Researching Dissociative Identity Disorder: Practical Suggestions and Ethical Implications

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ABSTRACT. This article’s purpose is to aid researchers who are interested in conducting research with dissociative populations, but who may not have extensive experience in this area. Researching dissociative identity disorder (DID) comes with many challenges. In this article, the ethics and logistics involved in selecting and implementing research methodology with DID samples are considered. This advice is centered in the author’s experience of conducting research with adults in North American hospital and community settings. Researchers in this area should design data collection procedures for maximum flexibility and participant comfort, while maintaining an acceptable level of scientific rigor. Training is essential so that both principal investigators and assistants are able to deal sensitively with trauma survivors. Psychology researchers have a unique ability to be aware of hierarchy and power in the experimental setting, and to consider these issues in order to convey respect for participants. doi:10.1300/J229v08n01_06 [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <http://www.HaworthPress.com> © 2007 by The Haworth Press, Inc. All rights reserved.]
The field of trauma and dissociation research is an exciting and expanding one. Nevertheless, it is also an area that contains many potential pitfalls. Background knowledge about dissociative identity disorder (DID) is essential in order to design and conduct accurate, sensitive, and meaningful research. Numerous correlational studies have confirmed a high incidence of childhood trauma—sexual, physical, and probably emotional abuse—in adults and children with dissociative disorders or very high levels of dissociation (e.g., Bowman, Blix, & Coons, 1985; Coons, 1994; Dalenberg & Palesh, 2004; Loewenstein, 1994; McElroy, 1992; Nijenhuis, Spinphoven, van Dyck, van der Hart, & Vanderlinden, 1998; Ross, Norton, & Wozney, 1989; Zlotnick, Shea, Pearlstein, Begin, Simpson, & Costello, 1996). Trauma that is high in interpersonal betrayal, especially trauma that takes place during childhood, is especially related to the development of dissociative disorders (e.g., Chu & Dill, 1990; Draijer & Langeland, 1999; Kisiel & Lyons, 2001). Because of this link between trauma and dissociation, researchers who study dissociative disorders are perforce working with highly traumatized populations. In addition to adhering to institutional review board (IRB) guidelines, researchers in this area should be sensitive to several additional ethical issues, such as planning for possible participant distress and assessing the role of power in the experimental setting.

Every person with DID is different, but there is an emerging consensus regarding its frequency and characteristics. The prevalence of DID has been estimated at 1% of the general North American population (Ross, 1991), although the rate of diagnosis is higher in women and among psychiatric inpatients (e.g., Gleaves, May, & Cardeña, 2001; Maldonado, Butler, & Spiegel, 1998; Putnam, 1995). Akyüz, Dogan, Sar, Yargiç, and Tutkun (1999) report that cross-cultural similarities in the expression and diagnosis of DID have been found in North America, The Netherlands, and Turkey. In their study of a general population in Turkey, Akyüz and colleagues found that the prevalence and presentation of DID were almost equal to those found in other parts of the world, even though the Turkish sample had no exposure to western psychotherapy and no public or media awareness of the disorder. Similarly, Maldonado and colleagues (1998) report that DID has been found in all racial and ethnic groups and all classes across various cultures, including: African Americans, European Americans, Asian Americans, and

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Hispanic Americans, and residents of Canada, India, Australia, New Zealand, The Netherlands, and the Caribbean (for a review of prevalence in various populations and countries, see Sar, 2006).

Although there are similarities in DID presentations across cultures, there may be differences in prevalence across genders. Compared with boys, girls may have a higher risk of encountering more types of abuse, more abuse perpetrated by caregivers, and more chronic abuse (e.g., Flett, Kazantzis, Long, MacDonald, & Millar, 2004; Freyd & Goldberg, 2004; Putnam, 1989, 1995). There is some evidence that men may have a more subtle DID presentation than do women, although there are very few other differences that are reliably found between men and women with DID, and those differences that exist may be due more to gender socialization than to the DID (e.g., Bowman, 2002; Loewenstein & Putnam, 1990). Bowman (2002) reported that, across 11 studies, women received the diagnosis of DID nine times as often as men. Ergo, research on DID is often conducted with predominantly female samples.

Given this background information, researchers should be prepared for a number of potential challenges when conducting studies of DID, some of which this article addresses. Researching DID can be difficult. Many of the limitations apparent in previous research are the inevitable results of the methodological and conceptual challenges inherent in conducting studies with this population. Those challenges, such as participants who are relatively difficult to recruit, who show immense individual variability in their behavior, and who may be emotionally fragile, limit all research in this area. This article addresses the ethics and logistics involved in selecting and implementing research methodology with DID samples. It is based on the experience of conducting research in both hospital and community settings (Barlow, 2005). The advice contained herein is necessarily a snapshot in time, created from situations encountered or considered during the course of this research project (Barlow, 2005). However, the advice has also benefited greatly from the insights and suggestions of the Dynamics Lab at the University of Oregon. This article is written to aid researchers who are interested in beginning research with dissociative populations, but who may not have extensive experience studying DID. The situations discussed pertain most directly to research in a university, clinic, or hospital setting, rather than a facility such as a prison, which brings additional restrictions. All of the advice pertains to research with adult participants.
DESIGNING AND IMPLEMENTING THE STUDY

Researchers who lack experience in the areas of childhood sexual abuse, trauma, and/or dissociation should seek an experienced collaborator who will know how to avoid many potential pitfalls and who can assure IRBs and granting agencies that the researchers are qualified to conduct the study. Working carefully with collaborators from the site where data collection will occur can enable researchers to better estimate which stimuli and techniques work best in that particular population. IRBs may not be well-educated about research on sexual abuse survivors, and it may be necessary to provide information about such topics as prevalence of sexual abuse and trauma, as well as normal or commonly accepted research methods in dissociation research. Below is an excerpt that was used in two full-review IRB applications, one for a university IRB and one for a psychiatric hospital IRB. Its definition of trauma and dissociation as public health issues is also attractive to granting agencies.

Benefits to science and humanity: Highly dissociative individuals often have an extensive history of traumatic experiences. Therefore, the research also has the potential to affect how science understands human responses to emotional trauma, how we define “normal” responses to trauma, and the study of individual differences in responses to trauma. Given the high rates of trauma experienced by the general U.S. population, a more thorough understanding of its effects is vital.

The protocols that used this text were both approved conditionally on their first review, which speaks highly of the effectiveness of including education about basic principles of trauma and dissociation. The university protocol application also included information about research practices such as chart review that were common in the hospital setting. An additional step that researchers can take in order to smooth the IRB approval process is attending an IRB meeting; this practice may save time-consuming rounds of revisions.

Having a collegial relationship with the human subjects compliance officer will aid the approval process and may also help researchers avoid potential pitfalls in submitting their protocol applications. IRB members may need reassurance of researchers’ qualifications to work with traumatized, dissociative populations. They may also have questions about the population itself, and they may need explanations of how DID appears in real life as opposed to in the movies. IRBs also
need to know that people with DID are more likely to hide than to flaunt their condition, and that it is difficult to malinger this condition for long periods of time (Kluft, 1986, 1987). As with any IRB communication, using non-specialist language is essential. It is also important to explain how DID relates to other areas of psychology and medicine, and why it is important and useful to study.

In designing a research project with DID participants, multiple measures are essential. Cognitive effects such as inter-identity amnesia or cognitive inhibition can be shown to exist, or not exist, in various forms, depending on how they are assessed (e.g., Dorahy, Middleton, & Irwin, 2005; Eich, Macaulay, Loewenstein, & Dihle, 1997; Huntjens, Postma, Woertman, van der Hart, & Peters, 2005; Nissen, Ross, Willingham, MacKenzie, & Schacter, 1988). As researchers learn from their participants, they may decide to analyze the data differently than originally planned, or to analyze different variables. While researchers should be wary of committing Type I errors due to performing too many analyses relative to the size of their samples, having multiple measures in data collection leave more options available for planned data analysis.

The ability of participants to complete various laboratory paradigms also depends on individual differences, including how long participants have been in therapy and how much executive control they have over their alternate identities. Measures of memory and information transfer may also be affected by how integrated participants are, and researchers should assess components of integration (Barlow, Freyd, & Chu, under review). Identities who are willing and able to come out in a laboratory or hospital setting, in front of a stranger and possibly on demand, comprise only a subset of the total DID system of alternate identities. Researchers should consider how these and other complex issues will affect their results, and should not assume the timing or presence of switching if it is not being verified, at the very least by self-report (e.g., Nijenhuis, van der Hart, & Steele, 2002). Researchers should also attempt to assess and/or control for the type of identity that completes each task (see Nijenhuis et al., 2002). Because participants with DID have differing levels of ability to complete laboratory tasks, it is helpful to design the data-gathering session in which useful data can still be acquired if the procedure must be modified or tasks left out. The more types of data that can be gathered within a reasonable time frame, while still maintaining the continuity and quality of the data, the better it is. If participants have an unexpected reaction to one type of task, there are several other types of tasks that will gather useful data even if one task must be eliminated.
Potential participants also differ in other ways. The perspective of this article is grounded in research within the North American mental health system, using mostly Caucasian participants. It is important to assess diversity of the participants when collecting any data and this guideline applies to DID research as well. The Western concept of dissociative disorders does not include experiences that are common worldwide, such as religious possession, animism, or communication with ancestor spirits. Depending on what aspect of dissociation or diagnosis one is interested in studying, this conceptualization may or may not prove limiting to participant recruitment.

It can be difficult and time-consuming to recruit participants with a diagnosis of DID, especially in sparsely populated areas or areas without large psychiatric hospitals focused on research and teaching. Recruitment techniques will depend on the aims and eligibility criteria of the study, but the snowball method may prove surprisingly effective when combined with recruitment through therapists, clinics, and support agencies. When obtaining referrals from clinicians, it is even more imperative to maintain confidentiality and to make the non-coercive nature of the study abundantly clear both during recruitment and in the informed consent process. Some research questions can be answered with the comparatively easy task of chart review, and require no further contact with participants.

When conducting chart review, researchers should bear in mind that charts may have inconsistent, incorrect, or incomplete information, especially about this diagnosis. Patients with DID are highly polysymptomatic, presenting with almost every other disorder in the DSM (American Psychiatric Association, 2000). Because of this factor, they often receive many comorbid diagnoses (e.g., Maldonado et al., 1998; Ross et al., 1989), such as posttraumatic stress disorder, substance abuse disorders, or borderline personality disorder. Depending on their insurance policies, some patients may want DID kept off their charts. It is also important to ask questions about medications, other drugs, and alcohol use when conducting reaction time or physiological research. Researchers should make clear what relationship, if any, the research has to the participant’s treatment, chart notations, or diagnosis.

Assessing Risk

Research on abuse survivors who have a diagnosis like DID, and who may be hospitalized, requires extra sensitivity to potential participant risks. The IRB standard for psychological “minimal risk” includes
stimuli that could be encountered in everyday life, for example, by viewing the nightly news. However, trauma researchers may be interested in studying participants’ responses to potentially distressing questions or information. Therefore, it is important to include, as do members of our lab, information in an IRB protocol about whether the proposed techniques and stimuli have been used in previous studies and how participants responded. Below is an excerpt that was used in two full-review IRB applications, one for a university IRB and one for a psychiatric hospital IRB, both of which were approved conditionally on their first review.

Psychological risks: Minimal. The questionnaire about trauma could potentially be upsetting. However, participants do not report distress when using this questionnaire in other research; in fact, they often report that the questions are important and valuable ones to include in research. Research indicates that asking these types of questions is not significantly distressing to participants, even those who have experienced traumatic events (e.g., Carlson, Newman, Daniels, Armstrong, Roth, & Loewenstein, 2003; Kassam-Adams & Newman, 2002; Martin, Perrott, Morris, & Romans, 1999; Newman, Walker, & Gefland, 1999; Walker, Newman, Koss, & Bernstein, 1997). The questions asked are similar to frequently encountered descriptions on the news and in other media. Carlson and colleagues (2003) studied the effects of asking about trauma in a sample of psychiatric inpatients. According to their findings, “70% experienced relatively low levels of distress, and 51% found participation to be useful in some way. . . . [P]erceived usefulness was not significantly related to any experiences or symptoms.” (p. 132)

These and other studies demonstrate that ethical and valuable research can be conducted on trauma survivors and highly dissociative participants. In order to minimize the risks to this population, research assistants and experimenters should be well-trained by a clinician experienced in working with dissociative trauma survivors. Researchers should know what to expect in the experimental session with highly dissociative participants. Before the study enters data collection, there should be a plan regarding what the experimenter will do in a session if a participant suddenly switches to a five-year-old identity. Will the procedure stop? Will age-appropriate language be used? Will additional verbal consent be necessary? Will another identity be summoned? What
if an angry protector identity comes out? What will the experimenter do if one identity withdraws consent, but another wants to continue? What if a participant becomes nonverbal or has a flashback? Will experimenters reassure participants, and if so, how? The consent process can also include making plans with the individual participants, such as asking them what procedures they use to help ground themselves, in case these techniques are needed later. Training should also focus on instilling in experimenters an attitude of participants’ competence in dealing with upsetting situations, and on emphasizing the normalcy of participants’ responses.

**Consent**

As far as possible within institutional guidelines, consent forms should be written in simple language that is easy to understand. Our laboratory has found an FAQ style to be effective at communicating the required information in a relatively painless manner. A consent form written as an FAQ can also be adapted easily for an actual FAQ page on a recruitment Web site.

Although the consent process already includes the information that participants may withdraw their participation at any time during the experiment, it may be necessary to reinforce this message throughout the experimental session. The procedure used in this research required only one signature on the consent form, which gave consent of the participant as a whole system; however, ongoing verbal assent was also incorporated. Highly dissociative people may be adept at camouflaging distress, and it is helpful to include a brief check-in periodically. A question as simple as, “How are you doing?” or “You doing ok?” after potentially stressful or triggering tasks demonstrates the researcher’s respect and concern for the participant’s well-being, as does the question, “Are you ready to go on to the next task, or would you like to take a break?” allow participants to take breaks as needed during the experimental session if they need to calm themselves. Researchers should consider ahead of time the potential effects on their results if some participants choose to take a break and others do not.

If researchers will be videotaping or audiotaping participants, they must follow IRB guidelines for explaining confidentiality and/or anonymity and what the uses of the tapes will be. Allow participants the opportunity to view their own videotapes after data collection is complete, but do not require it as a necessary part of the procedure. Be aware that some DID participants find viewing a videotape of themselves to be
very helpful for learning to recognize and communicate among identities, while others find the viewing to be extremely upsetting. This population may be uncomfortable being videotaped because of their trauma history; for example, they may have been used for pornography in childhood. Experimenters can make it clear when they are turning the camera on and off, and be aware that some participants may request that the camera be turned off or the tape erased if it covers topics that are uncomfortable for them to talk about. From the consent process, participants should be aware of the consequences (or lack thereof) of refusing participation in any part of the study. If a participant does request that the camera or tape recorder be turned off, be sure to take excellent notes about what goes on during that time.

**Respect and Power in the Experimental Setting**

Respect for participants can be demonstrated in ways beyond what is strictly required by IRB guidelines. For example, on the forms for my research studies as well as in my words and attitude, I attempted to convey to my participants my conceptualization of DID as a “condition” rather than a “disorder.” It is undeniably a “diagnosis,” but it need not necessarily be called an “illness,” mental or otherwise. While not downplaying the serious and potentially debilitating effects of DID, I emphasized the adaptive nature of DID symptoms and my interest in my participants’ experiences. I also made sure that I thanked participants for their time in addition to paying them, and I did not pathologize their behaviors, even (or especially) within the pathologizing hospital environment. In fact, one participant explicitly stated her appreciation of research that did not regard her DID as “freakish.” If participants asked about switching, I explained that switching or not switching was totally up to them, and that the experiment would work either way. I did not ask for certain kinds of switches, although I did remain alert for possible participant distress. After the conclusion of the experiment, I invited participants to share their thoughts on the experimental sessions. I also asked them which part or parts of them performed each task, and inquired about other parts that might have been helping or silently watching or listening. As each system of identities is organized differently, the more information that can be gathered about the identities participating, the better. Of course, the necessity of switching at certain times into certain identities depends on the research design; designs that require this level of control must necessarily use a specific subset of the population of people with DID.
Methodological Rigor versus Participant Comfort and Stability

Ideally, every experiment would be conducted in a scientifically rigorous and controlled manner. Certainly I would have preferred to have all of my participants come to our university laboratory, and indeed several of them did. However, due to the low density of potential DID participants, it is often less than feasible to conduct a medium-sized study in a controlled setting, even with the addition of grant-funded travel to a major teaching hospital. For example, some of my participants lived over 300 miles from the laboratory, and would not have been able to participate in the study had I not gone to them.

One benefit, however, of going to participants’ locations rather than asking them to come to a lab, if it is feasible to do so, is that it appears to be a good way to increase their comfort level as well as the sample size. I originally expected that participants would be uncomfortable letting a stranger into their homes, but my participants reported that being in their own homes made them feel comfortable and secure. Gendered power dynamics may have been in play here. My name in my e-mails and my voice on the phone are both obviously female, as were all of my participants, several of whom freely gave me their unlisted phone numbers as well as their addresses. To clarify, I did not automatically invite myself to participants’ homes. Instead, I gave them a choice of having the experiment take place in their homes or in another location such as a clinician’s office or rented office room; because participants lived in such disparate and unexpected locations, establishing complete laboratories was not feasible for this study. Participants unanimously preferred their own homes. They took the sessions quite seriously, spontaneously turning off their phones and telling roommates not to come in, thereby insuring as little disruption as possible.

Offering participants a choice of locations, at least for an initial meeting, may have helped participants see me as someone who was respectful of their privacy, safety, and space. Providing this option may be especially important for male experimenters. This option also reduces the burden of transportation for participants, which is especially important if they are low income or on disability leave, as were several of my participants. Several participants also found that having a pet or stuffed animal with them during the session helped them stay calm, which they would not have had in a laboratory setting. Another option is to conduct the experiment in the offices of the participants’ therapists, or to ask the participants whether they would like their therapists to be present.
during testing. In such a situation, it is important to clarify the therapist’s role and relationship with the experimenter and study results. Again, the ideal situation is to conduct all research in a laboratory setting, in order to reduce the potential for confusion regarding roles and boundaries. Unfortunately, in some geographical areas, this approach is not possible. Researchers should evaluate their designs in light of this control-validity tradeoff.

When working with DID participants, it is important to be aware of the demand characteristics inherent in the experimental situation, and of the power dynamics of the researcher-participant interaction within a patriarchal society (Rivera, 1989). People in positions of power have almost certainly betrayed participants in the past, by taking advantage of them, overtly abusing them, or failing to protect them from ongoing abuse. These dynamics are extremely salient when conducting research with abuse survivors, and researchers should be aware of how the multiple identities of doctor/patient, male/female, ethnic majority/minority, older/younger, sick/well, and scientist/subject interact. Jody Miller (1997) writes, “Although we are not dispassionate researchers who distance ourselves from our values and emotions, we continue to objectify our research subjects through the very power we employ as researchers” (p. 149). By designing a project and deciding how to analyze the data, researchers define what they will accept as “real” evidence and what variables they will study.

A small way for researchers to convey the importance of participants’ experience is through the language they use. For example, compare these two statements about filling out questionnaires: “Take as much time as you need” versus “Spend as much time as you want.” The former implies that participants are taking valuable time away from the researcher, and that they should take only as much as necessary. The latter implies that the session’s time belongs to the participants, to do with as they wish. This verbal cue is a subtle way to show that researchers respect participants and value their time, and that participation is always the choice of the participants themselves.

Participants and researchers both benefit from opportunities to collect semantically rich data. Researchers must not assume that there is only one perspective inside each person, or only one way that multiples act. Throughout the course of the experiment, treat participants as the experts on their own internal experience. Researchers should provide ample room on questionnaires for lengthy, disjointed, or multiple answers to each question. Tolerate ambiguity by allowing participants to skip questions, to guess, or to answer “don’t know.” Treat gender as an
open-ended question with an item that reads, “What is your gender?” rather than forcing a choice between two options. Some participants will want to write in the margins to explain why they answered the way they did or how they understood the question, so large margins or one-sided questionnaires will provide room for these comments. Experimenters may also need to allow extra time to respond to questions and forms so that participants can sort out their internal voices. On a final questionnaire, researchers can ask about the experience of participating and give participants a chance to write down what was good and bad about the experiment, and what they wish researchers would study about DID.

Additionally, survivors of abuse as severe as that which people with DID have lived through may have difficulties with writing and questionnaires. For example, in previous research one participant found writing difficult because she had not been allowed to write as a child, and another experienced stress and headaches when filling out any sort of forms (Barlow, 2005). Participants who switch into child identities may be temporarily unable to write. Researchers should create alternate procedures to have in place if needed.

Naturally, a scientifically ideal experiment would include none of these uncertainties. In a perfectly rigorous experiment, all participants would answer all the questions asked and never write in the margins. When researchers design a study, each element that is included serves a purpose, and varying these procedures is at odds with strict laboratory control. However, in any study there is always the possibility that participants will not respond to stimuli as expected. Every IRB-approved study allows participants to skip parts of the experiment in which they do not wish to participate, or to cease participation at any time without penalty. The degree to which a researcher can design studies that work around these potential disruptions depends, of course, on the specific subject matter and hypothesis-testing used. Researchers must decide for themselves what the correct balance of rigor and realism is. In a perfectly rigorous experiment, the researcher would always have perfect knowledge of and control over which alternate identities were present and participating in the experiment, and the timing of their appearance. Participants would be perfectly able to switch to specified identities on demand and remain in those identities, minimizing interference from other parts of the system, so that they could be tested one at a time. This level of executive control is not always continuously present in people with DID. In my study of how people with DID function in daily life, I
chose to forego some amount of laboratory control in return for better ecological validity in the demands on my participants.

In designing experiments, researchers should also be especially sensitive to potential triggers, such as feeling watched or judged, or restrictive apparatus such as MRI or EEG equipment. Arrange the experimental room so that participants do not have their backs to the door, and so that experimenters do not have to walk behind the participants. Many participants have unforeseen or idiosyncratic triggers (such as viewing mirror-reversed stimuli in one case), which is another reason to train researchers and assistants thoroughly. As with any participants, researchers should always get permission before touching participants, for example to attach electrodes or to put on headphones. In a study conducted by a researcher who is himself a multiple, West (1998) points out that this permission should also extend to personal belongings. In participants’ homes, researchers should never move objects without asking for permission (West, 1998); it is better to let participants arrange the situation as needed for the experiment.

**CONCLUSIONS**

The study of dissociation is a relatively small but growing field. It may seem complex and difficult for new investigators to initiate a study on participants with DID, and indeed it is. However, there are many enigmas to this fascinating condition that have yet to be empirically examined, and there are numerous areas for potential studies to explore.

Researchers invested in the well-being of their participants can begin the process of conducting sensitive research by educating and communicating with IRBs. Researchers in this area should also be aware of individual differences and design studies to accommodate them, while considering the delicate balance of laboratory control and ecological validity. Further, training is essential so that both the principal investigators and the research assistants on these studies are able to deal sensitively with trauma survivors. This sensitivity is enhanced by clear and non-coercive recruitment and consent procedures. Psychology researchers have a unique ability to be aware of hierarchy and power in the experimental setting, and to take these issues into account. Finally, participants are always the experts on their own internal experience. Recognizing this fact will facilitate ethical and respectful research with traumatized and highly dissociative participants.
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