ISSA Proceedings 1998 – Satisfying The Argumentative Requirements For Self Advocacy

1. Introduction

Recent advances in treatments for individuals with a Human Immunodeficiency Virus (HIV) infection or Acquired Immune Deficiency Syndrome (AIDS) have generated hope for renewed life for many who believed they would die prematurely from the disease, but have also created much confusion and uncertainty for those individuals and their physicians (Brashers, Neidig, Cardillo, Dobbs, Russell, & Haas, in press). Treatments are not equally effective for all individuals, the long-term efficacy and safety of many drugs are unknown, antiviral drugs and treatments can be used in many different combinations, and the selection of some drugs can lead to difficult lifestyle accommodations (e.g., drug regimens with large numbers of pills taken each day, rigid eating schedules, and uncontrollable patterns of diarrhea and nausea). These and many other factors must be considered when making decisions about treatment options.

Many individuals with HIV or AIDS have taken to educating themselves about treatments, reading scientific reports and engaging in activities such as journal clubs and discussion groups, so that they may make informed treatment decisions (Brashers, Haas, Klingle, & Neidig, 1998). These activities provide the basis for patients to argue for preferred treatments in discussions with their physicians. Yet, despite their increased knowledge about treatment options, many patients have difficulties in the process of advocating for themselves.

Why is advocating for oneself problematic? Argumentation often is seen as a circumstance which calls for objective reasoning. Individuals who need to promote their own interests (i.e., self-advocacy) in what might be taken as an argumentative context (e.g., requests for medications or treatments from a physician, letters of application for employment, or other requests for actions that benefit the advocate) often appear too interested in the outcome to remain sufficiently objective. Self-advocacy is a form of argumentation which can create

unique requirements, including how to promote one's self-interest while providing evidence and reasoning will be free from personal biases.

The requirements for self-advocacy argumentation are a function of norms and circumstances that vary across situations. In this paper, we explore the argumentative requirements of self-advocacy in the context of individuals with a Human Immunodeficiency Virus (HIV) infection or Acquired Immune Deficiency Syndrome (AIDS) and their interactions with health care providers. Literature on activism and self-advocacy will be reviewed as background. Data from a larger project on AIDS activism and self-advocacy is used to examine specific argumentative strategies reported by individuals to promote their interests in interactions with health care workers. The analysis will be used to explore claims about the unique argumentative burdens of self-advocacy, as well as to demonstrate how supporting self-advocacy claims may lead to perceptions of fallacious moves in the discussion (e.g., playing on the opponent's compassion or providing a personal guarantee of the correctness of the claim, see van Eemeren & Grootendorst, 1992).

2. AIDS Activism and Self-Advocacy

Despite repeated calls for establishing greater equality in the physician-patient relationship (see Ballard-Reisch, 1990; Frederickson, 1993; Hyde, 1987; Ratzan, 1993), research indicates that the typical physician-patient interaction is one in which the physician is dominant and the patient is submissive. After reviewing the literature on physician-patient communication, Brashers et al. (1998: 10) argue that:

The asymmetrical position of authority afforded physicians is a process that is both encouraged and sustained by behaviors of physician and patient. On one hand, although patients often desire to participate more in health-care interactions (perhaps to become more participative in decisions made about their health care), frequently they do not assert this desire. On the other hand, physicians are trained and often conduct the medical interview in a way that discourages, rather than encourages, patient input.

In addition to understanding the physician-patient relationship as imbalanced, most researchers of physician-patient communication assume compliance-gaining and persuasion efforts move in one direction. The physician is thought to be the persuader and the patient is the one to be the target. Physicians often are charged with getting people to do things they will not want to do (or might not

naturally do) -modifying diet, exercising, stopping smoking or drinking, or taking medications. Even within most "participative" decision-making models (e.g., see Ballard-Reisch, 1990), the patient's role is perceived to be twofold:

a. providing information about their personal circumstances and

b. accepting or rejecting treatments from among a set of alternatives supplied by the physician.

In practice, physicians often enact the role of persuader by adopting an authoritarian or a paternalistic style of communication. In addition to that, the patient, as the persuadee, often is thought to have social and psychological barriers to action, such as bad habits (e.g., smoking or drinking) or difficult life circumstances (e.g., inadequate income or psychological disturbances).

One group of individuals that has been particularly aggressive in challenging this "traditional" medical model of health care is comprised of AIDS activists, who have targeted changes at the social, political, and individual levels. Their targets have included changes in drug testing procedures, elimination of discriminatory policies, promotion of health care availability. Activists use a combination of symbolic protest strategies (e.g., marches and demonstrations) and persuasive efforts (e.g., meetings with high level governmental officials) to affect these changes. These collective practices have helped to shape a community of individuals infected with HIV, along with their friends, families, and colleagues. Fabj and Sobnosky (1995) contend that:

AIDS activism demonstrates that the strategies of redefinition and translation provide activists with the authority and the tools to publicize issues surrounding AIDS. As well as enlarging the scope of discussion in the public sphere, these strategies are important for the AIDS community, in that they allow people with AIDS to take control of the discourse surrounding the disease, and thus to define themselves as a community.

Brashers et al. (1998) argue that AIDS activists' communication behaviors at a collective level (political or social activism) mirror communication behaviors at the individual level (personal self-advocacy). While collective-level activism is aimed at changing policies and institutions, individual self-advocacy aims at reforming interactional patterns to provide optimal care for persons living with HIV or AIDS. For example, the ACT UP chapter in Paris proposes that a:

First general conclusion in the fight against the epidemic is accompanied by a whole new way of looking at certain givens: [for example], calling into question

the medical authorities and the doctor/patient relationship. Fighting AIDS is about teaching AIDS patients to regain the upper hand and establish a dialogue with doctors as equals, to give them a chance to choose their treatments and decide their own future. (see Brashers et al., 1998)

Because these behaviors are a challenge to traditional power structures in health care, they have the potential to alter physician-patient communication patterns. In their analysis of collective activism and individual self-advocacy, Brashers et al. (1998) found that some patients reported that their physicians responded positively to their attempts at self-advocacy, whereas some patients reported negative reactions from their physicians. Positive responses included efforts at "partnership building" and explicit recognition of the patient's contributions to the decision-making process. Negative responses to attempts at self-advocacy were characterized by downward spirals, in which physicians responded to the assertive behaviors of patients by engaging in controlling behaviors, which often frustrated patients and led them to increase their assertiveness, which influenced the physician's behavior, and so on.

Other findings indicate the activists and those with a self-advocacy orientation have unique behavioral and psychological characteristics. In a separate report, Brashers, Haas, and Neidig (in press) found that activists were more likely to report that they educate themselves about HIV illness and its treatments, behave more assertively in health-care interactions, and are more willing to be mindfully nonadherent than were nonactivist persons living with HIV/AIDS or the members of the general population. In addition, patient self-advocacy was correlated positively with Desire for Control, Desire for Autonomy in Health Care, and Preference for Involvement and Information in Health Care and correlated negatively with External Locus of Control (i.e., when individuals believe that circumstances are under the control of external forces, they are less likely to be self advocates), suggesting that those high in self-advocacy behaviors share a more general psychosocial orientation toward issues of control. Brashers, Haas, and Neidig (1996) also demonstrated that, in comparison to nonactivists, activists:
a. used more problem-focused coping strategies,
b. used fewer emotion-focused strategies,
c. were more likely to communicate with their physician, and
d. were more likely to perceive communication with their physician as rewarding. Brashers, Haas, and Neidig (1998) found that activist and those with higher scores on self-advocacy reported familiarity with more information sources.

3. Argumentative Requirements of Self-Advocacy in the Physician-Patient Context
Self-advocacy is a unique form of critical discussion which includes features of argumentation, as well as requests and possibly other types of speech acts. People engaged in self-advocacy must address two levels of argumentation. At the first level, the facts of the case must be established ("Is the medication safe and effective?" "Are there side effects that could make taking the medication difficult or impossible?" Can the patient make the lifestyle changes needed to take the medication?"). These are the normal expectations of pro-argumentation: the speaker must establish the grounds for accepting a standpoint.

At a second level, the self advocacy requires that the patient address the circumstances of the argument ("Is the patient competent to make a decision about treatments?" "Are political concerns preventing a fair and accurate representation of the data?"). These second level requirements of self-advocacy can be derived from an idealization of discussion procedures.

Van Eemeren, Grootendorst, Jackson, and Jacobs (1993) provide an ideal model of critical discussion (or argumentation) for "reconstructing argumentative discourse" which includes "higher-order conditions" needed to achieve resolution. *First-order conditions* form the basis for resolution-oriented discussion and include rules of the discussion (e.g., "Parties must not prevent each other from advancing standpoints or casting doubt on standpoints;" see van Eemeren and Grootendorst, 1992: 208).

Second-order conditions correspond, roughly, to the psychological makeup of the arguer" (van Eemeren et al., 1993: 32). Second-order conditions include conditions such that the participants:
a. are disinterested in the outcome (i.e., willing to change positions),
b. are able to offer valid reasoning and to account for multiple lines of argument, and
c. are skilled and competent in the subject matter under discussion.
Third order conditions "stress the importance of political ideals such as nonviolence, freedom of speech, and intellectual Pluralism as well as practical constraints and resources for empowering critical discussion" (van Eemeren et al., 1993: 33).

Realizing these higher-order conditions in actual practice are difficult (van Eemeren et al., 1993). In the physician-patient interactions, social and personal barriers to normative discussion exist. Physicians and patients may have

motivations other than resolution seeking (e.g., maintaining or challenging existing power structures). Patients who are motivated to persuade their physicians about some treatment are not likely to be "disinterested" in the outcome, particularly if they come to the interaction with a personal decision made. Patients may lack the "expertise" (or be perceived to lack the expertise) in the subject matter (i.e., medicine, virology, etc.) needed to debate issues. Patients may feel pressured to reach a decision quickly due to the severity of the consequences of not finding an effective treatment. Physician-patient relationships often are asymmetrical in power, time constraints of the medical interview can decrease the patient's ability to develop arguments, and patients may choose to discontinue relationships with their physicians rather than continue debate.

Rising from these deviations from the ideal model of critical discussion, several requirements for patient self-advocacy seem reasonable. *That is, the deviations from the ideal provide a starting point for examining the unique argumentative requirements of patient self-advocacy.* If there are real (or imagined) violations of the ideal model, discussants need to deal with them explicitly. For example, self-advocating patients must establish self-interest without appearing selfish. By this, we mean that the patient needs to be willing to develop arguments that advance a position other than "desire" (i.e., "I want this medication" is insufficient argumentation). Although some claim that all behavior is self-interested (Elster, 1990), some interests obviously are more self-serving than others. Self-advocacy also requires establishing sufficient competence to advance a position. Competence includes expertise in the subject matter, ability to argue effectively , and mental competence (e.g., freedom from emotional duress). Finally, self-advocacy may require "impartiality." Evidence may need to be externally verifiable, to prevent the patient from being perceived as his or her own witness.

In the following sections, a study of individuals living with HIV or AIDS is described as an initial attempt to verify and extend these predictions.

4. Method

Data were collected from an open-ended question included in a survey of 174 adults with HIV or AIDS. Participants were obtained from two AIDS service organizations ($n = 33$), ten AIDS activist organizations from throughout the United States ($n = 31$), and an AIDS clinical trials unit at a large midwestern teaching hospital ($n = 11O$). Participants in this sample self-identified as being HIV-positive ($n = 79$, 45.4%) or as having AIDS ($n = 92$, 52.9%). (Percents do not

add to 100 due to missing data.) The mean time since diagnosis was 57 months (range = 1 month to 156 months, *sd* = 40.59 months). The sample was composed of 155 males (89. 1 %) and 16 females (9.2%). Of those, 30 reported membership in an AIDS activist organization (17.2%) and 68 described themselves as "an AIDS activist" (39.1 %). All participants were asked to read and to respond to a brief scenario. The scenario stated: You recently heard of a new treatment that is not widely available. The treatment is still experimental, but you would like to obtain more information about it.

Participants then were asked to list all of the information sources they could imagine that they might use and to rate those on the likelihood that they would actually use that source of information. These data were analyzed for a previous paper. After participants completed the listing of information sources, additional instructions were given:

Based on the situation described on the previous page, please imagine that you have obtained information on the treatment and found that it was available on a limited basis if your physician recommends it. Now you would like to have your physician prescribe it for you. In the past, your physician has been reluctant to try new medications or therapies. What would you say to your physician to convince him or her to prescribe the treatment for you?

Results of this portion of the survey were analyzed for the present study. Themes which represented argumentative strategies were extracted from the data. These themes, along with concrete examples of the strategies, are presented in the following section.

5. Results and Discussion

Analysis of the open-ended responses led to ten general themes of self-advocacy strategies for persons living with HIV or AIDS, when they attempt to persuade a physician to prescribe an experimental treatment. These themes were:

a. establish facts,

b. establish expertise,

c. make conditional threats,

d. establish obligation,

e. describe other benefits,

f. accept responsibility,

g. describe severity of consequences,

h. establish self-interest,

i. promise to exercise caution, and

j. elicit counterarguments.

Together, these themes function to preserve the norms of ideal discussion and to persuade the physician to prescribe the medications. Clusters of themes indicate that rights, responsibilities, and expertise are important to the self-advocacy of patients with HIV or AIDS. Each theme and corresponding strategies are described in brief below.

Establish Facts. A primary task represented in the data was to establish the facts of the case. Establishing facts addresses the first level of argumentation by justifying the standpoint (i.e., building a case for the claim). Participants reported that they would share information and arguments that they had discovered as part of their "fact finding" (e.g., reading journals, talking to others with the disease).

As shown in Example (1), participants described a general strategy of sharing evidence to establish the facts:

1. "I would offer all available information on the drug to my physician and ask that he recommend it for me."

Establish Expertise. A second strategy noted in the participants' responses was the explicit acknowledgment of the patients' expertise. A major barrier to effective discussion in a technical field such as medicine is the need to comprehend and apply complex subject matter. Often patients are not prepared to discuss the technical details
of their care. Participants thus saw the need to establish expertise explicitly. An example of a comment from our participants intended to establish expertise is given in (2).

2. "I would let my physician know that I have taken the time to research the treatment."

In some instances, such as Example (3), participants suggested that they would present the text of the material (i.e., they would bring in the research articles and other evidence for the physician to examine).

3. "I would show him the information that I had received, so he could examine it. I would say, 'This treatment has recently been brought to my attention. I'd like for you to look over this article, and tell me what you know about this treatment, because I'm interested in trying it out.'"

This is perhaps a strategy designed to enhance the credibility of the information. It demonstrates that the validity of evidence is not subject to the memory of the patient and that it is derived from qualified experts.

Make Conditional Threats. Many of the responses of the participants contained conditional threats. These acts function to warn the physician that the patient will seek treatment elsewhere if the request is not granted. Examples of conditional threats in the data from individuals with HIV or AIDS include:

4. "If you don't [prescribe the medication], I'll go somewhere else!!"

5. "I'm going to insist that you enroll me in this treatment. If you cannot in good conscience do so, I understand, but I will find another physician who will."

6. "I will change doctors to somebody who will prescribe it."

These conditional threats were used in combination with other strategies that established the importance of prescribing the medication. It also was interesting to note that a number of participants said that they would change physicians without even making the request given the physician's past reluctance to try new therapies, as was suggested in the scenario.

Establish Obligation. Participants also reported the strategy of establishing that the physician had an obligation to the patient because of the "commercial" nature of the relationship. Examples of this strategy included:

7. "I hire my doctor to provide services for me. If they want to remain my employee they will read on my disease."

8. "You are working for, paid by, employed by, me."

Establishing obligation may be a strategy designed to diminish the effects of power and authority usually ascribed to the physician. One patient said he would preface his statement with "I hate to pull rank on you," which reverses the typical pattern of domination in the interaction.

Describe Other Benefits. This strategy involves acknowledging the altruistic potential of using experimental medications. Examples of this strategy include:

9. "There would be benefits to your practice."

10. "Even if the medication doesn't help me, it might help someone else."

11. "It is better to have tried than not to have tried at all. My life should be used to help prolong the lives of others in the future. This is the importance of experimental drugs."

Altruism demonstrates that the patient is not motivated solely by self-interest, which may help establish justification for engaging in critical discussion. Altruistic

motivation may seem to shift the argument from self-advocacy to more objective discussion.

Accept Responsibility. Participants also felt the need to accept responsibility for the consequences of the decision. Uncertainty surrounds the use of experimental treatments because of a lack of information on their safety and side effects (see Brashers, Neidig, Cardillo, Dobbs, Russell, & Haas, in press), which means that the decision must be made based on probabilistic thinking. Because issues like "long term safety and efficacy" cannot be resolved as part of the discussion, participants must address the concerns.

12. "I understand the benefits and the risks."

13. "I am willing to take responsibility for the outcome."

14. "I realize that experimental treatments are no guarantee and may be harmful, rather than the desired effect, but I am willing to take responsibility for my health care."

15. "If the treatment has a negative effect on my health, I am ready for this and hold myself responsible (not the physician) for the effects."

Accepting responsibility also increases the meaning of participation of the patient – emphasizing that the patient is ultimately responsible for his or her own well-being.

Describe Severity of Consequences. Another strategy for persuading the physician to prescribe medications was to argue for the severity of the consequences for the patient. Some individuals have tried other medications with no success. Individuals with a terminal illness may prefer experimental therapy over inaction.

16. "Dr. Smith, this is a matter of life and death. I don't have other choices at this point and I am prepared to take the risk if this new therapy can help slow down the progression of this disease – I'm going to die anyway without this medication, so why not take a chance?"

17. "I think I have the right to choose experimental treatments because of my prognosis."

Establish Self-Interest. Despite the need to establish that they were not solely motivated by self-interest, some participants used the strategy of establishing self-interest as a reason for prescribing the medication. This strategy often was invoked with notions of "rights," as in Example (18).

18. "Dear Doctor, I want to try this new treatment! It is my decision and my body.

I think I should have the right to decide what treatments I want to try experimentally."

Promise to Exercise Caution. To alleviate fears of unknown consequences, participants used the strategy of promising to monitor their progress with their medications.

19. "I might argue that, since I monitor my own health closely and try to stick to my treatment regimens, I would be a good candidate to obtain information about the effectiveness of this treatment."

As shown in Examples 20 and 21, this strategy also can be used to invite participation of the physician, which serves to acknowledge the control of the physician, and invites continued participation on his or her part.

20. "I would tell him I would like to have it prescribed, and that I'm willing to take the responsibility for the treatment, with his monitoring it."

21. "I am willing to take responsibility for this treatment with you monitoring the progress."

This strategy may indicate a willingness to continue discussion, and reverse the decision to take the medication if new information becomes available (e.g., if safety issues arise).

Elicit Counterarguments. Participants also noted the need to elicit counterarguments from the physician. This provided the patient with the ability to examine the arguments of the physician and to refute or respond to them. It also can serve to acknowledge the legitimacy of the physician's objections. Examples of this strategy include:

22. "First I would want to know why he would be so reluctant to prescribe the medication in the first place."

23. "I would explain my reasons for wanting to try the medication. I would listen to the doctor's reasons for not wanting to try the medication."

This strategy seems to encourage the physician to advance and defend standpoints, and thus encourages further critical discussion.

6. Conclusion

This study advances our understanding of self-advocacy in the physician-patient context. Self-advocacy is a form of argumentation which is guided in part by social conventions, has unique argumentative requirements, and requires explicit attention to the standards of ideal discussion. People engaged in self-advocacy

must address two levels of argumentation: the facts of the case must be established and circumstances of the argument must be addressed. Advocating for oneself may include demonstrating sufficient expertise to engage in technical debate, and negotiating when an issue may seem to be an intractable disagreement given the personal interests of at least one party in the discussion (see van Eemeren et al., 1993).

It is evident from this study that some individuals do give explicit attention to the requirements of self-advocacy. Participants dealt with issues of self-advocacy by invoking notions of rights, responsibilities, and expertise. For example, several participants detailed plans to demonstrate their expertise about medical issues. Elsewhere, Brashers and Jackson (1991) argued that AIDS activists penetrated the technical sphere by developing expertise in areas in which they might be thought to be nonexpert (e.g., virology and experimental methodology). Fabj and Sobnosky (1995: 182) contend that AIDS activists "blur the lines between the private, public, and technical spheres." The strategy of developing the competence needed to engage in public and technical debate may be used at the individual level to advocate for oneself with a physician.

Some strategies noted in this study, however, actually serve to move a discussion further from the ideal model. Asserting self-interest may serve to forestall discussion, and thus may violate rules of critical discussion (e.g., preventing others from advancing standpoints). Describing the severity of consequences may be a method for preventing an opponent from casting doubt on a standpoint. Other strategies, such as establishing obligation, simply may serve to reverse the power structure without regard to the effects of the strategy on the discussion.

To date, self-advocacy research predominately has focused on developmentally disabled or profoundly handicapped populations. These may be populations in which fear of "being taken advantage of" is great and the need to assert independence is valued. However, social and cultural barriers to self-advocacy exist in the general population, as well as in populations with chronic or life-threatening illnesses. These natural barriers cause deviations from the ideal model which must be accounted for in practice. As Janoff-Bulman and Wade (1996: 144) argue, "there are costs associated with advocating for the self " When patients are more participative, or do attempt persuasive efforts of their own, often it meets with negative results. Cerling (1989: 94) cites a study published in the American Journal of Medicine, in which "it was found that when an individual patient refused any particular medical treatment, the patient's very refusal was seen as evidence of the patient's incompetence to make a decision." Patients may

be less likely to violate norms of asymmetrical power distribution because of the force of those norms within society. As noted by Brashers et al. (1998), one participant in this study remarked: Sometimes I feel a little shy – do not want to make them [physicians] feel stupid or lacking information. I usually try to let them know that I respect them and follow their instructions, let them feel that they are in charge.

Future research should further develop and elaborate the strategies seen here into more general implications for analysis of message design. For example, the themes we developed here might help us to determine logics of message design. In O'Keefe's theory of message design logics, an expressive logic "reflects a view of communication as a process of expressing and receiving encoded thoughts and feelings" without particular attention to "the service of achieving effects" (O'Keefe & McCornack, 1987: 71). Expressions of self-interest may be diagnostic of an expressive design logic in the situation of patient self-advocacy. Conventional design logic "is based on a view of communication as game played cooperatively, according to socially conventional rules and procedures" (O'Keefe & McCornack, 1987: 71). Contingent threats, because of their emphasis on the consequence of rule violations may represent conventional strategies. Finally, rhetorical design logics reflect "a view of communication as the creation and negotiation of social selves and situations" where "meaning is a matter of social negotiation" (O'Keefe & McCornack, 1987: 72). Because of their sensitivity to context and negotiation of self, promising caution and eliciting counterarguments may be rhetorically-oriented. Although these distinctions are preliminary, future research that more clearly illuminates these links will provide valuable insight into the nature of self-advocacy.

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