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Consumers and Psychiatric-Mental Health Nurses in Dialogue

Sponsored by the
Center for Mental Health Services
Substance Abuse and Mental Health Services Administration
U.S. Department of Health and Human Services

Caring is Catching
(Stir it up)

When I see you care
it ignites something in me.

When you have a clean house and work in partnership
with your spouse and hold your babies close to your chest it ignites something in me.

When you are fully present and not absent-minded about our people
it jars my memory and I catch a fire.

When you see the beauty instead of the booty/bounty
it moves my mountain.

When you sit still long enough for me to look inside your eyes
it settles my dust.

When you speak tenderly and lovingly
it quickens my spirit

When you stretch as you reach for us
it steadies (anchors) my racing heart.

When you cry like rain for Our people
it refreshes the Whole atmosphere.

When I see You care
it ignites something in me.

When you care, I care
and we become uncompromised and revitalized.

-- Cheryl Taylor

Members of the Consumer and Psychiatric Nurses Dialogue
requested that this poem written by a group participant be included
in the monograph as an expression of their common hopes.

The Center for Mental Health Services

The Center for Mental Health Services (CMHS) leads Federal efforts in improving prevention and mental health services for all Americans. CMHS provides support, protection, and advocacy services for adults and children with mental illness, their families and their communities, through various programs designed to increase the quality and care of treatment options. Collaboration is one of the Center's activities, and the Departments of Education, Housing and Urban Development, Justice, and the Federal Emergency Management Agency are among its partners.

Among those who need mental health programs are: people with mental illness (some of whom are homeless); children and adolescents with a variety of mental health problems; people who are at risk of contracting HIV/AIDS; underserved residents of rural areas; and survivors of natural disasters. CMHS supports these populations through innovative demonstration programs, outreach and partnerships, and by providing opportunities for States and communities to expand their mental health services. One of the Center's objectives is to help communities develop effective consumer-run and self-help programs. Toward this end, CMHS sponsors small, focused activities such as dialogues. In July 1999 CMHS convened a dialogue between consumers and psychiatric-mental health nurses.

Background for the Dialogue between Consumers and Psychiatric-Mental Health Nurses

In clinical and community-based settings, both mental health consumers and psychiatric-mental health nurses realize the importance of establishing and maintaining rapport as an effective means of developing productive communication-thereby, increasing the likelihood of beneficial nursing care and treatment outcomes. Nurses have much to do with determining the manner in which consumers are afforded respect for their rights, personal values and choices, and the extent to which they are empowered to set their own goals and determine what care and services they will receive. Developing trust, mutual understanding and respect are essential ingredients in building this needed rapport and creating effective alliances in order to improve mental health care delivery.

In other settings; e.g., as in education and training, program planning and administration, policy development, and research, consumers and psychiatric-mental health nurses have not always been successful in creating trusting partnerships, nor developing effective collaborative initiatives. Attitudes of distrust and suspicion on the part of both groups toward each other may contribute to disagreements or tension between consumers and nurses in creating effective, cooperative partnership activities to improve mental health service delivery.

Meeting Context and Goals

Paolo del Vecchio, Center for Mental Health Services, welcomed the group and noted that it was a fortuitous time for a dialogue between consumers and psychiatric nurses because of the increased national visibility for issues concerning mental illness. The White House Conference on Mental Health recently concluded, and the U.S. Surgeon General is scheduled to issue a report on mental health in the near future.

Changes brought about by managed care are forcing debate and discussion about important mental health issues. Involuntary treatment and medication and the use of restraints are continuing problems, but they are attracting greater attention.

Mr. del Vecchio said that the dialogue was intended to lead to action, as well as to improve understanding among the participants. As a result of the recommendations coming from a previous dialogue between psychiatrists and consumers, CMHS is sponsoring the development of a 22-minute video that will be used to train psychiatric residents and other mental health professionals about how they can work in partnership with consumers to promote recovery. Several actions resulted from recommendations coming from a dialogue between psychologists and consumers. A series of local dialogues between the two groups took place at various locations around the country. The 1999 national meeting of the American Psychological Association included a major series of events focusing on collaboration between psychologists and consumers.

Mr. del Vecchio described the process by which the agenda for the dialogue was developed. A planning committee comprising two consumer representatives (Russell Pierce and Ann Marshall); two nurse representatives (Phyllis Connolly and Beverly Malone) worked with CMHS staff members via teleconferencing to identify issues and develop an agenda. Ms. Carole Schauer, Center for Mental Health Services, said that

CMHS and the committee wanted to provide a "level playing field and safe place" where consumers and psychiatric-mental health nurses could come together to discuss the factors that promote and hinder recovery and develop recommendations that would give a continuing life to the work of the group.

Experiences of Meeting Participants

Although the group was small enough (20 participants) for productive discussion, its members represented a wealth of experience. They included consumer advocates, professors of nursing, nursing association officials, a presidential advisor, and nurses in advanced practice. Several of the participants brought a dual perspective to the process; they were both consumers (or relatives of consumers) and professionals in the nursing field. Consumer advocates also brought a dual perspective to the discussion; they spoke as consumers and as professionals working within organizational structures. Geographically, the range covered the country-from Oregon to Texas and back to Maine-and included participants from small towns to major urban centers. The groups were also highly diverse in terms of culture and ethnicity.

Initial introductions revealed many of the themes that would persist throughout the 2-day meeting. The most basic of these was a concern with identifying ways that consumers and nurses could work together. In fact, one participant commented about how tired he became of "unending benevolence," adding that nurses should ask, "What can we do with you?" rather than "What can we do for you?"

One nurse had developed a practical strategy to enable nurses to reach a better understanding of life from a consumer's point of view. She lived for several nights on the streets with homeless people who have mental illness to broaden her own perspective. She then incorporated her new insights into training sessions that she offered to student and practicing nurses. In addition, she recruited residents from shelters; offered them help with public speaking; and then encouraged them to serve as speakers at educational sessions.

A basic commonality between the two groups quickly emerged: their perceived lack of power. One nurse commented, "I know about stigma. Nurses have the least amount of respect of any members of the medical profession. Their resources are the first to be cut." Another nurse commented that in many State mental hospitals, both staff and consumers are neglected or mistreated.

Issue Areas

The structure of the meeting was a progression from issues of personhood and relationship-respect, dignity, communications, language-to issues of the context in which the relationships occur-managed care, policy, involuntary treatment, staffing and training. However, participants quickly discovered that lines are not easily drawn between personal and contextual issues. Financial and time constraints imposed by the dictates of managed care, for example, powerfully influence relationships between nurses and

consumers and among staff members. Policies about involuntary treatment can work to destroy a consumer's dignity and undermine trust between staff and consumer. The importance of cultural competence was raised in a variety of contexts. Every issue can be viewed through the prism of power.

Following are some of the important issue areas. The general flow is from the personal to contextual and then to action. Each issue area, however, is linked to every other area in a variety of ways.

Language and Labeling

Consumers reported that language and labeling have powerful effects on how they view themselves and develop (or fail to develop) trusting relationships with nurses and other health professionals. The first comment raised in discussion was a request for "people first" language, which puts the person before the illness; e.g., "a person with mental illness" instead of "a mentally ill" person. According to participants, person-centered language promotes a person-centered recovery process.

Language and labeling can build barriers between staff and consumers by preventing an authentic personal encounter. Coupled with the stigma associated with mental illness, they rob consumers of their dignity and sense of individuality. One participant said, "Being a consumer is a very small part of my life. I'm so many other things." Nurses also acknowledged the importance of finding ways to get to know consumers as individuals. As one of them said, "It's hard to disrespect someone if you know him."

Some nurses had developed specific strategies to improve the personal relationships between staff and consumers. One nurse supervisor instructs her staff "to get to know the client first and then go to the chart." Consumers commented that it was important to have other consumers as integral parts of the medical staff. A participant commented that at our facility, "We make sure peer staff is the first contact at intake, rather than thick, intrusive forms." The consumer staff members provide an empathetic welcome to consumers coming to the facility and also help educate staff members about the consumer's perspective.

Boundaries

Although participants agreed about the importance of an authentic and trusting relationship between consumer and nurse, they held a great range of opinions about appropriate boundaries-in particular, touching of consumers. One consumer eloquently described her need to be held during a hospitalization and argued forcefully that touching is appropriate and necessary. But, as one nurse pointed out, "Psychiatrists are brought before ethics boards for touching." Another nurse said that the students she trains are afraid they will be sexually assaulted if they touch clients or that their actions will be misunderstood. Participants did note that the best practice is to ask a consumer before touching.

There was genuine disagreement about the extent to which friendships are possible between nurses and consumers. One consumer spoke about the importance of such friendships saying, "The consumer is relationship-starved." A nurse replied, "Being your friend may get in the way of being your therapist. I'm a coach, not your friend." In general, consumers expressed frustration about inequitable relationships: they were expected to reveal their most important secrets and thoughts to people who did not share even routine information about their own lives. It was also stressed that nurses bring many of their own histories and issues to their relationships with consumers and that it was important for nurses to recognize these.

There was also no single answer about how boundary issues could be handled better. One nurse said that she used to worry about touching all the time, but now felt comfortable and trusted her own judgment about what is appropriate. The change came about through time and experience. A consumer commented that no matter how well people are trained, some staff members remain "tone deaf' about relationships and appropriate boundaries. Power and sexuality issues make the establishment of appropriate boundaries particularly difficult.

Cultural Competence

One consumer, who had developed workshops on cultural competence offered a broad definition to the group. "Cultural competence is an educational process that includes the ability to develop working relationships across lines of differences. It encompasses self-awareness, cultural knowledge about illness and healing practices, intercultural communication skills and behavioral flexibility."

At one level, cultural competence relates to the ability to communicate via a common language. In fact, one nurse told of her mother's long stay in a mental hospital, during which time she never heard her native language. However, more subtle examples were also offered. A study showed that Puerto Ricans touch each other much more frequently than do Caucasians. A nurse told of the mistrust in the African-American community because of previous unlawful experimentation on African-Americans while they were hospitalized.

The group also mentioned that it is not necessary to define culture by language or place of origin because it is broader than both. It also includes being aware about disabilities and providing accommodations. People who are deaf, for example, have a culture that is rarely understood. In fact, one participant pointed out that consumers and providers live in two distinct cultures and that training programs could benefit by a recognition of the cultural differences.

There was a general consensus that additional training and education are greatly needed in the area of cultural competence. There was also acceptance of the idea that focus should be put on changes in behavior. It may be difficult or impossible to change attitudes, but it is possible to ensure that people do not act out their racism. One participant, said, "We all have 'isms,' and that's OK. But your behavior must be

appropriate." Efforts should be made to have the providers reflect the diversity of the people served.

Time

Constraints caused by lack of time in treatment and service settings were mentioned frequently in discussions of many issues. There was agreement between nurses and consumers that "good intentions" were frequently undermined because staff did not have adequate time for the work they were expected to do. One nurse said, "Time is the resource everyone is struggling over." It takes time to establish relationships, but time given to one consumer is often at the expense of another consumer. That juggling of priorities is important, because time is also a key element in recovery. One consumer said, "I've watched when they lined the patients up and psychiatrists took about 10 minutes with each patient. When a nurse took time with me, the connection kept me sane."

Lack of time also affects staff relationships. "Staff don't have time to relate to each other," according to one nurse. Lack of time limits opportunities for training and communication about consumers. Staff morale suffers, affecting patient care. Nurses spoke of the importance of taking time for themselves.

Power

The group described a complicated set of power relationships. Nurses, like other medical professionals, have a considerable amount of power over consumers, and they need to be sensitive to this issue. In fact, one consumer said, "Nurses have complete power over our lives." The power can be exercised in thoughtless ways. One consumer said that he had asked 20 of his peers about their relationships with nurses. "They said they remembered eating crappy food in the dining room and then coming back and watching the nurses order out and eat in front of us." A nurse supervisor said that she had to prevent her staff members from carrying extra sets of keys to the ward. Those keys were a symbol to the nurses of their desire to draw lines between themselves and the consumers and of their power over them.

On the other hand, nurses perceive that they also lack power. They are different from psychiatrists and psychologists because of their position in their staff hierarchy. One nurse commented, "Nurses sometimes feel as helpless as the patients." They are least able of the medical professionals to demand and keep resources, but they have the day-to-day, minute-to-minute responsibility for operation of the facility. One nurse offered this explanation of why nurses may appear to be rigid or wedded to their exercise of power. "Nurses have a responsibility to keep everything under control. It's as if the nurse is responsible for a family who has to be safe. Things can spiral out of control so easily." Both consumers and nurses need to be cognizant that "not being powerful doesn't mean that one is powerless."

Protection and Advocacy

The ambivalent position of nurses in terms of power has great impact in terms of their ability to protect and advocate for the consumers. One consumer spoke forcefully about the "veil of silence," contending that often when nurses observe abuses, they fail to report the offense. Instead, a veil of silence descends to protect the staff member. When an offense is reported, nothing is done. Staff continue in their positions despite many complaints against them. When obvious abuses go unpunished, great harm is done to the ability of nurses and consumers to establish the kind of trusting relationships that are necessary for recovery.

One nurse acknowledged the criticisms, commenting, "I've never seen nursing at such a low for advocacy," and also added that nurses who complain frequently are "set up" by the people who are abusing their power or are mistreating consumers. Another nurse described the dilemma of trying to act with integrity in a poorly run facility. "Every time I complain I use up a chip. If I constantly agitate, I'll agitate myself out of a job. I ask myself 'Should you stay and try to do what you can or speak up and leave?'"

The group mentioned several remedies for the problem. Nurses should join their professional organizations and take advantage of the power of strength in numbers. They should be educated about legal remedies provided by protection and advocacy legislation. A consumer advocate mentioned the power of bringing advocates to meetings with staff about consumer complaints and of making advocates a visible presence at facilities.

Medication, Involuntary Treatment, Restraints and Euthanasia

Issues about medication, restraints and involuntary treatment elicit particularly strong feelings from consumers. They involve a direct exercise of power by medical personnel over consumers and are critical to understanding the distrust many consumers have of the mental health system. Consumers report numerous experiences with forced medication and the use of restraints that denied their right to participation in treatment decisions, were disrespectful, aggravated previous traumatic experiences, and were psychologically damaging and physically dangerous. One consumer reported an experience in which she told a staff member that a particular medication would be hazardous to her health and was ignored. She was emphatic that health professionals should try to understand why patients refuse medication. Yet another participant stated that mental health professionals sometimes disregard the personal experience of being restrained and actively ignore and suppress that experience. Another participant commented that he and other consumers fail to understand why health professionals were forcing medication on them while simultaneously arguing against drug addiction. A nurse commented that her nursing students had difficulty understanding why consumers refused medication.

Some strategies have been developed to deal with aspects of these issues. Several consumers argued that any staff member who has the power to order the use of restraints should spend time in restraints so he or she can understand how they feel. Others supported the use of advance directives, in which a consumer specifies choices about treatment in the event illness renders one incapable of exercising choice. Consumers emphasized the importance of having ombudsmen working with nurses when decisions

are made about using medications and restraints. The group agreed that more dialogue is necessary about these issues.

Nurses can have an effective role in policymaking regarding involuntary treatment. Consumers expressed concern that involuntary treatment is increasing throughout the country. One consumer also reported an alarming trend to permit or encourage euthanasia among people with disabilities.

Managed Care

The proliferation of managed care programs is affecting the mental health system at all levels and in critical ways. Managed care program personnel specify the allocation of time and resources and influence decisions about treatment and relationships between consumers and medical personnel. A participant from a State with a particularly high concentration of managed care programs said, "Managed care is a serious threat to quality of care. I'm asked to make a woman stop complaining about incest in six sessions." A consumer said, "Managed care is really managed cost." Other participants complained about the shift in decision-making from medical personnel to managed care personnel. "Everyone has less autonomy under managed care," a nurse commented. Another nurse said that managed care companies were sending psychiatric nurses "to negotiate against us" when developing managed care contracts.

Several participants suggested that a political approach would be necessary to deal with the emerging problems. "We need a Patient's Bill of Rights that has enforcement mechanisms," said one nurse. A nurse noted that advocacy for staff could be beneficial to managed care companies because staff members would become more efficient.

Opportunities for Change

Throughout the dialogue, several participants encouraged the group to focus on their power to affect change, as well as on the barriers. One consumer insisted, "We should identify the power we have. There is power in the interstices. We have power in our day-to-day relationships." A participant commented, "We have 26 million nurses, which is the largest group of health professionals in the country." Another participant added, "Nurses and consumers are natural allies." A consumer advocate pointed out available legal remedies and the value of sending independent observers to facilities and meetings affecting consumers.

Other participants commented that the time was right for change because of the dislocations in the health care system. "People are confused. It's a good time to initiate changes," said one. Participants commented on the importance of providing support to people who are trying to bring about change. One nurse said that it's important to acknowledge the staff members who battle for consumers as individuals. "Go back and tell the lone soldier that he or she made a difference."

Further Dialogue

Participants frequently commented about the importance of the issues being discussed and the need for additional dialogue to explore them more fully. They also identified other topics that received only cursory attention because of the constraints of time. They included: economics of deinstitutionalization; safety issues; licensure/training; collaborative partnerships; stigma; sexuality; HIV prevention and care; persons with mental illness who are incarcerated; relationships and roles of different kinds of nurses, and communication.

Recommendations

Recommendations for further action came in three ways:

- Throughout the dialogue, participants suggested action steps that would address the problem under discussion.
- A group of participants met during the evening of the first day to develop draft resolutions that were presented to the full group the second day.
- During the second day, the group set aside a specific time period during which they developed a set of recommendations.

The recommendations ranged from broad statements of principle to concrete action steps. They came from individual participants without having a group consensus. Some recommendations are directed at a specific entity, e.g., nursing schools, while others would require system-wide change. Following is a synthesis of those efforts.

Statements of Principle

- Consumer involvement at all levels and stages of organizational management and delivery of care should be integrated throughout the system. We also acknowledge that quality treatment requires a team effort.
- Consumers have the right to accept or refuse services, including medication.
- Cultural competence needs to be exhibited by staff at all organizational levels in order to meet consumer and family needs.

Mental Health Care System

- Members of appropriate accrediting bodies need to be educated about the rights, views and needs of consumers.
- The mental health professions need to consider making an apology to consumers for past abuses of power and harmful treatment.

- A similar national interdisciplinary dialogue needs to be instituted to include consumer advocates, psychiatric nurses, psychologists, psychiatrists, social workers, and occupational therapists.

- Efforts need to be made to develop and fund pilot programs that demonstrate new methods of care, including the hiring of mental health consumers to work side-by-side with nurses and other providers.

- Efforts need to be made to encourage consumer-health care profession dialogues at every mental health facility about issues affecting consumers and mental health personnel.

- Efforts need to be made to pass a federal "Patient's Bill of Rights" legislation that protects consumers.

- Staff throughout the mental health system need to reflect the cultural composition of the groups served.

- Efforts are needed to increase the number of consumers hired to function as independent observers at mental health facilities.

- Expanded use needs to be made of consumer report cards that evaluate care from a consumer's perspective, and consumer self-help and advocacy groups.

- Work needs to continue in making psychiatric inpatient settings safe and restraint-free.

- Efforts need to be made to ease the transition of a consumer from an inpatient setting to the community. Such efforts will require knowledge of community resources and development of follow-up programs.

- Staff need to understand and focus on issues affecting the consumer's quality of life. Specific measures need to be developed and utilized to evaluate the quality of life.

- Efforts need to be made to develop treatment plans from a strength-based perspective, e.g., what persons are able to do rather than what they cannot do.

- Staff need to recognize consumer improvement and recovery.

Psychiatric-Mental Health Nurses

- Nurses are encouraged to join professional organizations that can work to set standards and bring about reform. These organizations can work to increase competencies and professional behavior.

- Methods need to be developed to encourage and enable nurses to work with consumers in community-based programs, rather than in hospitals.

- Nurses are encouraged to forge alliances with consumers about issues of common interest.

- Nurses are encouraged to forge alliances and network with each other for mutual support and to take care of themselves.

- Nurses and other health care professions are encouraged to make greater use of advance directives. The directive can provide treatment instructions, including whether or not family members need to be involved.

- Nurses need to be educated about the psychological trauma that can result from the use of restraints, and coercive and forced treatment.

- Nurses need to be educated about legal remedies offered by protection and advocacy legislation.

- Nurses need to be encouraged to continue dialogues similar to the CMHS-sponsored event in local settings.

- Nurses need to be educated about issues related to cultural competence, disability awareness, humanistic values, advanced therapeutic communication skills, effects of power in service provision, stigma, and discrimination.

Center for Mental Health Services

- CMHS needs to initiate a national multi-professional-consumer-advocate dialogue.

- CMHS needs to develop and disseminate video tapes that can be used to educate nurses about issues raised in this dialogue.

- CMHS needs to post this monograph on the Internet and disseminate it to nursing associations. Staff should solicit feedback from the associations that can be used for further action.

- CMHS needs to initiate dialogues between consumers and representatives of nursing organizations that were not represented at this meeting.

Consumers

- Consumers need to work with psychiatric nurses to develop training and education programs that can be offered at nursing conferences and at conferences of consumer advocates.

- Consumers and others need to advocate for resources that will enable CMHS to promote implementation of these recommendations and additional dialogues.

- Efforts are needed to encourage dialogues between consumers and health care professions at every mental health facility about issues affecting consumers and mental health personnel.

- Efforts are needed to pass a Federal "Patient's Bill of Rights" legislation that protects mental health consumers.

- Consumers need to be educated about legal remedies offered by protection and advocacy legislation.

- Work needs to continue in making psychiatric inpatient settings safe and restraint free.

Concluding Comments

Mr. del Vecchio thanked the group members for their participation, reminding them that "this is only a beginning. What's important is that we continue this dialogue at work, in conferences and in local communities and that we take action." A participant agreed with the need for further action and added that he judged the value of a meeting by how many ideas he took home with him. "I have eight pages of ideas." Other participants expressed gratitude for the high level of the dialogue and the willingness of group members to be open and authentic about their feelings. There was general agreement about the need for similar dialogues in a variety of settings.

Consumer and Psychiatric Nurses in Dialogue

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