TOWARDS A MODEL OF DISABILITY DISCLOSURE

Tonette S. Rocco

Abstract: The model of relational development and decline in close relationships and self-disclosure contains six agents: relational definition, time, attributional processes, liking, reciprocity, and goals. The purpose of the model is to describe the process of relationship development between peers. This phenomenology investigated disclosures between members of a minority group to a member of a majority group in the context of work. Each agent is discussed in terms of commonalities and differences between the agent and the experience of twelve participants with invisible disabilities interviewed.

Title I of the Americans with Disabilities Act requires adults to disclose information about the disability, provide requested documentation, and suggest accommodations (P.L. 101-336). The responsibility to disclose and seek accommodations rests solely on the disabled person. This type of disclosure is made for the purpose of accommodation and access to educational institutions, materials, or formal learning opportunities. Disclosure for accommodation most often occurs in formal learning situations such as training programs. Disabled people are expected by able-bodied co-workers to explain the nature and/or ramifications of their disability. Our workplaces become places of risk for disabled people when considering whether to disclose or not and how much information is appropriate (Dycke, 1999). Once disability status is disclosed, a person with invisible disabilities (could pass as an able-bodied person) becomes suspect and future interactions may be tainted (Rocco, 1997). While the disclosure experiences of people with visible disabilities are quite different (Rocco, 2001). Disclosure occurs in adult education and workplace settings by adults with and without disabilities for relationship development. Relationships between co-workers are important for informal learning to occur. Informal learning occurs in natural settings, which have the "potential for learning and in fact organize our learning" (Merriam & Caffarella, 1999, p. 396, italics in original). In contrast to self-directed learning projects initiated by the learner, informal learning at work can be initiated or facilitated by the co-worker with the knowledge or by the employee in need of the knowledge.

The way the disclosure is received, perceived, and acted on can make a difference in how the adult will approach a new learning situation at work, seek mentoring or other work relationships (Chelune, 1979). The question is how does disability disclosure between co-workers affect informal learning opportunities between coworkers that enable new employees or employees new to a department or position to learn their jobs in work groups, through mentoring, in informal non structured on the job training, or simply by interacting around a water cooler. Informal learning, non-structured on the job training, mentoring (whether formal or not), learning in organizations such as work groups, all of these forms of learning or structures to facilitate learning involve relationships between people. Relationships develop through personal disclosures, which can include information about one's experience and knowledge gained through work or outside of work. Individuals from minority groups find themselves in the position of having to explain their experience or teach a person from a dominant cultural group.

The Model of Relational Development and Decline

Self-disclosure involves the verbal presentation of information to another about the nature or cause of personal experiences, dispositions, past events, and future plans (Derlega & Grzelak, 1979). Telling someone "something truly personal" implies trust that the information will be kept confidential (Derlega, Metts, Petronio, & Margulis, 1993, p. 2). Derlega et al. (1993) propose a

model of relational development and decline in close relationships and self-disclosure. The model contains six agents (the foundation for the specific research questions): relational definition, time, attributional processes, liking, reciprocity, and goals.

The relational definition refers to the mutually transformative power disclosure has on a relationship and a relationship has on the disclosure. The relational definition represents individual and collective thinking about the relationship and appropriate behaviors. For instance, "when people disclose in certain ways, the recipient may be expected, or be forced, to define the nature of the relationship differently" (Derlega et al. 1993, p. 15).

Time assumes that relationships intensify gradually and systematically allowing message exchanges to develop from superficial to intimate. The timing of self-disclosure can affect the attitude of the recipient towards the discloser. Attributional processes explain why individuals tell something intimate. The recipient assigns dispositional, situational, and interpersonal attributions to self-disclosures. In a new casual relationship, dispositional or situational attribution simple means the recipient attributes the disclosure to the person's openness or to the situation at the time. Interpersonal disclosures are felt to occur because the person making the disclosure wants to redefine the terms of the relationship or the individual behavior through the making the disclosure

Liking assumes that self-disclosure leads to fondness and is determined by the recipient's perception. Disclosures that violate normative expectations will not lead to liking. The discloser may share too much information because they like the recipient and disclosures that elicit a negative response will not lead to liking.

Reciprocity implies the recipient will return a disclosure of the same level of intimacy generating a response "sensitive to the disclosure's self-imposed vulnerability" and "the conversational demand to be topically relevant" (Derlega et al. 1993, p. 34). Goals include achieving a degree of catharsis, managing a positive image, gaining information, and indicating relationship definitions (Derlega et al. 1993). Self-disclosure serves different functions including expression, self-clarification, social validation, relationship development, and social control (Derlega & Grzelak, 1979). Social control is used to achieve specific results, operating for a controlling, or even exploitive purpose. Relationship development is a vehicle for promoting, maintaining, or increasing intimacy in a relationship. Social validation elicits feedback to validate a person's self-concept. Self-clarification is talking about beliefs and opinions to clarify one's position. Expression is verbalizing feelings about a recent facet of a relationship or situation.

Data Collection and Analysis

Originally, when I began research on disclosure, my interest was in the phenomenon of disclosing disability for the purposes of accommodation. This struck me as a catch-22 to require people to disclose something that can and often is used against them in hiring and promotion decisions. This interest expanded to the phenomenon of disclosing of disabled people and the purposes for and consequences of the disclosure. This phenomenology has individuals as the unit of analysis (Creswell, 2003).

Research Questions

In order for mentoring to occur, contributions to a learning organization from an individual, for formal or informal group learning to occur individuals disclose information to facilitate

relationships with peers and supervisors. What effect does disability disclosure have on informal learning opportunities? What effect does timing have on co-workers' attitudes toward the disabled person and willingness to facilitate informal learning? What attributes are used to explain the disclosure? How does disability disclosure affect co-workers liking of the disabled person? How does reciprocity operate in the case of disability disclosure? What goals or functions does disability disclosure serve for a new employee or employee new to a department or position?

Data Collection

Structured interview guides asked about participant's experiences and perceptions of disclosure, accommodation, learning, and career progression (Patton, 2002). Twenty questions were asked during digitally recorded interviews that occurred in my home or office, participants' homes or offices, or by phone. Interviews lasted from forty-five minutes to two and a half hours. All interviews were transcribed verbatim, checked against the recording, and sent to the participant. No one added anything to the transcript. However, two participants sent additions via electronic mail to the interview immediately afterwards to clarify points they felt were important. These clarifications were added to the original transcript and not treated differently since the additions were sent within hours of the interview.

Participants

People with visible disabilities have different experiences with disclosure and disability then those with invisible disabilities who could pass as non-disabled people if they chose too. Because of this, two groups with twelve participants each was the goal. (This paper reports only on one group.) Thirteen individuals with invisible disabilities were interviewed, but one digital recording was so poor that it was not usable. In the invisible disability group, participants ranged in age from 23 to 63 years. The youngest participant was completing her undergraduate degree. Three participants earned undergraduate degrees; one had almost completed a masters degree. The remaining eight had masters degrees, four had terminal degrees such as doctorates and two were working on doctorates. Four participants were employed in white-collar positions. Eight were professionals and managers. Seven male and five female participants included African Americans (2), white European Americans (5), white Jewish Americans (1), and white Latins (4). One participant is Gay and the others are assumed heterosexual. The disabilities that participants had were learning disabilities, back and knee injuries, substance abuse, anorexia, asthma, speech impediment, diabetes, and autoimmune disorders (HIV, lupus, Krohn's, trigeminal neuralgia). Only one participant became disabled as a child. All others were young adults or adults when diagnosed.

Data Analysis

While checking the transcripts against the recordings, observations, reflections, and dialogue with the text/participants were noted in a journal as a first step in using writing as a method of inquiry (Richardson, 1993). The interview questions were grouped into five categories: learning, accommodation, disclosure, career, and last words. Responses to questions were placed on tables created for each category. Tables were read further reducing the data into an outline of themes and patterns (Miles & Huberman, 1994). Researcher's reflections and analysis were recorded in brackets on the outline to maintain a distinction between researcher and participants words (Creswell, 2003). During the data reduction steps observations and reflections were

recorded in the journal. Data were examined a second time using a priori categories from the six agents from the model.

Findings

The six agents are relational definition, time, attributional processes, liking, reciprocity, and goals (Derlega et al. 1993). The purpose of the model is to describe the process of relationship development between peers. Disclosures between members of a minority group to a member of a majority group take on different purposes. Each agent will be discussed in terms of commonalities and differences between the agent and the experience of participants with invisible disabilities.

Relational Definition

Disclosure is expected to have a mutually transformative power changing the relationship and the relationship should influence the disclosure. In the case of adults with invisible disabilities, three themes emerged relationship building, negative consequences, and no consequence. Relationship building occurred for two Anglo male participants, a recovering substance abuser and a man living with HIV. The men experienced disclosure similarly to the model. The disclosure produced a more dramatic difference in the relationship. The negative associations of criminality and immorality for both men made them careful, only disclosing to trusted others. The consequence was that their relationships with the recipients deepened. For the participant with HIV, he frequently had to disclose that he is Gay at the same time producing an emotional exchange for both parties that increased the recipient's liking for him and the likelihood of a reciprocal exchange. For many participants the disclosure had negative consequences such as retribution in the form of loss of job or lack of promotion, being the object of gossip, and fear of how someone might use the information. For an Anglo woman with an eating disorder, the risk was becoming the object of gossip. For an African American male with learning disabilities, the issue was having his disclosure ignored or having the disability equated with stupidity. He told me "I don't tell people because if you're LD and you're black, those are 2 big strikes against you. You tell somebody you have a disability they automatically think you're stupid or just, well I'll talk slower because they think you don't understand." This attitude is certainly not conducive to relationship building.

Time

Disclosure is expected to increase and deepen the relationship over time. For this group of disabled people timing was dictated by the level of trust, by a flare-up of the disorder, or forced because of an accommodation need. Relationships were not strengthened over time for ten participants.

Attributional Processes

Participants did explain their disabilities because it was their disposition to tell people, more often the disclosure was required by a situation, and in interpersonal relationships to change someone's behavior or to provide support.

Liking and Reciprocity

Self-disclosure should lead to fondness and a reciprocal disclosure of the same level of intimacy. This happened only in the case of the recovering addict and the man with HIV. Neither would have disclosed if they did not feel that this would lead to an increase in positive feelings and build the relationship. As one said "The man I consider my dearest friend and mentor, … there was something about him that I recognized in people who recover and I told him my story and I said, you know I see some of this in you. What was it? What was the pain that occurred in your life that led you …on this journey of exploring yourself and going inside? And then he shared his story … it was pretty cool." The recipients appreciated the trust placed in them. Both men have the luxury to develop a relationship because they are both healthy having lived with their conditions for over fifteen years and they have no need to disclose.

Goals

The model outlined four goals achieving a degree of catharsis, managing a positive image, gaining information, and indicating relationship definitions (Derlega et al. 1993). No participant disclosed to achieve catharsis. In order to manage a positive identity many participants chose not to disclose and/or to control the time and place. Positive images were not enhanced by sharing with another disability status. Gaining information was not a goal of participants either. Rather they shared information in order to help or inform others or to consciously control the amount of information shared because of the risks involved. Always the risk to disclosing was present. The Gay man is the only one who had a goal of relationship definitions and this was in terms of his sexual orientation not his disability, "And whether you come out because you have to make a statement or that you just are who you are and people either understand that or they don't. And it's their problem to deal with it."

Other goals exist for people with disabilities grouped into four categories: for others, for one's self-interest, not to disclose, and in case of an episode. When disclosing for others, the goals are to help, to motivate, to change attitudes, to alleviate fear, and as a teaching moment. When disclosing for one's self-interest the goals are to receive an accommodation, to get a job, or to get a break (special consideration). The goal of not disclosing is carefully considered, as an African American participant suggested, "Do you have to? Do you really have to? …Are you absolutely sure you really have to do this? And then … you need to understand your rights and responsibilities under ADA law." In the case of an episode the goals are "for my own safety" in the case of the recovering addict so someone is aware of the potential causes of a relapse and to inform someone what to do for them.

Implications

The model of relationship development is useful as a base line for examining disclosure. The model indicates that liking will be increased and that reciprocal disclosures will be made. This does not happen with disabled individuals in general. One interesting difference not discussed here is the issue of status of the disabled adult. A third of this group had upper management or professional positions. The participants that avoided disclosure the most, had lower level positions and are members of an additional marginalized group. More research needs to be conducted examining the consequences of disclosure between individuals of different power and status, the impact of disclosure on work relationships, and between teachers and students.

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Tonette S. Rocco, Florida International University roccot@fiu.edu