstanding the first of these reasons, the onus was primarily on the young person to define their psychological status. Evidently, this risked the possible inclusion of young people who were unwell. However, a *self-defined* status remains in accordance with the self-help ethos. If, for these reasons, the young person decided they were unable to participate in the project, they were offered an opportunity to gain information on available support services.

Despite my apparent respect for this ethos, the interview process gave rise to particular ethical concerns. All of the young people I approached and invited to contribute to the study advised that they *were* eligible for inclusion. They were not under the direction of the NSW Mental Health Act or the Guardianship Board; they were not currently experiencing a personal crisis or currently ill with a mental illness; nor were they recently recovered from an episode of mental illness.

However, during some of the interviews, the young person appeared to demonstrate signs of mania, depression, or psychosis. Although I repeatedly asked whether they wanted to postpone or cancel the interview, and whether they wanted to access relevant support services, none of them took up the offers. And herein lies the ethical dilemma: *should I have terminated the interviews, despite the young people's requests? Alternatively, should I have maintained adherence to the self-help ethos, and respect the young people's self-defined status?*

I chose the latter. But what of the repercussions? My conscience demanded that I maintain close contact with these few individuals throughout the duration of the project. Fortunately, none of them experienced acute mental health issues as a direct consequence of the interview. But what if they had? When should I have terminated the interview, if at all?

It is easy to suggest that the ethical justification of research be considered “situationally, case by case” (Berg, 2001, p. 62). Yet, it is difficult to suggest whether research interviews should be terminated when the interviewee explicitly prefers that it continue.

THE DISSEMINATION OF FINDINGS

The ethics of research demand the wide dissemination of findings—lest research is done for research's sake. However, this too can involve particular ethical challenges. As Berg (2001) suggests:

Even if researchers can protect subjects from harm during the course of research, they must also consider what happens thereafter as a direct result of the research. Particularly when conducting policy-laden research . . . what investigators learn from these subjects may change the subjects' lives—and not necessarily for the better (p. 62).

Self-Help Support Groups as a research interest fit comfortably into Berg's (2001) category of “policy-laden research.” The political implications for research concerning these groups—especially evaluative endeavors, have been cogently outlined by Levy (1984) and are said to include:

1. . . . the potential for altering the status of the helping profession, their role in the mental-health delivery system, and, perhaps most importantly, their economic well-being.
2. . . . a [possible] restructuring of the mental health delivery systems so as to maximize the role of self-help . . . such restructuring could pose drastic financial threat to existing human services agencies, both tax supported and eleemosynary.
3. . . . We live in an era of greater questioning of traditions and credentials as grounds for entitlement and access to power and status . . . should research on self-help groups yield findings compatible with this ethos, its impact is likely to extend far beyond the mental health arena in

challenging many of the fundamental assumptions upon which the structure of all professions rests in our society (pp. 157-158).

Some of those who are passionate about SHSGs may welcome drastic change to current mental health systems, especially if such change gives rise to these groups. There may be greater recognition from human service providers, as well as funding opportunities. But what of the potential for negative consequences to these SHSGs?

Would it lead to government intrusiveness in SHGs' operations? Would it alter some intrinsic qualities of SHGs that might reduce their effectiveness? Would it result in a reduction in the quality of health care as individuals are shunted to SHGs in the interests of cost containment when they actually require professional care? (Levy, 2000, p. 606).

Because of these concerns, I concur with Levy's (1984) sentiments warning researchers (as passionate as they may be about SHSGs) to give careful thought to how their research findings may be used by others—especially policy-makers and funding bodies. Although the study I was recently involved in is yet to be published, these issues may be best explored with those who might be directly affected by any consequences—the participants of SHSGs and the parent organizations that support them.

CONCLUSION

This article has explored several issues related to SHSG research. Drawing on a recent study that examined the experiences of young people in these groups, particular attention was awarded to the epistemological, theoretical, methodological, and ethical concerns that arose.

Although I cannot offer resolutions that can be readily applied to other studies, I do offer one approach to these dilemmas—an approach that may be *adapted* by others, depending on the nature of the project and the context it is situated.

Undoubtedly, others may have approached these dilemmas in different ways. They may even question the decisions I made. Such diversity sets the scene for healthy debate about how such matters should be addressed. However, healthy debate demands a degree of honesty from researchers who may not want to reveal past research “mistakes.” Yet, without recognition of these “mistakes,” we limit our own learning opportunities:

We need to be more public with our failures and our weaknesses, for by considering what we did not or could not do, we also bring about change, make . . . research stronger, and become better researchers (Morse, 2001, p. 4).

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