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Introduction

Admission to a hospital can be a stressful time for any patient and their family, friends and associates. Staff and professionals interacting with the patient can also experience stress and frustration, especially if the patient is in a heightened state of distress that manifests as anger or apathy. In addition to the disruption of familiar routines, any form of hospitalization comes with an invasion of privacy and autonomy, typically of the most personal and intimate of details. Frequently, these invasions include sharing a room with another person, restrictions placed on everything from what one eats to where one goes, to overseeing with whom one communicates. Additionally, invasive monitoring of one's bodily functions, repeated blood pressure and temperature readings, detailed accounting of urine and bowel movements can be routine during hospitalizations. Many individuals, if given the option, would avoid going to a hospital at all cost, due to the inhospitable nature of the setting.

Hospitalizations for a mental illness are more invasive and disempowering for patients and their families than hospitalizations for any other health condition. Hospitalization for a mental illness is frequently an unplanned and unscheduled event. Routinely, individuals with a mental illness are hospitalized against their will through legal procedures that vary from state to state, but which allow for forced or involuntary admissions. Contrasting the kind of care given to individuals with major physical health emergencies brought by supportive emergency medical technicians, being transported to a psychiatric hospital handcuffed and in the back of a police car, is not an uncommon experience for a person with a mental illness. During their stay in the hospital or other inpatient facility, individuals with a mental illness are likely to experience a variety of coercive measures and infringements upon their personal liberties that are unlike anything most individuals ever experience in a routine hospitalization. Such experiences may include forced medications, being physically restrained to a bed or a chair for a period of time, having personal possessions items taken from them, or experiencing isolation or seclusion, cut off from anyone else including fellow patients, hospital staff, family, and friends.

Under such circumstances, patients with a mental illness have been documented to experience a range of emotional reactions including loss of self-esteem, identity, self-control, and self-efficacy (Brophy and McDermott 2003; Danzer and Wilkus-Stone 2015; Hughes et al.

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2009; Rymaszewska 2007). Others have reported patient feelings of distress, sadness, and humiliation (Kuomanen et al. 2007), while patients have described hospitalization as depressing, unpleasant, and harmful (Olofsson and Jacobsson 2001). Such negative patient reactions are exacerbated when the patient is involuntarily hospitalized (Danzer and Wilkus-Stone 2015) and/or exposed to coercive treatment interventions, such as seclusion and restraint (Danzer and Wilkus-Stone 2015; Olofsson and Jacobsson 2001) and forced medication (Danzer and Wilkus-Stone 2015; Vuckovich and Artinian 2005). The immediate and long-term impact of these negative patient experiences upon their treatment engagement and the subsequent course of their treatment are significant, leading to a distrust of health care providers and provider systems, a disinclination to adhere to treatment protocols, or an unwillingness to seek out treatment when needed.

Given these considerations, strategies that can support patients to retain a certain degree of decision-making power and autonomy during periods of psychiatric hospitalization are essential. Maintaining as much decision-making power as possible while hospitalized reduces the degree of learned helplessness and institutionalization that patients experience. Additionally, research has demonstrated that patients' satisfaction with their psychiatric hospitalization, including those who were hospitalized against their will, can be attenuated by a variety of procedures. Patient satisfaction can be influenced by increasing (a) the information that is provided to the patient about various aspects of their hospitalization and treatment, (b) the degree to which health care providers treat the patient and family members with respect and engage them in the decision-making processes, (c) the degree to which the patient feels welcome, and comfortable, (d) the degree to which the facility operates with a set of rules and policies that are transparent and promote procedural justice and fairness, and the degree to which the facility provides a safe and structured set of activities and treatment programs, and (e) the degree to which the staff members support and relate to patients.

Even in the face of involuntary hospitalization and coerced treatments, such as medication and seclusion and restraint, patients can experience both satisfaction and empowerment during their psychiatric hospitalization.

In this chapter, we contextualize the actualization of empowerment and self-advocacy among persons with a mental illness during a period of inpatient treatment and hospitalization. We begin by contextualizing the experience of psychiatric hospitalization and highlighting the common experiences of hospitalized patients that impinge upon their autonomous decision-making abilities, such as involuntary hospitalization, seclusion and restraint, and coerced treatment. Next, we provide a framework for autonomous decision-making and self-advocacy within the context of inpatient settings. This framework provides a definition of self-advocacy and empowerment, the legal basis for such rights, and a summary of research that has been conducted on strategies for promoting self-advocacy and patient empowerment. Finally, we summarize organizational and patient-level strategies that can help promote patient self-advocacy.

Elements of Psychiatric Hospitalization that Impede Autonomous Decision-Making

The perceived or real threat to a patient's autonomy and empowered decision-making regarding their treatment are significant during their period of hospitalization. All too often, such hospitalizations occur against the wishes of the patient, and they frequently involve law enforcement along with a judicial order remanding the individual to the custody of the hospital for a specified period of time for observation and/or treatment. During this period, the individual may experience a variety of infringements against their personal liberties and decision-making capabilities along with degradation of basic human dignities. In fact, feelings of disempowerment and lack of control over their treatment is a pervasive and recurrent theme among patients hospitalized for a psychiatric

condition (Katsakou et al. 2012). The three most common ways in which patients' rights and liberties are restricted during a psychiatric hospitalization include involuntary hospitalization, seclusion and restraint, and force or coerced treatment, including medication and electroconvulsive therapy (ECT).

Involuntary Hospitalization

The involuntary hospitalization of individuals experiencing psychiatric symptoms has a long history in the United States and throughout the world. Despite its longstanding tradition, the practice remains highly controversial on a variety of moral and legal grounds (Dennis and Monahan 1996; Taylor and Bentley 2004), including evidence that involuntary commitments severely strain patient-provider relationships and further exacerbate an already deep reluctance to seek professional help (Danzer and Wilkus-Stone 2015; Jarrett et al. 2008).

Reported prevalence rates for involuntary admissions ranged between 4.4 and 36 % of all psychiatric hospitalizations in a comparative study of the countries comprising the European Union (Salize and Dressing 2004). The 10-year involuntary admission rate in Israel was reported to be 32 % of all psychiatric admissions for the period of 1991–2000 (Bauer et al. 2007). Most notably, a growing utilization of involuntary admissions was observed, climbing from 23.9 % of all admissions in 1991 to 38.1 % in 2000 (Bauer et al. 2007). This study also identified a variety of risk factors predicting involuntary hospitalizations, including a native-born Jewish male, aged 18–24 or 65 and older, single, less than 8 years of education, and diagnosis of schizophrenia or delusional psychosis (Bauer et al. 2007). Ironically, and unfortunately, comparable information on the rates and trends in involuntary hospitalizations in the United States is lacking (Riecher-Rossler and Rossler 1993).

A report issued by the Treatment Advocacy Center analyzed the quality of commitment laws throughout the United States, assigning letter grades to each state's quality of their inpatient

commitment laws and their utilization of those laws (Stettin et al. 2014). Three forms of commitment laws were evaluated, including those governing inpatient commitments, outpatient commitment, and emergency evaluations. The evaluative scoring of the states and the various elements of involuntary commitment varied widely. However, no state received an overall grade of "A" and, in fact, 17 states were assigned an overall grade of "D" or "F". In interpreting their results, the authors noted, "...the quality of the civil commitment laws in the vast majority of states remains far below what is necessary to provide a readily accessible path to treatment and recovery for individuals with the most severe mental illnesses who are unable to seek care for themselves" (Stettin et al. 2014, p. 25).

A number of qualitative studies, the majority of which have been conducted in European countries, has captured the emotional and psychological state of these patients at the time of their commitment and, later on, at the time of their discharge. At the time of their commitment, the majority of patients who were involuntarily admitted were displaying acute psychotic symptoms, violent acts, or suicidality (Johnsen et al. 2007). Most involuntarily committed patients retrospectively described being unwell and/or at risk at the time of their admission, and acknowledging their inability to accurately assess their mental or emotional state at the time of their admission (Katsakou et al. 2012). In a qualitative study of involuntary psychiatric hospitalizations, patient's narratives revealed four overarching experiences, including: not being respected as a human being; not being involved in one's own care; receiving care that the patient perceived as meaningless or not good; and being an inferior kind of human being (Olofsson and Jacobsson 2001).

Not surprisingly, individuals who are the subject of involuntary hospitalization commitment proceedings frequently express significant feelings of distress, anger, and betrayal at the time of their commitment. Loss of self-esteem, identity, self-control, and self-efficacy as well as diminished hope in the possibility of recovery have all been reported as affective dimensions of patients' experiences from involuntary

hospitalizations (Brophy and McDermott 2003; Danzer and Wilkus-Stone 2015; Hughes et al. 2009; Rymaszewska 2007). Interestingly, a consistent finding from this research is patients' retrospective acknowledgement of the appropriateness or justification for their forced treatment (Danzer and Wilkus-Stone 2015; Hopko et al. 2002; Katsakou et al. 2012). In fact, it has been reported that between 39 and 75 % of patients who were involuntarily hospitalized for their psychiatric illness reflected that their hospitalizations were appropriate (Katsakou et al. 2012).

Seclusion and Restraint

In addition to the experience of involuntary hospitalization, seclusion and restraint can be common experiences of psychiatric hospitalization. Restraint can involve either physical, mechanical, or chemical impediment of the patient, with the latter expression also referred to as sedation. Physical restraint involves the manual or mechanical restriction of movement and physical action of the patient, including such devices as leather cuffs and belts as well as locked and secured hospital units (Kaltiala-Heino et al. 2003; Lee et al. 2003; Mayers et al. 2010). Seclusion involves the placement of the patient in a locked room from which free exit is denied, and is thought to provide containment, isolation, and sensory stimuli reduction (Kaltiala-Heino et al. 2003; Meehan et al. 2000; Mayers et al. 2010; Morrison and LeHane 1995; Wynn 2002).

The involuntary physical or chemical restraint of the psychiatric patient and/or the forced isolation or seclusion of the patient is reserved and justified in the cases of patients whose behavior is viewed to be extremely violent toward self or others, or disruptive to the therapeutic milieu. Obviously, such extreme measures are highly restrictive and seriously undermine any sense of patient autonomy or empowerment. Ironically, little research has been conducted on the relative prevalence of these practices, and there appear to be minimal safeguards in place to ensure their appropriate application.

As reported by Hendryx et al. (2010), 2–6 % of all psychiatric patients will experience seclusion or restraint during their period of hospitalization (Busch and Shore 2000), with some older research evidence suggesting that a small proportion of patients may disproportionately account for a large amount of the seclusion and restraint incidents (Hendryx et al. 2010). Larger psychiatric hospitals have reported median rates of 3.65 and 4.61 days of seclusion and restraint incidents, respectively, per 1000 patient days. For the patient experiencing seclusion, research has indicated that the average duration of each episode is approximately 17 h, and that cumulatively, such patients may experience 67 h of seclusion (Hendryx et al. 2010). Within the same study, patients were estimated to experience an average of 22.1 h of restraints per episode, and an average of 115.9 h of restraints cumulatively over the hospitalization experience. As such, research suggests that the use of seclusion and restraint, while a relatively infrequent occurrence among patients hospitalized with a psychiatric condition, tends to be clustered among a small subset of patients. Further, this research suggests that patients may be secluded or restrained upwards for a full day when it occurs.

Coerced Treatment

Forcing or coercing a patient to receive treatment regardless of whether they have been court ordered to an inpatient facility is a highly controversial issue. Psychiatric patients may be pressured or forced to engage in programs, undergo procedures (such as electroconvulsive therapy—ECT), or take medications against their wishes. Psychological coercion in which the patient is pressured by family members or friends to comply (Kuosmanen et al. 2007; Strack et al. 2007; Strack and Schulenberg 2007). Coercive treatments have been described as intended to treat, help or cure the patient, regardless of the level of patient resistance, whereas coercive measures (i.e., seclusion and restraint) are often applied to control behavior or agitation (Kaltiala-Heino et al. 2003). Involuntary

or forced medications, the most common form of coerced treatment, has been seen as unnecessarily coercive, traumatic, and even punitive (Kaltiala-Heino et al. 2003). Olofsson and Jacobsson (2001) reported that approximately 1/5 of the patients did not know the reason for being subjected to coercion.

High levels of perceived coercion were found to exacerbate the negative effects of custodial institutionalization on personality, the patient's view of their inpatient hospitalization, and pre-existing hostile-dominant traits of some patients' personalities (Anestis et al. 2013; Danzer and Wilkus-Stone 2015; Georgieva et al. 2012). Patients reported experiencing fear and anger (Lucksted and Coursey 1995; Olofsson and Jacobsson 2001). The effects on the staff that use coercion are unknown (Kaltiala-Heino et al. 2003). Patients also reported that coercion and forced treatment negatively impact their relationship with the person(s) identified as initiating the pressure or force (Olofsson and Jacobsson 2001; Lucksted and Coursey 1995). Furthermore, studies indicate that the patient's legal status (i.e., voluntary versus involuntary) was not predictive of the patient's perception of being coerced (Eriksson and Westrin 1995; Lidz et al. 1995; Rogers 1993; Stender et al. 1997).

Patients who perceived less coercion tended to feel respected, treated fairly, and were more involved in decision-making processes concerning their treatment (Anestis et al. 2013; Danzer and Wilkus-Stone 2015). Programs that focus on coercion, and recognize that patients who refuse services are not a homogenous group and that there is a greater need to understand a patient's motives and reasons for the rejection, have shown success in using alternatives to coercion (Kaltiala-Heino et al. 2003).

Legal and Ethical Standards of Patient Autonomy

A cornerstone of the community's mental health movement of the past half century in this country and others has been rights of direct service

recipients to make meaningful, informed decisions about their care, their selection of providers, and the course and methods of their treatment. Emerging out of the civil rights movement of the 1960s, a variety of empowerment and self-advocacy voices began to be heard, including those of Ed Roberts and Judi Huemann that lead to the formation of the Independent Living Movement for people with physical disabilities. For people with psychiatric disabilities, the movement for patient empowerment and decision-making first began in Portland, Oregon by the likes of Dorothy Weiner, Tom Wittick, and Howard Geld. Mr. Geld, more commonly known as "Howie the Harp." The resulting manifesto of the psychiatric patient's movement was published by Chamberlain (1979) under the title, *On Our Own: Patient Controlled Alternatives to the Mental Health System*.

The growing mobilization and strength of people with physical and psychiatric disabilities set the stage for a number of legislative and judicial enactments that provide a framework for the recognition and protection of the individual rights and privileges of all Americans, regardless of their abilities and disabilities, including the Americans with Disabilities Act of 1990 (ADA), the Patient Bill of Rights of 1998, and the *Olmstead v. L.C.* case of 1999. Most significantly, *Olmstead* ruled that the unjustified segregation of persons with disabilities violated Title II of the ADA and required public entities to provide community-based services when such services are appropriate.

In 2003, the President's New Freedom Commission on Mental Health (2003) provided additional structure for the framework of a comprehensive, patient empowered mental health system in America. The Commission declared that the focus of services should be on recovery rather than symptom management, adding that the system presents barriers, which all too often add to the burden of mental illnesses for individuals, their families, and our communities. Consumers and family members are to "have access to timely and accurate information that promotes learning, self-monitoring, and

accountability” and individualized plans of care developed “in full partnership with consumers and families”. The partnership of personalized care outlined in the report hinges on choice of the health care professionals on the team, what and how care is to be provided, shared decision-making and providing persons with the option to agree or disagree with the treatment plan, and making available the highest quality of care and information to individuals and families, regardless of their race, gender, ethnicity, language, or place of residence. Implementing these recommendations from the President’s New Freedom Commission can stimulate inpatient psychiatric facilities to become recovery-focused and person-centered. Implementing treatment planning processes that share decision-making with patients, their representatives, and the provider staff of the facility, can significantly improve patient outcomes, patient satisfaction, staff morale, while reducing critical incidents and hospital readmission.

Strategies for Promoting Patient Autonomy and Decision-Making

A variety of strategies and approaches can facilitate the maximization of patient involvement and empowered decision-making during periods of psychiatric hospitalization. As noted in the preceding section, evidence demonstrates the value of maximizing patient decision-making and empowerment during such hospitalizations, resulting in a more satisfied patient, reduced rates of seclusion and restraint, and staff and patient injuries. Furthermore, evidence suggests that patients who experience greater decision-making and empowerment during their hospitalization are significantly less likely to be readmitted to the hospital. As health care providers face increasing scrutiny and financial penalty for patient readmissions, maximizing patient empowerment during psychiatric hospitalizations can be viewed as an insurance policy against such financial risks.

In this section, we present a variety of strategies that inpatient psychiatric facilities can take to support the decision-making and

empowerment of their patients. These strategies must begin with an orientation of the hospital ward milieu that is embracing of a strengths-based, recovery-enabled approach to the care and treatment of people with psychiatric disabilities. Within this recovery culture, a variety of physical, programmatic, and provider/staff changes in policies and procedures have been shown to maximize the empowered decision-making of patients (Rider et al. 2000).

Similarly, there are strategies that patients, along with their family members and other caregivers can take to maximize their empowered authority during a psychiatric hospitalization. These strategies should be activated during periods of psychiatric stability and prior to hospitalization to ensure that a patient’s informed treatment choices are duly recorded and legally recognized.

Facility and Staff Cultural Orientation

The dichotomy of how a patient is viewed and treated by medical personnel when hospitalized on a medical/surgical unit compared to a patient with a serious mental illness who is experiencing a relapse of a chronic medical condition on an inpatient psychiatric unit provides the backdrop for the needed shifts in staff approach, cultural orientation, physical plant design, programming and policies.

Staff view patients on medical/surgical units as having a physical injury or ailment to their body. Typically, there is no blame associated with their condition nor are they shamed when they have to be readmitted for a relapse or due to complications associated with their condition. In contrast, staff view psychiatric patients on a psychiatric unit who may cycle in and out of the facility as somehow responsible for their condition. For example, the patient may be seen as malingering, attention seeking, seeking refuge, or non-adherent with medications or with treatment more generally. In reality, the patient may not have stable housing, employment, or other adequate supports and services in the community that precipitated his or her relapse.

Patients with co-occurring substance use disorders are often faced with additional stigma and may be blamed and shamed by inpatient treatment teams, community treatment staff and by family members. Co-occurring disorders can be a significant precipitator to an individual's relapse and a significant challenge to address in inpatient settings. Inpatient staff need to recognize and address the hopelessness that one feels when they have relapsed. Often substance abuse is a primary issue that prompted the need for hospitalization, yet service and discharge planning processes fail to recognize it as a coping mechanism or examine the underlying issues that need to be addressed in a holistic and recovery-oriented approach. Acute intoxication is likewise one way that individuals are frequently screened out for inpatient treatment and other services.

Reframing how patients on psychiatric units are regarded is clearly needed. Supervisors and co-workers need to hold each other accountable for creating an environment that is recovery-oriented, strength-based and patient empowered. Consistent with the President's New Freedom Commission on Mental Health (2003) report, inpatient facilities should offer patients choice of who is on their team, what and how care is to be provided, opportunities for shared decision-making, an option to agree or disagree with the treatment plan, and making available the highest quality of care and information to individuals and families.

Gordon (2005) reported that mental health professionals' attitudes toward consumers' participation in service management, planning, and involvement in their care and treatment adversely impacts consumer involvement on inpatient psychiatric units. Inpatient facilities can empower and support self-determination by using a person-centered or patient-centered planning (PCP) approach. Stewart et al. (1995) focused on six interrelated concepts in patient-centered care: (1) exploring both the disease and the illness experience; (2) understanding the whole person; (3) finding common ground regarding illness management; (4) incorporating prevention and health promotion; (5) enhancing the provider-patient relationship; and (6) being

realistic about limitations and issues, such as the availability of time and resources. The interactions of these concepts include patient-as-person, clinician-as-person, shared power and responsibility, therapeutic alliance, and biopsychosocial model of health and illness.

The challenges to using a PCP approach in an inpatient setting may include the following: the patient's mental status (e.g., feelings of anger, betrayal, resentment, mistrust, lack of insight, and substance withdrawal issues); short length of stay and court time frames that require certain processes to occur in an expeditious manner; a focus on symptom reduction and discharge issues (e.g., lack of permanent housing); and family issues (e.g., availability during treatment team meetings and involvement, especially if they initiated the court ordered treatment). There are also opportunities to reduce these obstacles and facilitate the cultural shift to empowering patients and families in directing their care. Peer and family support on the units can aide in establishing rapport and bridge the transition to the community. Psychiatric rehabilitation and biopsychosocial models can be incorporated in the groups and inpatient programs. Ultimately the staff must shift their beliefs and recognize that the person is the expert in their own care and the family is a strength. Shifting power and the role of service providers to one that resembles a "consultant" who provides information, education and choice to support informed decision-making and not be a decision-maker or custodian responsible for directing and protecting the individual is critical. The PCP process itself promotes recovery, interdependence, accountability, personal responsibility, empowerment, self-advocacy and growth. Instituting a culture that supports the principles and practices of PCP starts with the executive leadership who must buy into the same philosophy.

Strength-based systems of care within hospital settings focus on the innate wisdom and strengths of individuals. While inpatient services are designed to support individuals when their symptoms put them at risk of harming themselves or others, the majority of patients are still able to communicate their preferences, hopes,

and needs. When staff assume that patients are unable to offer valuable insight into who they are and what helps them, they remove the patient from being an important team member from their treatment team. Walsh and Boyle (2009) conducted focus groups to explore psychiatric inpatients' strategies for coping with a mental illness and identifying opportunities for acute inpatient psychiatric hospital services to facilitate the patient's recovery and empowerment. The main areas of concern for the patients were related to lack of information, communication, relationships, activities, self-help, patient involvement in care treatment plans, and the physical environment.

The lonely hours spent while in the hospital setting can be overwhelming and create strong feelings of hopelessness. Being able to have a connection to even one individual on the team will help the patient believe they are worthy of attention and kindness. As the relationship is created through interactive engagement, patients become invested in their care, their progress, and adherence to the plan that they have contributed to. Staff members can engage with the individuals they serve on at a human level as well as at a professional level. Further, an individual that demonstrates a firm, unending belief that recovery is possible for the patient even in the face of overwhelming illness, is identified as the most significant contributor to an individual's recovery (Detillion et al. 2004; Frankel et al. 2005).

McCann et al. (2008) examined 47 mental health professionals' attitudes towards consumer participation in two inpatient psychiatric units using the Consumer Participation and Consultant Questionnaire. They reported favorable attitudes toward participation in management such as identifying quality services and having a say in determining the delivery of services, care and treatment, and mental health planning. However, they were less supportive regarding matters that directly or indirectly related to their areas of responsibility, authority or expertise (e.g., access to medical records, prescribing medications and staff education) and expressed uncertainty whether consumer involvement would increase the stress levels among staff. Recommendations

included developing guidelines for meaningful consumer participation on inpatient units, educational preparation for mental health professionals and the need for the mental health professionals to explore and discuss their own beliefs and practices regarding consumer participation.

Inpatient providers have also voiced an internal conflict between their need to protect and their desire to support a person's autonomy (Pellegrino and Thomasma 1987; Schwartz et al. 2013) and, if medicine is to achieve its goal of healing, these duties cannot remain in conflict (Pellegrino and Thomasma 1987). To support empowerment and create opportunities for patients to make decisions regarding their care, the inpatient staff and the milieu must espouse an orientation that is strengths-based and recovery-oriented in their approach to the care and treatment of people with psychiatric disabilities. Participatory dialogs is one organizational strategy that has been identified as a method to address this tension and create avenues for incorporating the principles and values of recovery to empower patients and improve inpatient care.

Participatory dialogs have been used in training mental health professionals and also in research and evaluation as a method to examine satisfaction with services. The SAMHSA (2012) guide, *Participatory Dialogues: A Guide to Organizing Interactive Discussions on Mental Health Issues among Consumers, Providers, and Family Members*, identified four goals: (a) to create better understanding and mutual respect among consumers, family members and professionals; (b) allow participants to speak from their experiences and belief systems in a safe atmosphere; (c) create partnership ventures through compromise and consensus; and (d) change attitudes and practices in the mental health system

Schwartz et al. (2013) used a provider-consumer dialog process to create positive changes in professional attitudes and consumer empowerment by exploring the tensions and personal values related to recovery in an institutional setting. This consumer-provider knowledge

exchange facilitated the development of patient–staff partnerships to support a recovery-oriented model of care. One of the former patients in the Schwartz et al. (2013) study provided the following insight, attesting to the dichotomy that exists within an inpatient setting: “I discovered that the idea of consumer empowerment is difficult for the clinician, who must give up some of his or her own power and, at the same time, readjust the understanding of responsibility toward the client”. Others voiced stories of feeling misunderstood and needing for their experiences to be acknowledged and not just their symptoms as exemplified by the following statement, “If you’re a crazy person and you scream, all they hear is the scream ... and you’re pathologized for being angry and having an emotion” (p. 114). Patients reported that they felt that providers’ stories took down the “shields of the profession and helped humanize the field of psychiatry” (Schwartz et al. 2003, p. 114). The researchers concluded that by naming and addressing inter- and intra-personal tensions, exploring divergence in values, openly addressing clinical concerns and risk, and including people with lived experience of mental illness in the design and delivery of services recovery-oriented care can be facilitated within institutional contexts.

Wadsworth and Epstein (1998) used a two-phased approach to build routine methods for staff at a major public psychiatric hospital to seek and receive consumers’ evaluative feedback and collaborate with the patients to make changes to services as a result of the feedback. The first phase included a dialog to exchange experiences and thinking between staff and consumers. The second phase explored how staff–consumer feedback could be incorporated into the organizational structure and culture. The researchers found that staff were “dismayed by their own disempowerment within the service services and structure” (Wadsworth and Epstein 1998, p. 359). Based on the findings, the researchers identified four essential sites for supported dialogs to occur: (a) organizational decision-making forums, such as hospital program and management meetings, board

meetings, staff selection and ethic committees, and feedback mechanisms; (b) staff–consumer dialog forums to examine beliefs, undiscussables and share thinking and assumptions; (c) consumer-only forums to provide emotional support to build on strengths to participate in such dialogs; and (d) staff-support methods, such as forums or other structures to support the staffs’ needs. Emotional responses staff wanted to speak about included their fear, anxiety, rage, frustration and feeling of being treated badly. They felt these areas were forbidden to discuss, as it would dismantle their authority, and the construct between the “us”—the health professionals who are responsible, in control, competent—and “them”—the sick, emotional, dependent, incompetent and irrational patients (Wadsworth and Epstein 1998).

Organizational Policies and Procedures

To transform services and embed a recovery philosophy of care, administrators and clinicians need to partner with patients to consider how recovery can influence an inpatient hospital’s policies, practices and environments (Smith and Bartholomew 2006). Modifying the development and review process of an inpatient facility’s policies and procedures to incorporate patient input is another key organization strategy that an inpatient hospital should implement to establish a recovery-oriented culture that increases avenues for patient empowerment, strengthens opportunities for self-advocacy, and supports self-determination and shared decision-making processes. Critical areas that should be examined include, but are not limited to, policies and procedures that relate to seclusion and restraint, medication management, collaborative documentation (which levels the playing the field and reduces secrecy when read to the patient), service and discharging planning, critical incidents and debriefings, and advanced directives.

Seclusion and restraint must be viewed as a treatment failure, and policy and procedures clearly need to be aligned with a “no force first” philosophy. Reductions in seclusions were found

after suggesting changes in the seclusion procedure to focus on better assessment and communication (Olofsson and Jacobsson 2001) and interventions to reduce the use of seclusion and restraint have been shown to be effective (Hendryx et al. 2010). Debriefing every incident with the patient and staff involved is critical. In addition, advanced directives can reduce the number of restraints and the need for seclusion. Staff initially may be concerned with the adoption of a no force first or zero restraint approach; however, it has been found that staff injuries actually go down if properly implemented.

Medication management and the associated policies should include expectations that the patient, psychiatrist, inpatient team, peer support specialist or advocate (upon request) participate in the discussions and decisions regarding education, initiation, modification or discontinuation of prescribed medication while hospitalized and prior to discharge. When forced medications are required, the patient should be involved to the greatest extent possible. Respecting the patient's autonomy when administering involuntary medications may seem like a contradiction, although it is possible to empathetically give the patients the choice between oral and injectable medications (Danzer and Wilkus-Stone 2015; Vuckovich and Artinian 2005).

Physical Plant and Environmental Programming

The physical structure of inpatient unit is important and can create barriers to self-advocacy among patients or it can create the kind of environment that empowers all of the people within it to engage, interact, and self-advocate. For the individuals being served on the unit, the physical barrier creates an "us versus them" environment. Patients feel separated from staff members and they see them as unreachable behind the glass.

An unexpected area that either contributes to or creates barriers against good self-advocacy for individuals who are being supported within an inpatient unit is the physical make-up of the units

and the environment within them. Within a hospital setting, barriers include the nurses station being a bubble—a glassed-in enclosure surrounding an area where nurses make notes, review charts, and engage with other staff members. Nursing stations that are enclosed create both a physical and an emotional barrier for both the staff and the patients.

The staff can remain inside their bubble and never allow themselves to get to know the patients on the unit. Engaging with and taking an active role in the wellbeing of the patients can increase satisfaction with one's work, as they interact and directly support individuals from admission to hospital discharge. While the nurses remain in their bubble, the emotional barrier prevents them from easy access to the very people who need them. Remaining inaccessible within a closed space prevents the development of relationships and reduces the chance for a working alliance to develop between staff and the patients. One might think that due to the patients' severe symptoms while hospitalized, there is no chance that a working alliance could develop. However, evidence has shown that severity of symptoms does not affect the development of a therapeutic relationship and that therapeutic relationship forms the foundation for a working alliance (Horvath 1994).

While there is a need for safety in units, a balance must be struck between harsh and uninspiring surroundings and beautifully designed units that are pleasing to the eye and comforting to the soul. The idea of *healing spaces* includes the physical space, the staff demeanor being kind, respectful, and hopeful, as well as a culture of recovery in which everyone on the team believes that recovery is possible for every patient. Spaces that are quiet, and policies that ensure flexibility with family visits, support the recovery of patients and provide comfort to family members. Family members and friends must have the same access to loved ones as exists within hospitals providing physical health care. The love and support from family and friends lead to higher levels of recovery as they do for patients recovering from a host of physical health concerns. Family, friends, and peer support workers on the unit can increase the

number of hopeful relationships that each patient has while in the hospital.

Having one set of standards for physical health care needs and another for psychiatric health care needs establishes stigma, and is a subtle form of discrimination. “A recurrent theme that runs through the mental health literature is the stigma attached to mental illness...” (Curtis et al. (2009). Identifying people with serious mental illness as somehow inherently dangerous or deviant has historically influenced the development of hospital environments. While many hospital environments no longer use a circular structure, it is not uncommon to see a centralized nursing station enclosed with glass from which staff can observe the activities of patients. The design that creates an observation point diminishes interaction, relationship, and thereby recovery. It is important that psychiatric hospital spaces support the privacy and independence of the patients. Supporting independence helps people to not lose touch with their life in the community. Today, the need to stay connected to the world using social media and email is important to many people. Having computers on each unit for patient use can assist in keeping them connected to their social supports.

Many studies have demonstrated the health benefits of healing spaces in a hospital setting (Francis and Glanville 2001; Ulrich 1984; Ulrich et al. 1991; Whitehouse et al. 2001). Soft furniture, open spaces and bright sunlight can improve the atmosphere of the hospital. Offering pleasant garden spaces, having indoor plants, or water features can contribute to a comforting supportive atmosphere. At the heart of the healing space is access to staff the reduction of barriers to relationships needed to support the patients to be able to practice good self-advocacy.

Services and Treatment Programming

The inpatient milieu including psychological, physical, social, political, and spiritual components of the hospitalization experience is more

than a mere predictor of patient satisfaction—it is a central experience in the patient’s hospitalization and has as much potential for destruction as it does for healing and remains an important but often neglected component of psychiatric treatment (Thibeault et al. 2010). A concerted effort to provide a welcoming and compassionate environment is needed as a part of the patient’s admission, introduction, and orientation to the unit.

The admission process can be overwhelming to anyone and especially to a patient who may be embarrassed, scared, distraught, experiencing severe symptoms, or brought to the hospital against their will. Staff should be patient, speak in a non-brisk manner, and recognize that an individual in an acute crisis may not be able to take in/process all the information being presented or may have trouble reading materials received in their admission packet. In order to support the person in making informed decisions regarding their care and ensure informed consent is provided, staff may need to wait until acute psychiatric symptoms that interfere with the patient’s cognitive processing (e.g., thinking clearly, processing information, paying attention or remembering information) or inhibit their ability to engage in a dialog (e.g., due to intoxication, hallucinations, delusions or paranoia) have diminished. Staff should consider repeating the entire admission process at a time when the patient is able to fully process the information while also allowing ample time for the patient to ask questions. Relatives and carers accompanying the patient should also be provided information about the hospital regulations, provision of services and treatment, carer support services and the opportunity to ask questions (Walsh and Boyle 2009).

It is important to orient the patient to inpatient setting by showing them around the unit and to acquaint them with the unit’s rules and protocols. Patients should be reassured that, in addition to their mental health concerns, their physical problems will be identified and addressed (Walsh and Boyle 2009). They must also be informed of their patient rights including the complaint procedure.

When appropriate, each of the members of the inpatient team should be introduced to the patient and their roles reviewed. Walsh and Boyle (2009) recommended that independent support should be provided (e.g., by an advocate, peer support specialist) and professionals (e.g., psychologists, psychotherapists, dual diagnoses experts) should be readily available.

The inpatient program needs to provide multiple activities focused on engaging the patient and offering a menu of services designed to empower and support self-determination in all aspects of care. The language used by medical staff and the services provided should be recovery-focused and it is essential for staff to continuously seek out the person's strengths rather than concentrate only on the deficits and symptomology of the illness. Strategies to reduce patients' experiences of vulnerability and abandonment, and strengthen processes that create a sense of connectedness, engagement, and affirmation should be instituted (Thibeault et al. 2010).

Boredom in the hospital can be detrimental to the patient and there needs to be opportunities for creativity that are age appropriate. Kiosks that allow a patient to explore information at their own pace and computer-/phone-based apps on topics such as recovery, health and wellness, and services available in the community can address not only monotony in an inpatient setting but can also be educational and empowering.

Staff should also recognize that people in crisis often turn to a "higher power" or seek a spiritual connection and find healthy ways to support the individual's needs instead of judging or trying to assess if their quest is "good or bad" or a byproduct of the mental illness. Non-denominational, faith-based, spiritual and religious materials and resources should be available on the unit in addition to traditional Christian-based information.

Patients report that their relationship with the nurses and clinicians is a key aspect of the inpatient milieu, and their person-to-person interactions on the inpatient unit creates meaning for them (Thibeault et al. 2010). Lack of privacy, the presence of specific barriers to

movement, and physically separate spaces for staff and patients are symbols of social separation, power imbalance, and erosion of personhood. Danzer and Wilkus-Stone (2015) found that patients were more satisfied when they experienced a hospital environment that was warm, friendly, safe, comfortable, and accommodated their individual needs based on reasonable rules and prepared them for discharge. Patients reported the needed for inpatient staff to help them settle into daily routines and get involved in structured daily activities. Activities, such as making art projects, taking walks, and playing games, were reportedly helpful for patients who were less verbal.

Another opportunity for patients to be empowered is to provide them avenues to participate in the decision process and negotiation of medications at initiation, when dosages are modified, and prior to discontinuation. Information on the reasons why a change of medication is being recommended should be provided, all concerns of the patient should be addressed, and user-friendly materials on medications also should be provided (Walsh and Boyle 2009). One study found that patients become highly reluctant and refuse medications when their autonomy is not respected during medication processes (Danzer and Wilkus-Stone 2015).

Walsh and Boyle (2009) endorsed negotiating the timing of discharge with each patient, with ample time allowed for consideration of practical arrangements regarding their returning home (e.g., taking into account patient's financial situation, issues with utilities, ensuring there is adequate food at home). Discussing with the patient a comprehensive discharge plan including involvement family, follow up services needed including support groups and outpatient mental health services. Discharge planning should start at the earliest opportunity to alleviate patients' fears and anxiety.

Peer Support Specialists

A Peer Support Specialist can help facilitate self-advocacy of all inpatients. A peer support

worker is an individual who is in recovery from mental health challenges, addiction, or a co-occurring mental health and addiction challenge. They work with individuals in a manner that validates the lived experience of having been in a psychiatric hospital or otherwise treated for mental health challenges, addiction challenges, or co-occurring challenges of mental health and addiction. Their job description includes spending time with individuals they are serving. They can talk with people help them practice what they want to say before meetings with treatment team members, support them in those meetings, and just be a good listening ear. The mutuality puts them on equal footing with those they serve and their lived experience is the key to an almost instant relationship. Another aspect of peer support is their value as an example that recovery is a fact, and once the people they are serving understand that they are in recovery, it ignites an inextinguishable spark of hope. The role, responsibilities, and outcomes of using peer support specialists inpatient psychiatric hospitals is covered in great detail by Franczak and Dye (2016) in this book.

Psychiatric Advance Directives

Enacted in 1990, the Federal Patient Self Determination Act addresses the rights of health care users (including mental health care) to stipulate in advance how they would like to be treated by health care providers when they are incapacitated and offset the perceived imbalance between health care consumers and providers. Under this federal law, an advance directive is defined as: “A written instruction, such as a living will or durable power of attorney for health care, recognized under state law (whether statutory or as recognized by the courts of the State), relating to the provision of health care when the individual is incapacitated” (42 USC § 1395 cc(f)(3)). Although this Act did not grant additional individual rights as this is still under the authority of state law, the federal law did require policies and procedures on advanced directives be developed by hospitals and other providers (including

psychiatric hospitals and other mental health providers) and healthcare plans. The right to accept or refuse medical treatment and have an advance directive and/or appoint a health care agent is mandated in state law. However, federal and state laws do not require individuals to complete any form of advance directive nor can advanced directives be required as a requisite for treatment.

The federal law also specifies mandates for entities in order to be paid under Medicare or Medicaid, including (1) written policies and certain procedures with respect to advance directives, (2) document in the patient’s medical record whether or not the patient has executed an advance directive, (3) comply with all State laws regarding advance directives, (4) not condition the provision of care or otherwise discriminate against an individual based on whether or not the individual has executed an advance directive, (5) inform the individual that complaints concerning implementation of these advance directive requirements may be filed with the state agency that surveys and certifies Medicare and Medicaid providers, and (6) provide staff and community education on issues related to advance directives. These mandates encompass both medical advanced directive and psychiatric advanced directives as individuals with mental illness have equal rights under this law.

Within federal law, and most state laws, individuals are allowed to combine advance healthcare decision-making and advance mental healthcare decision-making in one document or they can establish separate advanced directives. A single care agent may be appointed to address both health and mental health care issues or two different agents may be identified. Currently, there are 25 states that have adapted specific Psychiatric Advance Directive (PAD) statutes. PADs are legal documents that empower individuals to specify their wishes for future psychiatric care and appoint a proxy to make decisions should a crisis arise in which they become acutely ill, incapacitated and unable to express their desires. PADs allow individuals to plan for a crisis when they are feeling well and support the recovery process after a crisis as

interventions received are those that work well and are effective as specified by individual. During times when an individual is most vulnerable to a loss of autonomy and in need of assistance, PADs maintain a person's self-determination and ensure their preferences are known and honored (Kim et al. 2007). PADs give people control over their care and treatment especially when they are not able to voice preferences due to a mental health crisis. Communication between individuals and their families, friends, healthcare professional and other professionals is enhanced and individuals are protected from unwanted, ineffective and potentially harmful interventions and treatments. PADs are valuable empowerment tools as they give people control over their recovery through their own individual voice and personal choices.

Managed care health plans are required to provide information on advanced directives at the time of enrollment and patients are asked whether they have an advanced directive or provided information on advanced directives (including psychiatric advanced directives) upon admission to a hospital. However, when a patient is unable to state whether they have an advanced directive and is unable to receive information due their mental illness, the provider should give the information to the family or surrogate instead. The provider is still required to give the information directly to the patient once they are no longer incapacitated.

PADs are a non-coercive alternative to involuntary hospitalizations that support autonomy and self-determination and reduce mandated treatment and involuntary hospitalization when a person cannot express preferences or needs. An advance instruction or a healthcare power of attorney (HCPA) may be included in the PAD. PADs are typically not developed when an individual is in a psychiatric inpatient setting and should be created when the individual is well and able to indicate his or her future treatment preferences with the understanding that they will be honored during periods of decisional incapacity.

Advance instructions may include who to contact, when to contact them, relapse factors, preferred methods for deescalating a crisis

situation, preferences for medications, treatment interventions that should or should not be initiated, refusal of specific treatments (e.g., seclusion, restraint, ECT), and choice of particular hospitals or crisis facilities. Although some states limit the timeframe, typically a PAD is valid until revoked. Usually, a patient can revoke their PAD at any time unless declared incompetent or incapacitated, or they identify in the PAD that they may not revoke it at times when they are in the hospital or otherwise in a crisis. State laws vary and typically a signature of a witness or notary public is required, but most states do not mandate an attorney to sign.

Some organizations have developed formats that blend PADs with Wellness Recovery Action Plans and crisis intervention plans. Additional areas that may be addressed in a PAD include what the person enjoys doing, things that relieve stress and make the person feel better, triggers and strategies for controlling symptoms, indicators that the person is not doing well/warning signs, current medications and those to avoid, who to notify and contact information for service providers, and family members and other who the person wanted involved in their care.

The HCPA, also referred to as a healthcare agent, healthcare proxy, or durable power of attorney for health care, allows a second party to act on the individual's behalf should they become acutely ill and unable to make decisions about treatment. This representative makes treatment decisions on the individual's behalf (that is, using substitute judgment for the client's known preferences) when they are unable to do so (Appelbaum 2004). When possible, these decisions are to be consistent with preferences and choices outlined by the patient. The HCPA requirements may also vary from state to state, but they typically require that the individual, witnesses, or a notary public sign the document. In addition, there needs to be a signature indicating that the appointed agent appointed has accepted the responsibility to make mental health treatment decisions on behalf of the patient. The health care power of attorney and/or mental health care power of attorney may also need to be filed and registered with the Secretary of State in

a form prescribed by the Secretary of State. The National Resource Center on Psychiatric Advanced Directives (<http://www.nrc-pad.org>) has a plethora of information on PADs, including state by state information, information for patients and consumers, health and legal professionals, and family and friends, current research and legal issues, and resources.

Providers document in the medical record whether the person was provided with information on PADs and if the advanced directive was executed. Individuals are encouraged to carry a copy of their PAD with them, share copies with service providers and family members, and have copy in a convenient location so that, in case of an emergency or crisis, they have easy access and can remember where to retrieve it from. PADs should also be included in the medical record and, with expansion of electronic medical records, organizations should be able to flag the person's file to indicate that one has been developed and shared with other service providers.

A variety of clinical outcomes may result from the use of PADs, including but not limited to treatment engagement, treatment satisfaction, treatment adherence, and working alliance. Additional benefits of PADs include increases in service utilization which can also positively impact crisis early intervention and crisis management by deescalating the crisis, identifying alternatives to hospitalization, timely notification of clinicians and family members regarding decomposition, or (if hospitalization is required) improved inpatient management strategies (Van Dorn et al. 2010).

Although advanced directives for persons with a serious mental illness date back to the 1970s, and despite the multitude of benefits of PADs, this process is still rarely used. In a survey of 193 social workers, few had knowledge of PADs, with only 5 % reported being very familiar with advanced instructions and only 15 % reported being very familiar with HCPAs for mental health (Scheyett et al. 2008). Van Dorn et al. (2010) reviewed the literature and examined four studies on the prevalence of or demand for PADs and concluded that, although

individuals expressed great interest in completing PADs, the rate of completion remained low. Lack of both support and knowledge of PAD is a barrier because the majority of individuals require some level of assistance in completing them (Peto et al. 2004).

Studies have shown that although individuals with serious mental illness report great interest in completing a PAD, the low rates of completion have also been associated with illness-related barriers, consumers misunderstanding of PADs, lack of resources to complete PADs, inability to identify a proxy decision-maker, and complexity of the PAD process (e.g., having witnesses sign, documents notarized, and filing with medical record or registry). Swanson et al. (2003) described the majority of consumers (77 %) reported that they lacked the understanding of how to complete a PAD on their own. In another study, three-quarters of the 462 participants reported barriers related to the actual PAD documents and one-third indicated barriers with external support for PADs, including having no one they trusted to make decisions on their behalf (Van Dorn et al. 2006a, b).

In another study, Kim et al. (2007) found that although study participants were enthusiastic regarding the implementation of PADs, they were concerned with clinicians' lack of knowledge of PAD. Some participants even reported being uncomfortable at even mentioning they had a PAD as they were fearful of receiving a negative response or receiving an involuntary treatment while receiving hospitalization.

The clinician's knowledge and attitude toward PADs impacts implementation and whether the patient's preferences are honored or even inquired about. Although clinical issues, including concerns with the identified treatments, have been acknowledged as a barrier, environmental issues such as the inability to access the PAD or ability to reach the HCPA during a crisis situation appear to be of more concern (Van Dorn et al. 2006a, b). Srebnik and Brodoff (2003) found that 90 % of clinicians surveyed would be more likely to support directives if a clinician endorsed the client's competence at the time the document was completed, although there is no

required demonstration of competence needed when an individual completes medical advance directives.

Clinicians concerns that PADs will not allow them to treat patients aligned with community standards of care are not supported by the empirical research. Kim et al. (2007) cited two studies that reviewed over 340 completed PADs and found that none refused all treatment. Furthermore, the U.S. Court of Appeals for the 2nd Circuit struck down a state law that allowed mental health professionals to override a person's advance refusal of psychotropic medications.

Van Dorn et al. (2006a, b) reported that only 4–13 % of mental health patients receiving outpatient services had completed a PAD. In another study, the strongest predictor of the use of advanced directives was when a surrogate decision-maker was involved in the crisis. Directives were over five times more likely to be accessed for people who had repeated crises, suggesting that use increases as patients and clinicians become familiar with the crisis circumstances that trigger accessing directives. Those without a substance use diagnosis were four times more likely to have a directive accessed and individuals without prior outpatient commitment orders were six times more likely to have a directive accessed. Individuals who were identified as “higher functioning” and having fewer hospitalizations were also more like to have advanced directives accessed (Srebnik et al. 2003).

Despite these barriers, interventions to increase the completion of PADs, including a structured facilitated process using a semi-structured manualized interview and a computer-assisted program, have been successful (Kim et al. 2007). Outcomes associated with these interventions include improvement in treatment satisfaction, working alliance, competence to make treatment decisions and reductions in coercive crisis interventions including police transport and involuntary commitments (Elbogen et al. 2006; Van Dorn et al. 2006a, b). All parties involved, including inpatient and outpatient services providers, service recipients and family members, need to be educated on how to

complete PADs and the positive outcomes attributable to this powerful tool that supports self-advocacy, self-determination and empowerment. As PADs become more popular, they could usher in a new era of revolution in medical decision-making, greatly increasing patient authority over medical decisions (Hoge 1994).

Conclusion

Psychiatric hospitalization is unlike any other form of hospitalization. Individuals who experience hospitalization for their psychiatric illness are frequently hospitalized against their will and can be subjected to treatment and programming procedures to which they do not consent and/or experience radical infringements upon their decision-making authority. This chapter summarized the extent and experience of patient's psychiatric hospitalizations while offering a number of facility and patient-based strategies that can enhance patient decision-making and autonomy.

It is reasonable to assume that access to psychiatric hospitalization will increase in the future as a result of healthcare reform. Significant increases have been reported in the individuals with health insurance as a result of Medicaid expansion and the establishment of government subsidized health insurance plans. Similarly, healthcare reform has required that health plans insure parity in access and reimbursement for mental health and substance abuse treatment, consistent with coverage for medical and surgical procedures for other health conditions. As a result, it is reasonable to assume that more inpatient facilities will offer psychiatric treatment and that more individuals may have access to this form of treatment as needed. As inpatient psychiatric care access increases, it will be critical that such facilities implement the types of actions outlined in this chapter. Similarly, as more individuals obtain health insurance and gain access to care, it will be essential that they and their families establish the legal mechanisms that will ensure adherence to the patient's treatment wishes during inpatient care.

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