

Advocating for the Rights of the Mentally Ill: A Global Issue

**Jeanette Rossetti EdD, RN Assistant Professor Northern Illinois University School of Nursing
1240 Normal Road DeKalb, IL 60115 Phone: (815) 753-9956 Email: rossetti@niu.edu**

**Patricia G. Fox, PhD, FAAN Associate Professor School of Nursing, Northern Illinois University
School of Nursing 1240 Normal Road DeKalb, IL 60115**

**Kenneth Burns, PhD, RN Professor and Associate Chair Northern Illinois University School of
Nursing 1240 Normal Road DeKalb, IL 60115**

Accepted for Publication: January 2005

[No of References: 16]

Abstract:

The media has shared with the American public horrors of abuse towards prisoners of war in recent newscasts. Prisoners, and others in vulnerable positions, can fall victim to neglect and abuse at the hands of their captors. Often, human rights can be violated. Therefore, people in vulnerable positions need advocates who will defend and protect their rights. The role of advocate is familiar to nursing professionals. In the mid-1980's advocacy grew attention due to disclosure of human rights abuses in mental health facilities. Today, world- wide, nursing leaders continue to confront abuses in multiple settings. In the United States, the Human Rights Authority was specifically developed to address issues of abuse of persons with physical disabilities and or mental illness. Globally, nurses will want to support the development and enforcement of policies that protect persons in vulnerable positions.

A Global Issue:

According to the World Health Organization (WHO) (2004a) 450 million people worldwide are affected by mental, neurological or behavioral problems. Another interesting fact is most middle and low-income countries devote less than one percent of their health expenditure to mental health. This leads to mental health policies and treatment options receiving low priority. Because of this, the WHO has placed a high profile focus on the importance of mental health by launching the mental health Global Action Programme. This program focuses on partnerships to enhance countries' capacity to combat social stigma, reduce the financial and undefined/hidden burden of mental disorders and promote overall health. Human Rights is one area that the organization is committed to by ensuring policies and evidenced-based interventions are enforced. (WHO, 2004a) Globally, countries have varying beliefs and attitudes associated with mental disorders and mental health. Formulating mental health policy is vital according to WHO (2004b). Major depression was found to be the leading cause of disability worldwide according to the National Institute of Mental Health (2001) and ranked second only to ischemic heart disease in magnitude of disease burden.

Human Rights:

Human rights as defined by the United Nations System and Human Rights (2000) are: *“universal legal guarantees protecting individuals and groups against actions which interfere with fundamental freedoms and human dignity”* (¶ 2).

There are a variety of issues related to the preservation of human rights in the area of mental health. The WHO (2001) warns about mental health issues described as the undefined and hidden burden. The undefined burden of mental problems refers to the economic and social burden that families and communities suffer as a result of mental illness. The shame and embarrassment that can be felt by those affected by mental illness, due to social stigma, is considered to be the hidden burden. These burdens are difficult to measure and quantify and therefore can be concealed and unreported. Because the mentally ill are particularly vulnerable, they are at a higher risk to have their rights and freedoms violated.

The World Health Report (2001) strongly encourages the respect of human rights and states that mental health policies and programmes should promote the following:

- Equality and non-discrimination
- Privacy
- Individual autonomy
- Physical integrity
- Right to information and participation
- Freedom of religion, assembly and movement

The Report encourages healthcare professionals to fulfill their ethical responsibilities towards the mentally ill by protecting them from discrimination and safeguarding their human rights.

Psychiatric nurses have a vital role as advocates in promoting human rights. Grace, Fry, and Schultz (2003) found that nurses working in the specialty areas of mental health and substance abuse, identified protecting patients' rights and dignity as the most frequently encountered issues. Further noting the mentally ill are at greater risk as mental illness has the potential to rob patients of their ability to protect their basic rights. The authors conclude that nurses need support to manage the ethics and human rights issues they experience. For example, in-service education can provide nurses with information related to support services available in their institution, such as ethics committee consultation, available counseling services, and online ethics education resources.

Patient Advocacy:

In the U.S., the American Nurses Association Code of Ethics (2000) calls for nurses to promote, advocate, and strive to protect the health, safety and rights of patients. A variety of nursing authors have explored the concept of patient advocacy. According to Copp (1986), advocacy involves intervention for vulnerable people who require it. This includes patient teaching and anticipatory guidance resulting in the reduction of patient problems. For example, individuals with chronic health diseases, who are homeless and those in crisis situations, can be exposed to problems resulting from exposure, nutritional deficits, and brutality. These resulting problems require preventative interventions. Advocating for human rights, according to Copp, is "acknowledging the humanity that links nurses with all vulnerable populations" (p. 262). Smith's (2004) discussion of the role of nurses as patient advocates highlights specific conditions that contribute to the need for advocacy. The conditions include the vulnerability that is created by the patient's illness, the complexity of health information and health care systems and the risk for the loss of human rights.

Halter (2002) reports advocacy by psychiatric nurses is an integral part of care for victims of mental illness and associated social stigmas. Therefore, it is imperative that psychiatric nurses have a thorough understanding of how they can advocate for the rights of their patients. There are a variety of ways the role of advocate can be demonstrated in the area of mental health nursing. Educating patients about their rights, supporting their autonomy in decision-making, and upholding policies and procedures regarding their rights are just a few examples. Serving as a psychiatric nurse and nurse educator has provided the opportunity to promote the role of advocate by contributing as a member of the Human Rights Authority (HRA) in the U. S. The HRA investigates alleged violations of the rights of persons with disabilities. This includes persons with mental illness, cognitive disabilities, physical disabilities, and the aged disabled.

Clinical Example:

Consider this example many nurses and other health care professionals encounter. A female inpatient on a locked psychiatric unit refuses to attend the next scheduled group. When told she must attend she begins to scream and yell, calling out obscenities to staff and patients in the day room. The mental health staff requests she go to her room and upon her refusal escort her to the quiet room. She continues to be verbally abusive. The staff nurse requests she take medication to help her calm down. Sitting down on the bed the patient calmly apologizes stating she does not want the medication due to the side effects she encounters. Again, the staff nurses requests she takes the medication. She refuses and then is held down by staff and given an injection against her will.

Discussion:

The above is one of many examples of when a patients' right to refuse treatment is not honored by health care professionals. Does the patient have a right to refuse to go to a group session? Does the patient have a right to refuse medication? Under what circumstances can these rights be violated? According to the mental health code, the patient does have a right to refuse treatment unless they are a danger to themselves or others. Not honoring this right is a violation of the mental health code. This leaves an important question. What measures are in place to monitor the possibility of this violation from occurring?

Due to abuses that were occurring in institutional facilities in the U. S., governmental agencies were charged with ensuring that the rights of the disabled were upheld. The HRA, as reviewed earlier, is the investigative arm of the state's Guardianship and Advocacy Commission, charged with the task of investigating potential abuses of the disabled. According to the National Alliance for the Mentally Ill (2004), four of the ten leading causes of disability in the U. S. and other countries are mental disorders. These include major depression, bipolar disorder, schizophrenia, and obsessive-compulsive disorder.

Uniquely, the Authority utilizes citizen volunteers to conduct investigations of alleged violations and abuses to make corrective recommendations to the providers of services. The membership of the HRA is made up of nine volunteers. Three by statute are themselves providers of disability services, one each from the area of mental health, developmental services, and rehabilitation services. The other six members are private citizens who may they have a disability, have a family member who is disabled, or be interested in advocating for the disabled. (Human Rights Authority 2004).

The nursing professional collaborates with the HRA in a variety of ways. For example, nurses often provide access to the Commission for their patients by offering the phone number or making a phone call when necessary. Often, nurses are interviewed by the HRA for information related to the particular patient's allegation. Nurses also serve on the HRA; their expertise provides much insight into the alleged abuses and/or potential violations of the mental health code during the investigation. Nurse's knowledge of hospital policies and procedures, psychiatric programming, and psychotropic medications can be valuable to the investigative process. In addition, being part of the investigative team offers the nurse opportunity for continuing education related to the mental health laws and their interpretation. As a nurse educator, having the opportunity to be part of the investigative team has provided countless opportunities to keep abreast of the current mental health code and offer students examples of day-to-day challenges that the nursing professional faces. Finally, serving on the HRA provides the opportunity to serve as an advocate for the rights of the physically and mentally disabled.

Initiation of an Investigation:

A complaint of an alleged violation of human rights can come to the Authority in a variety of ways. Notification can come from a service recipient, a staff person at the facility, or another concerned party. The complaint might take the form of a letter or a personal presentation before the HRA at a monthly public meeting. Sometimes investigations are initiated by the HRA itself if there is a reason to believe a rights violation has occurred. Hospitalized patients must always have access to the Authority and contact information should be readily available on the unit. As stated earlier, advocate teams conduct fact-finding investigations to determine whether or not a complaint is warranted. The investigation can include meetings with service providers, medical record reviews, site visits and policy reviews. A report is filed, sent to the provider and made public. If the allegation is substantiated recommendations are made to ensure compliance with established policies. Frequently, the provider resulting in a complaint necessitating further education misinterprets the Mental Health Code. Other times, the allegation is unsubstantiated and duly noted in the report.

What warrants an Investigation?

There are several reasons when the HRA should be notified. The following clinical examples and discussions describe some of the actual reasons for notification, including what would warrant an investigation.

Clinical Example:

This example highlights a complaint of an alleged mail restriction. A client diagnosed with schizophrenia claimed that his outgoing mail was not being delivered to the HRA, his attorney and a variety of other parties. Upon investigation it was noted that due to his illness the client was writing copious amounts of material and his handwriting was rather difficult to interpret. Often the mail delivery system of the hospital was unable to mail the client's letters due to the mailing address being illegible. During the investigation an interview occurred with the client's case manager who stated he was aware of the client's concern and had made up pre-labeled envelopes to the parties the client preferred to communicate with. In this case, the hospital personnel had intervened and assisted the client so that his right for outgoing mail was not impeded. The investigative team followed up with the client who reported satisfaction regarding his outgoing mail.

Discussion [1]:

A frequent complaint involves the patients' right to visiting, mail and phone calls. Recipients of mental health services are allowed to have visitors, to make and receive phone calls and to have uncensored mail. The Authority may be called when visiting; phone or mail privileges are viewed as being unjustly restricted in some way. During the investigation the clinical record is reviewed to determine the rationale for any such restriction and documentation related to the issue. Interviews with staff members and current patients may also occur to identify current practices. If a restriction is unjustified, and the allegation is substantiated, recommendations are made to the facility. At times, due to safety issues when a client is a danger to themselves or others, a restriction has been warranted. For example, if a client had been threatening to harm another person it may be appropriate to limit contact with the person due to the homicidal threat. In this case the client's doctor must order such restriction and follow up is made to the patient in question explaining the rationale for the restriction. Finally, proper restriction of rights documentation is completed by nursing staff.

Clinical Example:

Another case reports an adult client calling the HRA notifying them that her therapist communicated with her mother and shared confidential information without the client's consent. Upon investigation it was noted that there was no written release of information in the medical record authorizing any member of the treatment team to offer clinical information to the client's mother. In this case, the client's confidentiality was breached and the allegation was substantiated.

Discussion [2]:

Clients have a right to privacy and confidentiality. Those who believe that their confidentiality has been broken in some way can request an investigation by the HRA. Depending on the allegation, interviews and reviews of documentation will most likely occur to determine if the allegation is justified. It is imperative that staff properly document when a client gives permission for their clinical information to be shared with others.

Earlier, a clinical example highlighted a client refusing treatment, which included medications, and going to group therapy. It is important to note that all treatments are subject to patient refusal. This of course, becomes complicated when the patient is determined to be a danger to themselves or others. In addition, recipients have stated that they have been punished or restricted in some way due to their refusal of treatment. Being a threat to themselves or others is a legitimate reason why refusal of medications may have not been honored or why restraint or seclusion was necessary. It is important to know that a patient should never be punished or unjustly restricted for refusing treatment. Policies and procedures related to all of the above are closely monitored in addition to the investigative process.

The lives of thousands of persons with disabilities have been positively affected by the work of nurses, other health care providers and volunteers who have acted as advocates in supporting human rights. Psychiatric nursing experience is also invaluable during the investigative process of alleged violations due to the nurse's expertise in this area. In addition, patient advocacy offers nurses opportunities for continuing their education in issues of mental health policy.

Implications for Global Health:

The World Federation for Mental Health (WFMH) advocates for the rights of the mentally ill worldwide. Their aim is to investigate human rights abuses against the mentally ill and educate people about human rights violations (BBC News, 1999). As previously noted, most middle and low-income countries devote less than one percent of their expenditures towards mental health. This has serious consequences, as health policies, legislated community care facilities and treatments for those with mental illness may not receive a high priority (WHO, 2004a).

It is imperative to note the importance of upholding the rights of the mentally ill globally. Almeida and Vasquez (2002) in an informal briefing to the Ad Hoc Committee of the United Nations International Convention state, "Persons with mental disabilities frequently are victims of cruel, inhuman and degrading treatment, and in addition are isolated in psychiatric institutions under deplorable conditions that negatively affect their health and at times can even threaten their own life" (§ 1). Therefore, immediate action was recommended to protect the physical and psychological integrity of thousands of adults and children who were without human rights.

The rights and fundamental freedoms most frequently violated in psychiatric hospitals globally include: the right to be treated with humanity and respect, the right to a voluntary admission in psychiatric institutions, the right to privacy, freedom of communication, the right to receive treatment in the community, the right to provide informed consent before receiving any treatment and the right to appeal to an independent and impartial tribunal that determines the legality of the detention (Almeida and Vasquez, 2002).

Conclusion:

Globally, advocating for patient rights is an integral part of the nurse-patient relationship. Copp (1986) reminds us "It is obvious that when individuals lose power to represent themselves, and their needs, wishes, values and choices, others must advocate for them" (p. 255). Patients with mental illness are often in vulnerable positions, nurses have a multitude of opportunities to represent and intervene on their behalf. It is vital for psychiatric nurses to be knowledgeable of their particular country's mental health code as it relates to patient care. Not only must nurses balance patient care needs, they must uphold patients' civil liberties and ensure the safety of others. Educating patients, families and communities of patient rights is another opportunity to decrease potential social stigma and discrimination of the mentally ill. Finally, nurses can be involved in pursuing investigations of human rights violations by volunteering their time to this cause. Throughout the world, nurses must pursue patient advocacy and continue efforts to maintain the dignity of their patients

References:

Almeida, J. M. C. & Vasquez, J. (2002). The Pan-American health organization's (PAHO) advocacy strategies for the promotion and protection of the human rights of persons with mental disabilities and their family members. Informal briefing at the August 2002 United Nations International Convention, New York. Retrieved August 20, 2004 from:

<http://www.un.org/esa/socdev/enable/rights/adhocunbrief6.htm#top>

American Nurses Association (2000). Code of ethics for nurses. Retrieved August 31, 2004, from: <http://nursingworld.org/ethics/code/ethicscode150.htm>

BBC News (1999, October 13). Defending the rights of the mentally ill. Retrieved September, 17, 2004, from: <http://news.bbc.co.uk/1/hi/health/187750.stm>

Copp, L. (1986). The nurse as advocate for vulnerable persons. *Journal of Advanced Nursing*, 11(3), 255-263.

Grace, P. G., Fry, S. T., & Schultz, G. S. (2003). Ethics and human rights issues experienced by psychiatric-mental health and substance abuse registered nurses.

Journal of the American Psychiatric Nurses Association, 9 (1), 17-23. Retrieved August 20, 2004 from: www.apna.org

Halter, M. J. (2002). Stigma in psychiatric nursing. *Perspectives in Psychiatric Care*. 38(1), 23-29.

Human Rights Authority (2004). Service profile. Retrieved on June 30, 2004, from: <http://gac.state.il.us/hra/hrasp.html>

National Alliance for the Mentally Ill (NAMI). (2004). Facts and figures about mental illness. Retrieved January 22 2004, from: <http://ocd.nami.org/helpline/factsandfigures.html>

National Institute of Mental Health (2001). The impact of mental illness on society. Retrieved September 7, 2004 from: <http://www.nimh.nih.gov/publicat/burden.cfm>

Smith, A. P. (2004). Patient advocacy: Roles for nurses and leaders. *Nursing Economics*, 22(2), 88-90.

The United Nations System and Human Rights (2000). Guidelines and information for the resident coordinator system. Retrieved August 2, 2004 from: http://www.who.int/topics/human_rights/en/

World Health Organization (2004a). Mental health. Retrieved August 20, 2004 from: http://www.who.int/mental_health/em/

World Health Organization (2004b). Mental health: Policy and services. Retrieved August 20, 2004 from: http://www.who.int/mental_health/policy/en/

World Health Organization (2001). Mental health problems: the undefined and hidden burden. Retrieved on August 20, 2004 from: <http://www.who.int/mediacentre/factsheets/fs218/en/>

The World Health Report (2001) Mental Health: New understanding, new hope. respecting human rights. Retrieved on August 20, 2004 from: <http://www.who.int/whr2001/2001/main/enchapter4/004a5.htm>

Copyright of International Journal of Psychiatric Nursing Research is the property of International Journal of Psychiatric Nursing Research. The copyright in an individual article may be maintained by the author in certain cases. Content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.