Empathic Communication Between Dental Professionals and Persons Living with HIV and AIDS

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Abstract: We studied changes in the affective and empathic responses of sixty-three dental school faculty, students, and staff to people with HIV/AIDS following an HIV/AIDS training session. Empathic response was measured using a modification of the Gallop Staff Patient Interaction Scale, with five statements to which the provider responded at baseline and three times during and after the training. Data were subjected to theme analysis and analysis of empathic level of response, where a theme is a central idea that can be identified by expressed language. Results indicated that themes of provider response included the role and importance of maintaining health, reassurance, comfort, and hope. Negative responses were rare, accounting for only 3 percent of responses. Following the training, themes were expressed more fully but usually did not change. Changes in level of empathy usually paralleled changes in themes. These data describe the measurement of empathy in dental providers dealing with people with HIV/AIDS and changes in the themes and levels of empathy following an HIV/AIDS training session.

People with HIV/AIDS have special needs for dental care. Many of the oral lesions that may develop with HIV infection cause significant pain and discomfort, and the failure to obtain appropriate dental care may be life-threatening in some cases. Generally speaking, oral manifestations of HIV infection are important diagnostic signs, with certain lesions signaling progression of the illness. The oral manifestations of HIV infection are in addition to the normal range of oral diseases common to the general population, which also require treatment. Dental care is therefore of great importance in the care of these patients.

Studies of dental health care professionals and students have been consistent in showing increasing willingness to treat persons with HIV infection. At the same time it appears that dental practitioners continue to have mixed feelings about the epidemic and the people infected. Bennett et al. quoted respondents who described resentment of persons with HIV and AIDS, fears of contagion, decreased job satisfaction, and preferences for referring HIV-positive patients if they could. Although 83 percent agreed that “they have tender feelings for HIV-positive patients,” more than one-third found it “hard to be sympathetic.” These attitudes are reflected in patients’ fears of discrimination and rejection by dentists and with nondisclosure of their HIV status.

Whatever may be the dentist’s intent, the interaction between the patient and dentist will lessen or reinforce the patient’s anxieties. Respectful communication that supports patient disclosure also helps the dentist provide appropriate care that is adapted to the particular needs of the patient. Interpersonal skills are obviously critical to the quality of the provider-patient encounter; they include effective communication and fostering a sense that the patient is understood and accepted. These are the characteristics of an empathic exchange. Providers who develop an empathic understanding may see the patient as more real and therefore perceive his or her needs and demands as more reasonable. For the patient, interaction with an empathic health care worker may serve to enhance the sense of self and to relieve anxiety and shame. This is important with HIV infection because patients who disclose their status may at the same time reveal personal and possibly stigmatizing information about themselves and may be uncertain about the reaction they will get.

In this article, we present the results of a study of the affective response of dental personnel in the HIV/AIDS context. The goal of this study was to
investigate changes in the level of empathic care following a seminar on managing HIV/AIDS in dental practice. In doing so, we also explored themes in the responses of dental school personnel to people with HIV/AIDS and investigated the adaptation of an existing measure of empathic response, the Staff Patient Interaction Response Scale (SPIRS), to the dental context.

The SPIRS has been used to measure the affective response of other categories of health care providers in a number of clinical situations, including the care of persons with HIV/AIDS. Given the complexities of conceptualization and measurement that have been encountered in research on empathy, successful adaptation of the SPIRS will be useful in addressing this important aspect of dental provider behavior.

Methodology

The study was conducted in a southern United States dental school, as part of the evaluation of a training seminar “At Ease with AIDS.” Subjects were dentists and dental students, dental hygienists and hygiene students, and other faculty and staff. The seminar was developed and administered by trainers of the AIDS Education and Training Centers of Texas and Oklahoma.

The training consisted of four parts. An opening didactic session included epidemiology, risk assessment, and the dentist’s role in HIV/AIDS care. This was followed by a two-hour session of clinical interaction with surrogate patients, each of whom had a lesion that might be considered a manifestation of HIV. In the third part of the seminar, the trainees reconvened to discuss their experience. Finally, there was a presentation from a person with HIV/AIDS and a role-play between a dentist and an HIV-positive patient. This design was intended to emphasize attitudinal and skills objectives in communicating with the HIV-positive patient.

The study was approved by the relevant ethics committees, and informed consent was obtained from those who took part in the program. Data were collected through surveys. The instrument was administered at four time points: prior to the seminar (pretest), after the didactic session (time 1), after the clinical session (time 2), and after the presentation and role-play (time 3). Unique identifier numbers were used to link surveys completed at the four time points. To assess the effectiveness of the training program, the pretest responses were used as a baseline to identify the number and types of responses and particularly to identify any that we considered unsatisfactory. We compared later responses to see if the number and quality of these had improved and if so, which part of the intervention appeared to be associated with the change.

The instrument consisted of five stimulus statements with instructions for respondents to write in their immediate response. The stimulus statements were modeled on those of the SPIRS. The SPIRS instrument consists of a series of hypothetical statements that a patient might make. Respondents write what they would say in reply to the patient, and these statements are scored for the affective level displayed. Initially used to measure the expressed empathy of nurses, the SPIRS has been used to examine whether patients with a stigmatizing diagnosis receive qualitatively different care than do patients with other illnesses. The SPIRS has also been used in the HIV context, to study the affective response of hospital staff to persons with AIDS and to assess the effect of an intervention with this caregiver population. In this study, we modified the stimulus statements to make them relevant to the dental care situation, as follows:

Statement 1: It’s not really worth looking after my teeth; I won’t be around very long.

Statement 2: I really like having someone who understands people with HIV work on me.

Statement 3: Life’s not worth living—there’s nothing much they can do for me any more.

Statement 4: Why do you work on people with HIV/AIDS?

Statement 5: I have nightmares about infecting with HIV the dentist who treats me.

Each of the five statements addresses a distinct concern that might be expressed by a patient with HIV/AIDS. The statements were developed based on observations from previous training programs.

The responses to each of the stimulus items were treated as a set, yielding five sets. Each set of responses was entered verbatim into a database, using spreadsheet software. The responses in each set were then grouped by theme, before a comparison was made across sets to identify common and dis-
parate themes. According to Spradley, a theme is a pattern of thought that connects domains and something that people within the target area will accept as valid. A domain is considered to be a symbolic category that contains related words. In many cases, the themes of a content area may not be explicitly expressed, and hence must be uncovered by the actions and descriptive language and rules of the target group. After identified domains, possible unidentified domains, descriptive examples, and other data have been noted, the existing domains are compared and contrasted to find the themes and organizing domains. In our analysis, we followed a model of qualitative analysis that consists of a search for the parts of a concept, the relationship between those parts, and the relationship of the parts to the whole.

In additional coding, we explored differences in the affective content of responses. In the SPIRS, Gallop et al. used ten response types and three corresponding levels of care derived from their data. Responses at the lowest level of care—no care—were belittling or contradictory or offered platitudes or clichés. Responses at the intermediate level—solution—were explanatory, provided information, or sought an explanation of the statement made by the patient. At the third and highest level of care, responses showed affective involvement of the caregiver, expressing care or addressing the patient’s feelings or self-esteem. We retained the definitions and ordinal structure of the three levels of care, but modified the response types in the solution and affective involvement levels. In these we essentially retained the response categories, but our treatment of them was more ordinal. Although they are categorically distinct, the three types of responses at the “solution” level also show a progression, from little to greater engagement. We also collapsed the original four categories of affective involvement to two because the categorical distinctions used in the SPIRS were blurred in the responses we obtained from our subjects. Responses were scored independently by two raters—one a behavioral scientist, the other a dentist—and both with experience of HIV dentistry. Discrepancies were resolved through discussion, with the goal of consensus.

Results

A total of eighty-three subjects attended the seminar. Data were unavailable for twenty of these, so the analysis is based on the surveys completed by sixty-three subjects (fifteen dentists, twenty-three dental students, twelve dental hygienists, four dental hygiene students, and nine others, including a dental assistant, researchers, and a social worker). Of the 1,260 individual responses (five statements per participant, at four time points), sixty-one were missing, leaving 1,199 responses for coding. Items left blank were coded as no response. We also included responses such as “none” and “no idea” in this category, but noted them as perhaps a distinct subgroup. Blank items and the category of no response were also distinguished from missing data. The category of missing data was used when the answer sheet was not returned. For each stimulus statement, about half the response sets contained one or more missing data points.

Themes

A number of themes were identified. These included the attainment of dental health as a goal in itself, but also as a component of overall health or as a means to greater comfort or longevity. Dental health was also presented as contributing to making the patient feel better about himself or herself. A second common theme addressed the patient’s need for reassurance, both as to prospects for the future and for the immediate dental encounter. These were addressed through prospects of a cure for AIDS and for the acceptance of persons with HIV being treated without stigma. More generally, there were statements of caring and concern. In some cases a willingness to help the patient was tied to statements of having a desire or accepting a responsibility to treat all patients, regardless of health status. Competence in doing so was related by many respondents to having received the appropriate training and to having confidence in the effectiveness of universal precautions.

If we compare the responses to all five stimulus items, hope for a longer life and the possibility of a cure for HIV disease were addressed in answers to statements 1 and 3. The focus of answers differed, however, in that responses to item 1 considered dental care an important factor in longevity, whereas the responses to item 3 were phrased in terms of life itself being valuable. Similarly, comfort was a major theme in response to items 1, 2, and 3. In questions addressing items 1 and 3, physical comfort was equated with dental health, but with item 2, the em-
emphasis was on a positive encounter between the patient and provider.

Other themes that emerged in response to more than one stimulus statement were those of training, competence, and confidence in working with the HIV-infected patient and the motivation for doing so, with responsibility and anxiety interwoven in these responses.

Levels of Care

The majority of responses were in the solution category. Respondents explained rules or processes or offered advice or reassurance. An exception to this was the distribution of responses to statement 2, where the highest proportion of responses showed affective involvement. The proportion of responses showing affective involvement among the five stimulus items ranged from 7 to 38 percent. This was a wider range than that for responses categorized as showing no empathic care. In the latter group, the number of negative or belittling responses ranged from four to eleven and never exceeded the number of platitudes or clichés. The proportion of inappropriate responses (those that ignored or belittled the patient) was less than 3 percent among all responses, and was 2 percent for three of the five stimulus items.

Changes in Themes and Levels of Care During the Training

Most respondents gave consistent answers across the training program. Where changes occurred, these did not appear to be related to the stage of the intervention. In general, changes in levels of care paralleled changes in theme. In most of these cases, an increase in level of care was related to the introduction of an additional, frequently complementary theme, or expansion of a theme used at a previous time point. Similarly, a decrease in level of care most often followed the omission of a theme.

For example, although dental health is a common theme in all the responses of subject 47 to stimulus item 1, the change in level of care occurs when the respondent introduces the additional themes of patient comfort and willingness to help, alongside the theme of dental health:

(Respondent 47, stimulus item 1): “It’s not really worth looking after my teeth; I won’t be around very long.”

Pretest: Oral health care is my field. I think it is very important.

Time 1: I’d like to help you maintain your oral health to keep you as comfortable and disease-free as possible.

Time 2: I’d like to help you maintain your oral health to avoid any discomfort.

Time 3: Poor oral health can adversely affect your overall health.

The responses at pretest and time 3 show the level of care we categorized as solution, stage 1. In contrast, in our interpretation, the other two responses, which go beyond information about the role of oral health, represent affective involvement.

In contrast, we did find a few cases in which a change of theme or level of care emerged from a different focus instead of an additional theme. That is, the response at one or more time points was different from that at others. The responses of respondent 7 to stimulus item 1 at the pretest and at time 3 both focus on the role of dental health care in maintaining the patient’s overall (physical) health. The other valid response, at time 2, focuses on the other part of the stimulus statement—that is, “I won’t be around very long”—so that the theme is different. For this set of responses, however, there is little difference in the level of care:

(Respondent 7, stimulus item 1): “It’s not really worth looking after my teeth; I won’t be around very long.”

Pretest: We need to take care of your teeth so that they don’t become a potential source of infection.

Time 1: missing

Time 2: You don’t know that for sure. The better you take care of yourself, the better off you will be long term.

Time 3: We need to take care of your teeth because they are an important part of your overall health.

Both theme and level of care changed in the response of respondent 72 to stimulus item 5:

(Respondent 72, stimulus item 5): “I have nightmares about infecting with HIV the dentist who treats me.”

Pretest: I would think that is a normal fear for a concerned and caring person to have.

Time 1: If all precautions are used, that really should not be much of a concern. I appreciate your concern.
Time 2: Thank you for your concern. But by using all the necessary precautions, we both will be at minimal risk.

Time 3: Appreciate your concerns. Use precautions and we will both be fine.

The theme at the pretest is one of validating the patient’s feelings, indicating a high level of care. The other responses are at the level of solution, with themes of information and reassurance.

**Negative and Belittling Responses**

We were particularly interested to explore changes in responses that were negative or belittling, as these are the most problematic for the development of a comfortable provider-patient relationship. Responses that appeared to ignore or misunderstand the patient’s statement were included in this category. Nearly half of the inappropriate responses were made at the pretest. Most of the subjects making these statements did better in later responses, following exposure to the training program.

Although most were at the intermediate solution level, focused on explanation or offers of hope, in two cases responses during or after the training progressed to affective involvement:

(Respondent 36, stimulus item 2): “I really like having someone who understands people with HIV work on me.”

Pretest: I’m not your man, can’t relate.

Time 1: As a health care provider I feel obligated in helping my patients by understanding all possible problems.

Time 2: I’m a doctor. It’s my job to understand the disease in order for me to care for you.

Time 3: It’s my job. I want to be a doctor so I can take care of my patients.

There was no improvement from the hostile or belittling category for only three of the respondents. One of these was confined to the response to a single stimulus item and appeared to reflect a misunderstanding of the given statement. The other respondents who were consistent in offering inappropriate responses did so for two and four items respectively. For four respondents there was a single inappropriate response not made at the pretest stage. Three of these followed platitudes, so that the change in response was not dramatic.

Two of the others were “isolated,” that is, they were single negative responses following previous responses that offered hope for the future and affirmed the value of life:

(Respondent 66, stimulus item 3): “Life’s not worth living. There’s nothing much they can do for me any more.”

Pretest: You should live each day to its fullness.

Time 1: There’s always new research going on.

Time 2: Yes, a lot of people live a long time with HIV.

Time 3: There’s always new hope each day. We don’t have pity parties.

**Other Findings**

In general, the same themes were found in responses made by faculty, staff, and students. For students and faculty, 50 to 60 percent of the responses were at the level of solution, just over 10 percent at the level of no care, and 15 percent showed affective involvement. The proportion of students with negative or belittling responses was equal to or exceeded that of faculty for each stimulus statement. In contrast, the pattern for affective involvement was inconsistent. Students and faculty showed affective involvement at approximately equal levels for stimulus statements 2 and 5, with the proportion of students being higher than that of faculty for statements 1 and 3 and lower for statement 4.

We identified a category of responses in which subjects indicated that they had “no idea,” had not thought about the issue, or found it too difficult to answer at the time of the pretest. This is notable because in some cases the respondent was able to complete the item following training, which may indicate that there is a contemplative stage, in which the respondent formulates an answer.

**Discussion**

In this exploratory study we examined the impact of a training program on the expressed empathy of a group of dental health care workers and students to persons with HIV/AIDS. We also investigated the adaptation of an existing measure of empathic response to the dental context.

**Main Findings**

We found a number of themes in our analysis. The role and importance of maintaining health, especially dental health, featured prominently. Res
insurance, comfort, and hope were among other themes represented. Respondents addressed fear of infection, with most expressing confidence in universal precautions.

Almost all respondents indicated a willingness to work with people with AIDS. We recognize that these findings may have been influenced by the context of the study, with the tendency to give socially desirable answers. This should be considered against the fact that participation was mandatory, so that our respondents were not self-selected by an aptitude for or special interest in working with people with HIV.

We identified a range of motivations, including duty or obligation, ethical responsibility, and a desire to help someone in need. Several participants stated that they would not discriminate against these patients or that the patient with HIV/AIDS was no different from any other patient and that all patients were and should be treated the same. Very few respondents openly rejected the patient, though an interesting finding was a distinction made by some between knowing about the disease and understanding the person with the disease. More commonly, respondents stated that they felt they had enough training in HIV management to be competent and comfortable in doing so.

We consider most of the responses to our hypothetical patient to be appropriate. In designing the stimulus statements, we intended to convey the difficult emotions that accompany rejection, isolation, guilt, fear, and impending death. Among the most empathic responses were those that spoke directly to these. They included responses in which the subject spoke of respect for the patient and others in which the patient was asked to share his or her story to help the dentist learn about the experience of living with HIV infection. Although most respondents did not display this level of affective involvement, they were able to address at least some part of the patient’s need for reassurance through sharing knowledge about the course of HIV.

Gallop’s studies of affective response, using the SPIRS, have involved several categories of health care workers but not dental personnel. In the SPIRS, empathy is assessed from the responses health care workers make to the statements of a hypothetical patient. In this study, we have demonstrated that this methodology can be applied successfully to the dental context. This is a useful finding, as availability of this simple methodology may facilitate research and training that improves this important aspect of dental practice. Previous studies with the SPIRS suggest that, among health care workers in a variety of disciplines, the majority express a level of empathic care that is moderate rather than high and that empathic care is lower with stigmatized individuals or populations.

Interventions to improve the affective response of providers are clearly more important for caregivers who have weak skills than for those whose affective involvement is already at a moderate or high level. We observed some increase in the quality of response to our hypothetical patient after a training intervention. Although we cannot demonstrate this change in statistical terms, an important finding of the qualitative analysis was the improvement among the subjects who were initially most negative in their responses. We suggest that any improvement beyond the belittling or contradicting type of response, even to the level of cliché, is likely to be significant to the patient. We are also encouraged that the training stimulated some respondents to recognize and begin to consider these issues, perhaps for the first time. It is preferable that the clinician at the chairside of an HIV-infected patient is prepared to address his or her needs. The findings of minor change in affective involvement among some of our subjects may be due to a ceiling effect among those who began at a high level of empathic care.

Inconsistent changes in the level of care make it impossible for us to identify which components of the training program may be most effective. One possible confounder in our intervention is fatigue. Tiredness following a seminar that addressed emotional issues and repetition of the survey four times in one day may also be explanations for the rather high nonresponse rates.

Limitations

The findings reported here should be interpreted with the following caveats. The participants were students, faculty, and staff of a dental school and may not be representative of other dental health care workers. We expect that academic dentists will have different interests and priorities than their practice-based colleagues. Also, students would not have had experience of dentistry prior to the HIV era and would not make some of the unfavorable compari-
sons that might be made by older, experienced practitioners.

Our data consisted of the responses of participants. As with all self-reported data, the information we have indicates how subjects said they would respond and not what they said in a real encounter, which may have resulted in socially desirable answers. Further, empathy is not manifested only in the verbal component of a response. Affective involvement is also communicated, for example, by touch, tone of voice, and facial expression. We did not have information on these attributes. Our results are based on the investigators’ analyses of written responses to stimulus statements. We were not able to incorporate interpretations from the participants or from people with HIV/AIDS, who may both have offered insight that would ground our results.

The validity and reliability of our results may also have been affected by missing data. We had no data on twenty of the eighty-three persons who attended the seminar, and of the remaining sixty-three, half were not complete at all time points for the entire set of five stimulus items.

Suggestions for Future Study

Our findings suggest a number of avenues for future research. Further development is needed in the understanding of empathy as a construct. We need to refine the methodologies by which empathy is investigated, to facilitate future investigations. An understanding of the empathic relationship and the availability of standardized measurement tools will also help dental educators develop training programs that provide learning experiences to help students develop communication skills. It will be useful to identify the way dentists respond to a range of patients. At the same time, the nature of HIV and AIDS—the role of dental care in medical management and the perception by many of those infected that dentists may not treat them well—makes a compelling case for the study of empathy in AIDS dentistry.

Conclusion

We conducted the study in the second decade of the HIV epidemic. It appears that the dental health care workers and students we studied had come to terms with HIV as a part of practice. We found high levels of willingness to treat, consistent with other studies, but less evidence of the mixed feelings toward the epidemic and the communities infected and affected by HIV than have been reported elsewhere. These differences are illustrated in the comments of some respondents that HIV is “part of the job, and part of dentistry.” Prior to the HIV era most dentists perhaps had fewer demands made on their empathic skills. Many would not have routinely treated such ill patients, particularly when the illness is as emotionally charged as HIV infection. HIV has changed all this, and has brought special needs for empathy in dealing with a serious illness that is stigmatizing through its associations with homosexuality and drug abuse and fears of contagion.

Improvements have occurred since the early days of the illness, when outright rejection of people with HIV did occur in some dental practices, but fears of discrimination and rejection persist in the client population. It is incumbent on dental providers to remember this and be attentive to the verbal and nonverbal messages they convey. The ability and skills to display empathy provide one with the means to reach out to a population in need.

Training programs for dental and dental hygiene students should include components that address empathic communication, and empathic communication should also be the focus of continuing education for practitioners. The technique we have tested here, an adaptation of the SPIRS developed by Gallop, appears to be an appropriate way of assessing affective response, as well as the effectiveness of interventions directed to improving this aspect of the provider-patient interaction.

Acknowledgments

We thank Drs. K. Vendrell Rankin, William Binnie, Terry Rees, Jacqueline Plemons, and John White and Ms. Barbara Ervin for their work in implementing and conducting the HIV/AIDS training program; and Drs. Sena Narendran and Nahid Rianon who gave valuable guidance in the preparation of the manuscript. This study was supported by funding from the Health Resources and Services Administration, through the AIDS Regional Education and Training Center for Texas and Oklahoma, under cooperative agreement No. 5D35-PE-00116-03.
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