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“Just How Much Did That Wheelchair Cost?”: Management of Privacy Boundaries by Persons with Disabilities

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Abstract

Persons with physical disabilities were studied to determine how they communicate when they perceive able-bodied persons are expecting or demanding disclosure about their disability in new relationships. An interpretive analysis was performed on 350 pages of transcribed data from interviews with disabled adults. The results showed that disabled persons were able to describe the communication of able-bodied others and their attributions when disclosure was demanded or expected. This study revealed communication strategies disabled persons use to manage disclosure. These strategies were discussed as regulating privacy boundaries, whereby disabled persons seek to be acknowledged as “persons first” by controlling dissemination of private information.

One salient communication issue we face in early phases of relationships is how much information to reveal about ourselves to the other. This is a complex decision all communicators make, but it is particularly challenging when one of the interactants in the new relationship possesses a social stigma (Goffman, 1963): for example, AIDS, mental illness, or physical disability. Previous research on one type of stigma—physical disability—has shown that disabled persons experience a demand for information about their disability in early phases of relationships with able-bodied persons (Braithwaite, Emry & Wiseman

1984; Thompson, 1982; Thompson & Seibold, 1978). To more completely understand how persons in new relationships make choices about revealing private information to others, examining the disclosure of persons with disabilities will further our knowledge about disclosure and privacy.

Persons with physical disabilities represent one group of stigmatized individuals who face challenges in relational initiation. It is difficult for able-bodied persons to imagine instances where strangers would ask them to reveal normally private information about their health, bodies, sexuality, or personal habits. While such requests for information would be unusual for most able-bodied persons, they are not unusual for persons with physical disabilities. It is well supported in the literature that able-bodied persons often experience high levels of uncertainty and discomfort in new relationships with disabled persons (Braithwaite, 1985, 1989; Deegan, 1977; Goffman, 1963; Heinemann, Pellander, Vogelbusch, & Wojtek, 1981; Kleck, 1966; Marinelli, 1974; Worthington, 1974). This uncertainty has a negative effect on these relationships (Farina, Sherman & Allen, 1968; Thompson, 1982), resulting in a lack of contact with and information about disabled persons on the part of able-bodied persons (Belgrave & Mills, 1981; Gosse & Sheppard, 1979).

An earlier study (Braithwaite, 1985) revealed that disclosure is a salient issue for persons with disabilities in their new relationships with able-bodied persons. Braithwaite (1985) found that the perceived demand for information about the disability would most likely occur in the initial meeting or within the first few interactions with a newly met able-bodied person. Subjects reported that able-bodied persons regularly request disclosure on such topics as the extent of the disability, sexuality, costs of assisting devices (such as how much a power wheelchair costs), or how their disability occurred. A review of the literature on disclosure and disability (Braithwaite, 1987) concluded with a call for research on the self-disclosure behavior of persons with disabilities when they communicate with able-bodied persons in early phases of new relationships.

Privacy Regulation by Persons with Disabilities

Especially when the disability is visible (e.g., a person who has had polio or uses a wheelchair), revealing information concerning the disability is a primary message decision for the person with the disability (Thompson & Seibold, 1978). Persons with disabilities who disclose information about their disability are revealing information about their own health and body that would ordinarily be considered private between persons who do not know each other well (Goodstein & Reinecker, 1974).

Several scholars have argued for reconceptualizing disclosure as a process of regulating privacy boundaries (Altman, 1975; Delegate & Chalking, 1977; Goodstein & Reinecker, 1974; Petronius, 1988, 1991). This privacy perspective is adopted in this present research. Petronius (1988) argues that concentrating on managing privacy boundaries rather than on self-disclosure moves us away from the premise that "openness is good" and is a more dynamic and theoretically sound way to address the risk-laden nature of revealing information to others. Westin (1967) defines privacy as "the claim of individuals, groups or institutions to determine for themselves when, how and to what extent information about themselves is communicated to others" (p. 7). Implicit in Westin's definition is the right of

individuals to have selective control over access to the self. Not only does privacy imply a selective control over information, but Petronio (1991) argues that the right to control one's privacy boundaries provides a sense of individuality. Petronio and Braithwaite (1987) discuss the control of one's privacy boundaries as giving the individual a way "to exercise the 'need' and 'right' to regulate the balance between privacy on the one hand and openness on the other" (p. 68).

Communication between persons who are able-bodied and disabled in early phases of relationships is replete with implicit and explicit demands for information about the disabled persons' disability (Braithwaite, et al., 1984). Able-bodied persons are often fearful of offending the person with disabilities who might be sensitive about discussing their disability. Similarly, the person with disabilities is faced with conflicts as well, wanting to be appropriately open about their disability while trying to avoid the risks and costs of talking about their disability. Risks and costs include: embarrassment, unwanted sympathy, being misunderstood, or making the self or other uncomfortable (Braithwaite, et al., 1984).

Even though there has been relatively little research done in this area, the literature suggests that openness about one's disability is good for the relationship, and some have suggested that persons with disabilities should disclose about their disability in order to help able-bodied persons feel more comfortable (Goffman, 1963; Hastorf, Wildfogel & Cassman, 1979; Thompson & Seibold, 1978; White, Wright, & Dembo, 1948). Thompson (1982) reviewed eight studies about self-disclosure by persons with disabilities and concluded that able-bodied persons reacted more positively toward persons with disabilities who engaged in self-disclosure and even more positively when the information revealed pertained to their disability. In fact, able-bodied persons preferred that persons with disabilities disclose about their disability even when the act of disclosure made the person visibly nervous (Evans, 1976; Hastorf, Wildfogel, & Cassman, 1979; Mills, Belgrave & Boyer, 1984). Why does revealing produce such positive results? To able-bodied persons, when persons talk about their disabilities, this may indicate they are comfortable with it, so the able-bodied person feels more comfortable as well. In their research, Hastorf et al. (1979) concluded that when persons with disabilities disclose about their disability, able-bodied persons will like them more than when they do not disclose. However, Thompson and Seibold (1978) found little support for this claim, arguing that disclosure does reduce tension and uncertainty levels of the able-bodied person but does not increase their *acceptance* of the person with disabilities. Even so, Thompson recommended originally persons just disclose about their disability saying that, "There are few imaginable instances when such disclosures could lead to a loss of control, hurt the other person, or when it would be of more benefit to lie about the disability" (1982, p. 201).

Braithwaite et al. (1984) argued that, when coming from the perspective of an able-bodied person, it is difficult to disagree with these conclusions. Talking about the disability does seem to make the able-bodied person feel more comfortable. There is an implicit assumption that what is good for the able-bodied person will be good for the person with the disability as well. Yet, there is an omission in this analysis; the function and outcome of revealing private information for disabled interactants have not been assessed. To date, there are limited data to indicate how persons with disabilities use disclosure in their communication with able-bodied persons.

The purpose of the present study was to ameliorate the research bias toward able-bodied persons and to obtain the perspective of persons with disabilities on their use of revealing information about their disability. The question guiding this research was:

How do persons with disabilities communicate in early phases of relationships when they perceive that revealing information about their disability is expected or demanded by able-bodied others?

Method

An interview methodology was used to allow the researcher to attempt to qualitatively study communication from the perspective of the disabled interactant. Merton and Kendall (1946) argued that the interview methodology facilitates bringing out information important to the informant and uncovering what is on the informant's mind, rather than simply gathering the reaction of the informant to what is on the researcher's mind. This study used a semi-structured "focused" interview technique (Rarick, 1984; Spradley, 1979), which targeted the perceptions and experiences of the subjects. The interviewer prepared a list of questions and probes, "but the emphasis of the interview is on allowing the interviewee to report his/her experience of the stimulus situation from the interviewee's own point of view" (Rarick, 1984, p. 62).

Procedures

Data were drawn from 350 pages of interview transcripts gathered from face-to-face interviews with persons who had visible physical disabilities. The 24 subjects for this study came from referral from other interviewees. First, the researcher contacted several disabled subjects who had taken part in a pilot study (Braithwaite, 1985) and these subjects volunteered to generate lists of possible subjects the researcher might contact. Second, at the end of each interview conducted, subjects were asked if they could suggest persons who might be willing to be interviewed by the researcher. All of the subjects who were called by the researcher agreed to participate in the interviews. Several guidelines applied when contacting subjects. All subjects were adults and had visible physical disabilities (e.g., quadriplegia, paraplegia, or effects of polio). Subjects did not have communication disabilities (e.g., deafness or speech disabilities) so as not to compound the communication problems being addressed in the study. The researcher contacted subjects of varying age, disability type, length of disability, and occupation, and interviewed approximately an equal number of males and females (46% males, 54% females).

The researcher contacted the subjects by telephone, briefly described the purpose of the study, and determined subjects' willingness to participate. Subjects agreed to meet the researcher for an interview of approximately one hour in length. Subjects were met at the place of their choosing (their own office or home, in most cases). The researcher asked for permission to audiotape the interviews, guaranteeing anonymity of the subject. No subject refused to be audiotaped.

The interviews were structured around a series of open-ended questions and probes. The researcher asked the subjects to discuss their communication behavior with able-bodied

others in initial and early phases of relationships. Subjects were asked to discuss specific problems, if any, they had in communicating with able-bodied persons new to them. They were asked to discuss their attributions of their own and able-bodied others' behavior. Finally, subjects were asked to recall and describe ways they communicated in specific situations to overcome communication problems they identified earlier (communication strategies). The 24 interviews ranged from 30 minutes to 100 minutes in length, with the average interview lasting approximately 50 minutes. The interviews were audiotaped and transcribed.

Analysis of Data

These data were analyzed in two stages. First, the researcher arranged the content of the interview transcripts into three response categories that were set up a priori from the pilot study (Braithwaite 1985). These three categories were: (a) statements describing communication behaviors of able-bodied others, (b) statements describing attributions of the behaviors of self (the subject) and able-bodied others, and (c) statements describing communication strategies that the subjects reported using in interactions with able-bodied others. For example, this subject's statement was coded as a communication strategy:

Because there's time, there's times that people come up to me and say point blank, ask me, you know, "how did you get in that wheelchair?" Well, I'll ask, "Which story do you want? Do you want the real story, do you want my story on Viet Nam or do you want my story about my romantic endeavors?"

Second, the data were analyzed and arranged into three categories of communication issues that were discussed most frequently by the subjects: (a) dealing with issues of discomfort and uncertainty, (b) dealing with issues of disclosure, and (c) dealing with issues of help. The sample statement above was coded as a communication strategy using intentional embarrassment employed by a disabled person when dealing with issues of disclosure. For the present study, only the data dealing with issues of disclosure are reported.

The researcher analyzed the interview transcripts via an interpretive perspective in order to maximize the rich data from the transcripts and to allow for a fuller understanding of the communication behavior of these disabled subjects. The interpretivist sees reality as constructed through words, symbols, and behavior of humans, and the interpretive approach centers on the study of the consensual meanings created and shared by human actors (Putnam, 1983). The interpretive researcher, according to Bogdan and Taylor (1975), is concerned with understanding human behavior from the actor's own frame of reference. The present research represents a departure from the able-bodied focus by soliciting disabled persons' perspectives on their communication with able-bodied persons.

Interpretive scholars look for basic recurring patterns of behaviors that are universal to the population under study (Bormann, 1983; Katz, 1983) and seek to expand the domain to which their explanations may be generalized. With these data, the interpretive researcher does not stop collecting data when a certain size of sample is achieved, but, rather, stops collecting data when patterns of discourse are discovered. The discovery of such patterns provides useful knowledge for communication scholars. To begin to make a case for

generalizability beyond the sample population in the present study, care was taken to include subjects representing diversity in disability type, age, sex, length of disability, and occupation, with the intention of providing a variety of perspectives.

Results

These data are reported in three general analysis categories: (a) able-bodied persons' communication behaviors, (b) subjects' attributions of self and others' behavior, and (c) disclosure strategies used by persons with disabilities.

Able-bodied Persons' Communication Behavior

In the interviews, subjects discussed issues of privacy frequently with the researcher, indicating that deciding whether to disclose and what to disclose was a decision that was bound to come up early in relationships with able-bodied persons, if not at the first meeting. From these data it was clear that able-bodied persons often ask questions about the individual's disability. In the analysis of these data, able-bodied persons' behaviors fell into two general categories: asking questions about the disability and obtaining permission to ask questions.

Asking questions

In the interviews, subjects reported that able-bodied persons usually asked them questions about their disability early in the relationship. One subject reported, "Because there's times that people come up to me and say point blank, ask me, you know, 'how did you get in that wheelchair?'" (1:2).¹ Most of the time, these questions are asked in a first meeting when the "time seems right," as one subject described:

Pretty frequently they do ask a question about the disability in the first meeting and usually it's in a pretty good context. Again, usually after you've talked a while somebody will say something, "Well, you know, hope you don't mind if I ask, but what are you doing in a wheelchair? How did you get there?" (5:1)

Subjects reported that there are a variety of different questions able-bodied persons will ask them, ranging from questions about how the power wheelchair works to more personal topics such as sexuality. Observed one subject, who is quadriplegic:

. . . they'll start, "How do you get up in the morning? How do you eat?" Just all kinds of things. They'll ask, "You don't mind if I get personal, do you?"
 "Naw, go ahead, what do you want to know?"
 "Um, do you, do you go out on a date, you know . . . can you?"
 "Sure, yeah, hey, it might be better!" (21:1)

Subjects reported that children who are strangers often approach them and ask questions such as: "Why are you in a chair? Can you walk? Who helps you to bed? I mean they ask you anything they want to know . . . So after these hundred questions, then they're

fine" (7:1). Subjects described that while children react with questions, the adults accompanying them often react negatively to their enquiries of the disabled individual, telling the child to be quiet, not to stare or point, to leave the person with the disability alone, or physically pulling the child away from the person with the disability.

Not only do children who are strangers ask questions about the disability, but subjects describe adult strangers "on the street" asking questions about their disability. One subject, who has had polio, observed:

Well, I've had people walk up to me on the street and say, "Oh isn't it wonderful that you get out of the house?" and people ask me, "Well, how do you get dressed in the morning?" Perfect strangers walk up to me off the street and ask me, "Can you cook?" or, you know, "Do you have any feeling in your legs?" (13:3)

Subjects did indicate that such intimate questions from strangers are less common than similar questions from able-bodied persons with whom the person with disabilities has a beginning acquaintance.

Subjects also reported instances when able-bodied strangers did ask them questions after they had provided help to the person with the disability:

Oh, people in physics class . . . They'll catch you glancing around the room at something and they'll come over or they'll hold the door open and they'll ask you, "How long do the batteries last on that thing (the power wheelchair)?" You know, and then that kind of, they ask questions that they know aren't dumb. And it kind of leads into something else. (12:2)

Finally, subjects observed that some able-bodied persons ask questions indirectly, in the form of statements or talking about disability in general, to "work up to" getting more specific information from them. Observed one female subject, "Or if somebody starting talking about handicaps in general, and, you know, that they were indirectly asking me about myself . . ." (9:3). This indirect approach signals to the person with the disability that the able-bodied person wants information from them. It will then be up to the individual with the disability to choose whether to pursue the indirect line of questioning or not.

Obtaining permission to ask questions

While able-bodied persons are likely to ask questions of the person with the disability, subjects explained that they may preface their questions by determining if it is acceptable to ask questions. They may preface questions with, "Do you mind if I ask what happened?" (2:1), or "I don't want to offend you, but . . ." (20:1), or "Would it bother you if I asked . . ." (23:1). In each case the able-bodied person waits for permission to go ahead and ask the question(s) that they had in mind. Some subjects cited examples of able-bodied persons who asked whether it was acceptable to ask a question after they had a negative experience with another person with a disability. One subject described an example of an able-bodied person who said to her, "Well, if you don't want to answer that's OK because I asked someone once and they really didn't want to answer" (7:1).

Attributions of Behaviors

Clearly the subjects were able to describe the communication of able-bodied persons who desired disclosure about the disability. In the interviews subjects also described their own attributions for both the able-bodied persons' behaviors and their own behaviors in disclosing situations. These attributions fell into three main categories: (a) wanting questions answered, (b) disclosure to increase comfort, and (c) reasons for avoiding asking questions.

Wanting questions answered

By far the most common explanation that subjects with a disability provided as to why able-bodied persons wish to ask questions of them is curiosity. These subjects assume that able-bodied persons they do not know wonder about their disability. Having questions, the able-bodied individual has to decide whether to ask them or not. Said one subject with a rare disorder that has left her a quadriplegic, "And I know, that for the most part, they want to know what's wrong with me and why I'm in the chair. And yet, they don't know whether I'm open enough to talk about it" (11:1). Subjects perceived that able-bodied persons live with the uncertainty until the pressure to ask their question becomes so great that they ask. One subject talked about starting a new job:

It's like people build up these questions and as soon as they know you well enough, these questions just bubble out . . . and there is some slack time in the afternoon . . . where you're sitting around maybe go have coffee, then it's just like these questions will bubble out . . . And they'll say, "once saw a handicapped person who was doing this and what was that all about?" (8:3)

While the subjects attributed a need for information to the able-bodied persons who want answers to their questions, subjects also indicated that most able-bodied persons did not want or need much detail. Even subjects who have less familiar disabilities find that questioners will usually be satisfied with a minimum amount of explanation while the relationship is in its early phases. One subject, who has a rare form of mixed connective tissue disorder, reported that she will usually tell people who ask that she has a form of arthritis and that label will usually satisfy the questioner (24:1).

Disclosure increases comfort

Subjects reported that obtaining answers to questions is one way that able-bodied persons will relieve their discomfort with disabled persons and some reported using talking about their disability as a method to get the disability "out of the way" and make strides toward an improved relationship with the able-bodied person. After the researcher asked a subject what happens once she discloses about her disability, she observed:

Well, then hopefully they [the able-bodied person] will just judge that if they like me they like me, you know, and if they don't that's because all able-bodied people don't like each other either. It, it [the disability] shouldn't have anything to do with the reason. . . . It kind of puts it aside. (20:2)

Several subjects reported trying to put themselves in the place of the able-bodied person, as did this male subject:

Probably since they want an answer . . . “What’s going on?” or “What happened?” . . . I do that in a lot of instances, you know, I just switch positions. Like what would I do if it was this way, that way. And I know that, boy, if had a friend that was in a wheelchair just since high school, well there would be a lot of questions. And it doesn’t bother me when people ask me questions like that. (12:2)

These subjects reported trying to empathize with the able-bodied person, seeing self-disclosure as one way to put the other at ease, and to try and move past the discomfort about their disability.

Reasons for avoiding asking questions

Subjects, in their interviews, attributed to able-bodied persons a desire to know about their disability, but indicated that not all will ask the questions they want to. There are two explanations that the subjects used to explain this phenomenon. First, the able-bodied person perceived the disabled person might be sensitive about their disability or might not want to talk about it. The subjects often characterized these able bodied individuals as avoiding asking their questions until they “can’t stand it anymore.” Recalled one subject:

I think people generally try to avoid it (the disability) until it’s so obvious that they have to say something. People really try to act like you’re not having a problem, like you walk upstairs like anybody else, when, in reality, you’re taking them double-steps like a toddler. They just avoid it until finally they aren’t comfortable with you or just can’t stand their curiosity anymore. (24:1)

A second reason for avoiding asking questions is that subjects perceive the able-bodied person is uncomfortable about the issue of disability and avoids asking questions because they are afraid of dealing with the issue of disability in their own life, a kind of “ignorance is bliss” approach.

Finally, when adults prevented children from asking questions of a person with disabilities, subjects perceived that the adults themselves were uncomfortable around disabled persons. When the child confronts the disabled person directly, this heightens the discomfort of the adult. Observed one subject who has had polio:

If a little kid comes up to me and asks, “What happened to your arms?” I say, “Well, nothing is wrong with my arms.” . . . And I proceed to tell them that thing is a crutch and it helps me walk . . . and by that time the mother is beginning to drag them off. And, you know, I ache, I just talk over the mother. The mother is saying, “Billy, don’t say that. Get away from there.” And I’m just talking with the kid and ignoring mother because she should be explaining to this kid that, you know, that when they see somebody different that “Oh well, she just must need help walking” or something. (6:8)

Disabled Persons' Disclosure Strategies

Having a perception of the attributions of able-bodied persons' behaviors and an understanding of the meanings these behaviors have for disabled persons, this last section presents the disclosure strategies persons with disabilities reported using. These strategies were coded into four categories: (a) responding to questions, (b) delaying disclosure, (c) dealing with inappropriate questions, and (d) initiating disclosure.

Responding to questions

It is clear from these data that persons with disabilities expect that the subject of disability will come up in conversations with able-bodied persons who are strangers, often at the first meeting. Subjects reported that they do not disclose randomly, but in most cases will disclose in response to a question posed by the able-bodied other. Said one subject:

If they have asked a direct question I will answer it very directly and then immediately change the subject if it has no bearing on what we're talking about . . . I'd much rather get that out of the way right at the beginning, get all that out of the way, answer their questions and then just go on with the purpose that for some reason we've been thrown together. (13:1)

All the subjects indicated a willingness to answer questions if certain conditions of appropriateness are met including appropriate: relationship characteristics, context and topic, motivation, and mood.

First, subjects indicated that they will disclose about their disability if they perceive that disclosure is appropriate to their relationship with the able bodied other. The relationship is deemed appropriate if it is somebody they know, they like and with whom they feel comfortable, and they expect to interact with in the future. The one exception to the relationship condition was with children who were strangers asking them questions. Subjects reported that children are "more honest" than adults and they indicated a willingness to "tell a kid anything" (4:1). Subjects reported they are educating children by telling them about disability, hoping that children will grow up with more positive attitudes than their adult counterparts.

Second, subjects reported that they will disclose if disclosure is relevant and appropriate to the context and to the topic being discussed. Often the matter of disability comes up as a normal part of conversation, for example, when "talking about what happened when we were kids" and some aspect of disability naturally is raised (14:1). One male subject reported that he does not mind disclosing if he perceives the context is appropriate:

No (I don't mind), not in the appropriate context. . . And usually I'll give them a little brief description and say, "I'm a quadriplegic" or "I broke my neck swimming." Depending on the context, again, I will usually not get into it too much at a party with somebody that I just met that I'm not intending to have necessarily any relationship with. (5:1)

A third condition of appropriateness was the perceived motivation of the able-bodied person in asking about the disability. Subjects routinely differentiated between "healthy curiosity" or showing of concern versus questions that they deemed nosy or based on inappropriate or "morbid curiosity." One female subject differentiated between people who are "concerned and really curious" versus those who are "just being nosy" (6:3). Subjects reported evaluating the motivation of the able-bodied person asking for information and choosing to disclose only if they deemed the motivation appropriate.

A fourth condition of perceived appropriateness of disclosure concerned personal characteristics of the disabled sources, most often their mood and feelings of comfort or discomfort. Several subjects reported that they are shy and found it hard to talk about themselves in any context. These persons were less likely to want to talk about their disability than persons who did not see themselves as reticent. Several subjects whose disabilities occurred later in life reported that they were more outgoing since the onset of their disability because they now needed to take more initiative in forming relationships. Several subjects whose disabilities occurred early in their lives, such as those with polio, spina bifida, or cerebral palsy, reported that they felt very uncomfortable answering questions when they were younger, especially in their teenage years, but do not have problems answering questions as adults.

Along with level of comfort, mood plays a role in determining whether the individual will be willing to disclose. One woman described her willingness to answer questions as dependent on her mood by saying, "Sometimes it's like, hey, I don't want to be bothered. Other times it's, I probably tell people more than they want to know!" (9: 1). In situations when they are not in the mood to discuss the disability, many subjects reported becoming sarcastic or giving a rude response to the questioner. Said one subject, a quadriplegic:

There are times when I'll give people a story or I'll just throw it back at them . . . make them feel uncomfortable by their asking a dumb-ass question . . . as "What's wrong with the leg?"
 "There's nothing wrong with my legs."
 "Why are you sitting in a wheelchair?"
 "It's comfortable. I got drunk one night and they wheeled me out in this." But, again, that's if I'm in a little bit of a rowdy mood. (5:3)

Delaying disclosure

A second strategy reported by subjects was that of delaying the inevitable questions by able-bodied persons until the person with the disability can establish themselves as a "person first," rather than being seen as a "disabled person." One subject discussed how she used this strategy:

I've learned through experience that the first thing that we communicate about is some common area. And so I make a point of talking about politics . . . And I also think I'm a really good listener, and so initially when I meet somebody new I make a point of covering a wide range of subjects . . . I take their mind off the fact that I'm disabled . . . because eventually they're gonna want to know what

my disability is, and they're eventually going to have all sorts of concerns and questions about that. And then that's gonna become a focal point of our relationship . . . what I'm trying to do is establish some links before we get to the point where we talk about the disability. (16:1,3)

In this situation, the person with the disability communicates to carve out the niche of a "normal person" for themselves, hoping to keep the disability from becoming an early focal point of the relationship (5:6). Many times in the interviews, subjects cautioned that too much disclosure about their disability will cause able-bodied persons to think that disability is all that disabled people want to discuss. By talking about "normal topics" the person with a disability lets able-bodied others know that they have a wide range of interests and expertise.

Dealing with inappropriate questions

When a question or questioner does not meet the disabled persons' conditions for appropriateness, subjects reported a variety of strategies for dealing with the situation. These strategies range from indirect strategies to more direct confrontation.

The first group of strategies reported in the interviews involve an indirect approach including: (a) changing the subject to avoid the question they do not want to answer, (b) ignoring or avoiding the question or questioner, (c) withdrawing physically from the person who asked the inappropriate question, or (d) asking the offending person to leave them alone. When asked by the researcher if he would answer an able-bodied person's question about his disability, one subject responded:

Rarely if somebody comes up to me on the street. I will tend to try and point out that that's really not appropriate, that I'm with somebody and I'm trying to talk to them; they're being a nuisance or that their questions are inappropriate for the fact that I do not know them . . . I'll start out by being polite and say "I'm really trying to talk to this person, I really don't want to talk to you." (5:1)

While subjects reported that they may be polite "on the outside," they are often suppressing an angry verbal response. One subject, who is paraplegic, discussed a situation where an able-bodied person asked if she could drive her own car:

I would very politely and gracefully say, "Oh, yes, I drive. I have this neat little gadget for hand control in my car." And I would describe it to you and I'd try to educate you, but inside of me I would be going, "You stupid motherfucking idiot, how dumb. That I'm here and you're way back there a hundred thousand miles away, and, and here I had really given you more credit than that." So, my opinion of you would have dropped immediately. I would have continued to be real graceful and polite, but I would not have spent a whole lot more time talking to you. (16:1)

A second group of strategies was more direct, telling the questioner that the information requested is "none of their business" (13:2) or responding in a sarcastic or rude manner. Often the person with the disability will respond to the inappropriate question with humor. Recalled one male subject who broke his neck in a diving accident:

Because there's times when people will come up to me and say point-blank, "how did you get into that wheelchair?" . . . I always remember one little old lady . . . she came up to me, "Oh, you poor boy." . . . so I told her I had to parachute out of my jet in Viet Nam and I landed in a tree and broke my neck. (1:3)

Often this humor uses sarcasm to let the offender know they have asked an inappropriate question. One female subject recalled answering an inquiry about where she got her wheelchair by saying "I stole it from a black guy in the alley" (4:1).

If the able-bodied person continues to persist with their questioning after the above strategies are employed, subjects reported escalating the confrontation:

I kind of go through stages, you know, my verbal behavior escalates as the person's persistence in different requests goes on. If I get to the point, excuse the language, "But just get the fuck out of here" and they're not gone then I really get—I'll either try to motor away or really get pissed and I'm not beyond rolling over toes, really. I have been in situations where I, you know, there's really no other alternative. (5:4)

The subjects did report, however, that situations warranting confrontive behavior were the exception rather than the rule.

Initiating disclosure. While disclosure about their disability most often occurs in response to an inquiry by the able-bodied person, subjects explained there are times when they would initiate communication about themselves and/or their disability. Subjects reported that they may resort to disclosure about their disability if they attribute to the able-bodied person greater discomfort than they normally encounter, making disclosure "absolutely necessary." One subject said she would disclose if the other person seemed "real uncomfortable" and seemed to be letting that discomfort block the reason they were coming together in the first place (13:1). One subject, who is quadriplegic with no motor function below her neck, explained that she will notice the able-bodied person looking at her hands or legs trying to determine whether she could move or not. At that point she might ask them to hand her an object, giving her the chance to explain that her hands "do not work very well" (11:1).

A second way to initiate disclosure is for the person with the disability to bring up their disability indirectly. Reported a subject who has had polio:

The first few times they come over they don't usually bring it [the disability] up but somehow or other I might get around to saying "I had polio when I was younger" and stuff. And then they'll usually ask some questions after once I have

opened it up and they probably feel a little more comfortable with it . . . it makes them feel more freer that they can ask, you know. (19:1)

Not only does bringing up the disability indirectly and “working it into the conversation” help the able-bodied other feel more comfortable, this may also function to tell the able-bodied person how the person with the disability feels about their disability. One subject discussed how this put the disability “in perspective”:

It says, I’m Aries, I’ve got hazel eyes, I’m competitive, I’m fun to be around and I also happen to be disabled. And that’s just the way life is. And if you try to make anything more of it you’re going to be S.O.L. because there’s nothing more to be made of it. So it kind of puts it in perspective as far as I’m concerned, although I rarely bring up the disability. (16:5)

Subjects see revealing private information as a way to reduce discomfort and uncertainty of the able-bodied person, to get the disability “out of the way” in new relationships, to let the able-bodied person know how they feel about their disability, and to let the able-bodied person know how they feel about discussing their disability. Bringing up their disability in this way also functions to put the disability “aside” in able-bodied persons’ minds, to be able to get on to other issues in the relationships (20:3).

Discussion

It is clear from these results that making choices about revealing private information does play a significant role in the communication between able-bodied and disabled persons. First, in the results reported, subjects demonstrated an awareness of the communication behaviors of able-bodied persons and, second, articulated their attributions for the behaviors of self and able-bodied others. Third, subjects described the communication strategies they employ to control the dissemination of information about themselves and their disability. These results are significant because they provide a picture of revealing private information in relationships between stigmatized and nonstigmatized persons in more depth than has previous research. Additionally, the results provide evidence to question the prescription that persons with disabilities should *always* disclose about their disability. While disclosure may make able-bodied people feel more comfortable, disclosure may not always be advantageous for the disabled person, either relationally or personally. Just meeting the needs of the able-bodied may fail to meet the needs of the disabled person. These data demonstrate that persons with disabilities make active choices about disseminating private information, based on a number of factors.

Results of this study demonstrate that persons with disabilities live in a world of reduced privacy. While able-bodied persons may choose to reveal private information about their health or bodies, persons with physical disabilities attribute a perceived demand to discuss their disabilities with able-bodied persons. Due to the visibility of their disability and due to the fact that they will be expected to talk about the disability, persons with

disabilities reported a sense of lost privacy. These data reveal that disabled persons constantly make choices about how they wish to regulate their privacy boundaries, and boundary regulation gives them control over the communication relationships they maintain with other people (Petronio, 1988, 1991; Petronio & Braithwaite, 1987).

From these data, it is clear that persons with disabilities control access to private information in such a way as to be seen as "persons first," a theme which ran throughout the interviews. While communicating the desired impression of self to the other, controlling private information also influences how disabled persons see themselves. An individual's identity, self-esteem, and sense of autonomy are dependent upon having control of one's own private information. Derlega and Chaikin (1977) maintain that "How one regulates self-boundary control mechanisms may ultimately contribute to an individual's definition of self" (p. 105).

Conditions and Ramifications of Revealing Private Information

These data revealed that disabled persons do not disclose indiscriminately. Petronio, Martin, and Littlefield (1984) identified four conditions that are prerequisite to revealing private information: (a) relationship characteristics (i.e., the relationship level is appropriate for revealing), (b) context characteristics (i.e., the context or situation is perceived to be appropriate for revealing), (c) source characteristics (i.e., that the source feels comfortable revealing to the intended receiver), and (d) receiver characteristics (i.e., that the intended receiver is perceived to be trustworthy or is liked by the source). In this analysis, for an individual to choose to reveal private information, these characteristics must be met (Petronio, Martin & Littlefield, 1984). Along with these four conditions for revealing, they found that persons will also consider the possible ramifications of disclosing private information. The results of the present study demonstrate that persons with disabilities do consider these conditions and ramifications as criteria for deciding what, if anything, to reveal about themselves and these disclosure choices call into question the prescription for disclosure about the disability.

Relationship characteristics

Thompson (1982) suggests that the content of a message may be what determines the other's reaction toward the person with the disability. We know that the target person must consider the disclosure appropriate to the type of relationship between the individuals (Chaikin & Derlega, 1974). So, while revealing information about one's disability may be one way to decrease the uncertainty an able-bodied person has, there is no evidence to indicate that revealing personal information about disabled persons' health and body would be considered *appropriate* for new relationships.

One facet of appropriateness is the level of intimacy expressed in the message. Strangers generally become more intimate over time (Altman & Taylor, 1973) and to talk in detail and with feeling about one's disability may violate the norms of intimacy and appropriateness in early phases of relationships. If this is true, how is the able-bodied interactant to respond when communicating with a person who has a disability? How can the able-bodied interactant disclose with the same level of intimacy as the person who talks about a serious disability? For example, if a disabled person discusses the accident in which

she broke her neck, it would seem highly inappropriate for the able-bodied person to disclose his own experience of having an accident in which he broke an arm. These data reveal the importance persons with disabilities place on appropriateness as they are deciding whether to disclose.

Context

Petronio, Martin and Littlefield's (1984) second condition for disclosure is appropriate context. The literature has not paid attention to the context for disclosure about the disability. The present data reveal that persons with disabilities do consider the context before deciding whether to disclose about their disability, for example, whether they are at a party, on the street, or at work. The results indicate that persons with disabilities have a series of strategies they use in dealing with able-bodied persons' inappropriate questions that do not meet these criteria.

Flexibility of disclosure patterns is stressed by Chelune (1975), who noted the importance of being able to adapt disclosure patterns to a greater range of interpersonal situations. A blanket prescription to disclose about one's disability violates the norms of appropriateness of context and does not take into account, for example, whether the person is at work, at a party, or in a medical setting. This study reveals that persons with disabilities will only disclose about their disability after carefully considering the appropriateness of the context of the interaction.

Source characteristics

Petronio, Martin and Littlefield's (1984) third condition for disclosure is that the source have the proper characteristics for communicating about the disability, for example, whether the source feels comfortable in disclosing to the potential receiver. Subjects in this study noted the importance of feeling comfortable when talking about their disability. For most of the subjects, talking about themselves and their disability was not a difficult thing to do. Sheer repetition may explain why this is so, since subjects reported that disability will eventually come up in conversations with newly met able-bodied persons.

Mood was a particularly important source characteristic in the present study. Subjects reported that there are some situations or some days when they simply do not feel like talking about their disability. This source characteristic of mood is the most unpredictable of the source characteristics; interactants in new relationships lack the ability to predict the actions of persons they do not know well. Persons with disabilities admit that, when they do not feel like revealing, they may withdraw from the questioner or even become sarcastic or rude.

Receiver characteristics

Petronio, Martin and Littlefield (1984) found a fourth condition of disclosure, that persons will consider the characteristics of the receiver before deciding whether to disclose. When disclosure is perceived by the receiver as non-personalistic, that is, when the receiver perceives that the source would tell this information to anyone, the receiver may avoid interactions with that person (Derlega & Chaikin, 1977). Is disclosure about one's disability to a new able-bodied acquaintance a violation of this criteria of personalness? This study does

not provide an answer to this question and more research is needed to determine whether disclosure about a disability violates the receiver's perception of the importance of the personalistic nature of disclosure. If the receiver feels that the individual who is disabled reveals this information to everyone, the desired effect of the disclosure might be lost.

Ramifications of revealing

While individuals consider the four conditions before revealing, they will also consider possible ramifications of revealing, predicting likely outcomes of the choice to reveal or not reveal private information (Petronio & Martin, 1986). In the literature on communication between able-bodied and disabled persons, there has been little prior consideration for the ramifications of revealing private information for persons with disabilities. The present study revealed that persons with disabilities do indeed consider the potential outcome of revealing information about their disability and that they communicate in such a way as to avoid two negative ramifications: (a) perceiving disability as a sickness, and (b) keeping disability from being the sole focus of the relationship.

Talking about one's disability may result in the disabled discloser being perceived as helpless or sick, which, in turn, crystalizes the cultural stereotype of disability as a disease-like condition (Emry & Wiseman, 1987). Disclosure about the disability may only reinforce the view of the disabled person as "sick" due to the common view of disabilities as handicaps rather than characteristics or limitations. Subjects seem aware of this potential ramification, controlling their private information to prevent this outcome.

Results of this research indicate that persons with disabilities control their own privacy boundaries to keep the focus of the relationship off their disability as much as possible. As these subjects indicated, once they have disclosed, the disability may become the basis for all future interactions with the able-bodied other. This is an outcome clearly unacceptable to the persons interviewed. This focus on the disability will have a negative impact on an ongoing relationship and subjects in this study were clearly aware of these implications, using the communication strategies identified in this study earlier to avoid this problem.

If the response to the disabled person's disclosure has able-bodied persons perceiving them as sick and/or judging them solely on the basis of their disability, perhaps this accounts for previous research findings that disclosure reduces uncertainty of the able-bodied person but does not increase their *acceptance* of the disabled person (Thompson & Seibold, 1978). The able-bodied person may feel comfortable knowing more about the disability, but if this knowledge does not increase their acceptance of the disabled person, no great advantage for the disabled person is gained. Certainly, further research is needed to determine the effects that the communication strategies described by these subjects have on their relationships with able-bodied others.

While the previous literature reviewed prescribes disclosure as a way to decrease the uncertainty of able-bodied persons, there is simply no basis for assuming that persons with disabilities do not or should not consider both the conditions and ramifications of opening their privacy boundaries. Surely these same conditions and ramifications must be extended to apply to persons with disabilities as well as to able-bodied persons. Advising persons with disabilities to disclose about their disability is asking them to give up selec-

tive control over their own self boundaries. It is imperative that research on communication between disabled and able-bodied persons looks at the functions and outcomes of communication for both interactants. To fail to do so risks high costs to persons with disabilities without achieving acceptance "as a person first," which they so frequently report is their primary goal when communicating with able-bodied others.

Conclusion

This research sheds some new light on the role that revealing private information plays in early phases of relationships for one stigmatized group. There is evidence to suggest that the strategies found in this study provide a series of options for members of stigmatized minority groups to use in their communication with the majority culture (Braithwaite, 1990). Further research should be done to see whether the same demands for disclosure exist and the same kinds of privacy regulation strategies found in this study may be used by other stigmatized groups.

The data from the present study provide us with a taxonomy of communication behaviors and strategies that may serve as a basis for future studies. One direction for future research would be to use the findings of this study as a descriptive framework of privacy boundary regulation behaviors of stigmatized individuals. The goal would be to move beyond the self-report data of interviews to more naturalistic settings. The "diary: diary-interview" method, developed by Zimmerman and Weider (1977), is one way to gather such data. Using this methodology, the researcher approximates the observational setting by asking subjects to keep an observational log (diary), and uses the diary data to formulate interview questions for the subject. The purpose of the methodology is to gather observational data as the subjects write about what occurred and then to gather the interpretations of the subject about what they have observed. Use of this methodology will provide one opportunity to build on findings from the present study and move into new directions in this area of inquiry.

Endnote

1. Names of the subjects are not included in the report to protect their anonymity. Subjects are identified only by number and quotations are cited by subject number and page number on the coded transcript, hence (12:4), refers to subject #12 and a quotation from page 4 of the coded transcript.

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