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An Infusion Model for Including Content On Elders with Chronic Mental Illness In the Curriculum

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ABSTRACT: *Older people with chronic mental illness (CMI) are experiencing longer life expectancies that parallel those of the general population. Due to their experience of having CMI, these older adults present unique issues that affect service delivery and care provision. Content on this population is often omitted in the curriculum, which leaves students unprepared to practice with these clients. This article proposes an infusion model that can be used in baccalaureate or graduate foundation courses to increase exposure to elders with CMI.*

People with lifelong disabilities have experienced increased longevity along with the aging of the general population. Individuals with chronic mental illness previously lived shorter and more restricted lives. With increased lifespans and changes in service systems from institutional to community-based care, however, greater numbers of people with psychiatric disabilities are living into late life. Although estimates of the prevalence of elders with chronic mental illness (ECMI) vary, a NIMH study indicates a minimum of four million older persons with a mental disorder (Aiken, 1990). Chronic mental disorders experienced by the elderly include schizophrenia and other psychotic disorders, bipolar disorder, depression, anxiety disorders and personality disorders. Elders with CMI, therefore, are increasingly coming to the attention of service providers in health, gerontological and mental health related fields.

For many adults, a psychiatric diagnosis is a chronic disability that affects their adulthood and late life stages. The experiences of a person with CMI can have a dramatic impact upon health and resources in later life. Such issues include the functionality of the person's social support system, the effects of extended psychotropic drug usage and other health related changes, a lack of appropriate community resources and family dynamics involved in providing care for an older member with CMI.

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Demographic forecasts herald the explosion of the elderly population and point to the increasingly large number of elders who will make up social workers' caseloads in the 21st century. The need for additional social workers who have expertise in gerontology has been well documented (Kropf, Schneider, & Stahlman, 1993; Lubben, Damron-Rodriguez & Beck, 1992; Peterson, 1990; Solomon & Mellor; 1992). Particularly, there is an omission in educating students about the unique needs and experiences of groups of vulnerable older adults, such as elders with lifelong disabilities (Kelly & Kropf, 1995; Kropf, 1996; Turk, & Overeynder, 1993). The importance of focusing on elders with CMI is highlighted by the fact that mental health has long been a major field of practice for social work practitioners and currently represents social workers' primary area of practice (Gibelman & Schervich, 1993). The high level of social work involvement in the mental health arena coupled with the rapid growth of the elderly population will result in an increased number of elders with CMI who seek the assistance of knowledgeable social workers. The strategy that is advocated here to address this reality is to promote awareness of ECMI through the infusion of content into the foundation sequence of the social work curriculum. An infusion strategy is advocated over a discrete course offering since this method provides all students with some exposure to this older population. In addition, the curriculum in many schools may not provide enough flexibility to mount an elective focused on this content. An infusion model is presented to provide faculty with content that can be included in undergraduate or graduate foundation courses.

AN INFUSION MODEL FOR ECMI CONTENT

Infusion of content about ECMI provides students with an opportunity to learn more about how aging and mental health issues intersect to affect service provision. ECMI clients have a high level of service contact through health, psychiatric, aging and legal services. Unfortunately, practitioners in these service settings are often unaware of the cumulative impact that aging and mental illness have on individuals and their families, and on service needs, options and resources. By including information concerning elders with CMI throughout the curriculum, students will gain knowledge about the needs of and issues related to ECMI on various system levels. Therefore, infusing content related to ECMI can prepare students for the multi-dimensional challenges that are involved in practice with this vulnerable older client group.

Human behavior in the social environment (HBSE)

The HBSE sequence addresses theories and knowledge of human development from a biopsychosocial perspective and includes information concerning how social forces and cultural systems affect individual functioning and well-being. In this sequence, the experience of living with a chronic mental illness, the associated experiences of stigma and discrimination, and the impact of CMI on family developmental stages should be addressed.

Many elders with CMI first became ill when they were in their 20's or 30's. Therefore, these individuals have lived the majority of their adult years with a psychiatric disability. This type of disability often leads to abnormal experiences of early and middle adult years, which then differentially shape their experiences in later years (Cohler & Beeler, 1996; Quam, 1986). Poor communication skills, problematic behaviors and difficulty maintaining stable relationships are common among those with CMI. For this reason, males with CMI are less likely to marry and CMI females have a higher incidence of divorce. Those with mental illness who do marry, in general have fewer children and more childless marriages (Clayton, 1994; Winocur, 1994). The relationships that mentally ill persons have with their spouses and children often become seriously strained over time. Research suggests that many family members eventually burn out after years of caring for a mentally ill relative (Cutrona, Schutte, Suhr & Russel, 1991). Difficulties maintaining stable relationships also result in smaller friendship and social support networks. In addition, those with CMI often have a lower occupational status and broken or non-existent employment histories (Clayton, 1994; Goodwin & Jamison, 1990; Winocur, 1994).

The combination of these factors can lead to the amplification of common challenges faced by the elderly. Smaller family and social support networks are associated with aging due to the death or incapacitation of family members and friends. In addition, elders often have more difficulty taking advantage of existing supports because of mobility problems. For an elder with CMI, the loss of a key relative or friend may seriously attenuate or even destroy a fragile social support system. Available financial resources also typically shrink with advancing years due to retirement, increased health related expenditures and widowhood. For elders with CMI, a history of low status, low paying and short-term jobs often results in a lack of financial security such as limited or no pension plans. Those individuals whose mental status negated the possibility of paid employment, must rely on meager SSI payments (Goodwin & Jamison, 1990; Winocur, 1994). Therefore, many ECMI face their later years with seriously diminished social and financial resources.

The majority of ECMIs alive today were first hospitalized in the 1930's and 1940's when institutionalization was a common experience for those with florid psychiatric symptoms (Sherrell, Anderson & Buckwalter, 1998). Many ECMI have histories of repeated institutionalizations and treatment with more primitive forms of electroconvulsive therapy (ECT) and with early psychotropic medications. As a result, many elders with CMI are very distrustful of the mental health system and of the hospital environment. These perceptions may compromise both their ability to work effectively with mental and medical health care providers and their willingness to follow through on health care recommendations. Long-term use of neurolyptic medications, commonly used to treat schizophrenia, carries a high risk of serious side effects such as tardive dyskinesia (TD), involuntary and repetitious movements

of face, trunk and limbs. While TD is inconvenient and uncomfortable for younger persons, this condition can pose serious threats to elders who may already be at an increased risk for falls (Jeste & Wyatt, 1987).

Issues related to the impact of CMI on family development and on the functioning of late-life families are also highly relevant. The onset of CMI can disrupt normative patterns of family development. Young adult children typically move away from home, start to accept emotional and financial responsibility for themselves and begin to form lasting relationships (Jordan & Franklin, 1995). This trajectory, however, is disrupted for those whose psychiatric symptoms emerge in early adulthood. Those whose symptoms emerge later, however, may marry and begin a family. A mental disorder at this stage of a family's development can result in severe strain in or the dissolution of a marriage. Parenting may be erratic due to recurrent mood swings or psychotic episodes. At times, children are asked to prematurely assume adult roles such as caretaking for an ill parent and younger siblings (Lefley, 1991). As a result, children may grow up experiencing a mixture of emotions including shame, guilt, confusion, fear, and love, which they carry with them into their adult years (Johnson, 1990). These dynamics can have serious implications when a person with CMI becomes frail in later years and requires additional assistance. Many times spouses are no longer involved with the CMI elder. While some adult children are very willing to assume caregiving responsibilities, others may be reluctant to re-engage with their ill parent and take on this role. Thus, the disruption to family functioning that begins early in the CMI person's life often continues and poses serious challenges to the operation of later-life families.

Practice methods

Foundation practice classes provide a theoretical framework for direct practice which informs students' development of assessment and intervention skills. This practice content, according to the CSWE guidelines, is also to include techniques and skills for practice with clients from at-risk populations (CSWE, 1994). ECMI are an example of a largely overlooked at-risk population that can benefit from assessment and intervention grounded in the ecological perspective. In order to effectively practice with ECMI, special attention must be paid to relationship development, illness and treatment history, special family dynamics and distinctive resource needs.

The relationship building tools of "tuning in," active listening, empathy and non-judgmental acceptance, are particularly important when working with ECMI. These elders, who struggle with the dual stigma of mental illness and age, are often used to being discounted. In addition, they may have some difficulty expressing themselves, describing their experiences, and fully understanding questions due to the combined effect of mental illness and age-related factors (e.g., hearing impairment or expressive aphasia). Future practitioners should understand the importance of eliciting these elders' perception of their situation and of validating

their emotional responses in order to gain valuable information and build trust and rapport. Equally important is the skill of obtaining a thorough illness and treatment history. Elders with CMI have varying experiences of treatment by the mental health community. While some elders' experiences may have been positive, others have had negative encounters with mental health services. Such information will provide important clues to the elder's potential level of trust, cooperation and follow-through and to possible barriers that may exist.

To understand the meaning of the symptoms that the elder presents, the symptom history should be explored. It should not be assumed that current symptoms represent the typical pattern of illness recurrence. While this may be true, new symptoms or patterns of symptoms can emerge as the elder's illness evolves over time (Goodwin & Jamison, 1990; Winocur, 1994). Such a change can have serious repercussions. On the other hand, new symptoms may not be related to the chronic mental illness at all but, rather, to physical or cognitive factors such as infection, medical disease, functional impairment or dementia. A wide range of medical illnesses and conditions can cause or exacerbate psychiatric symptoms. Unfortunately, medical problems that produce psychiatric symptoms are often undiagnosed in mentally ill elders (Schmidt, 1986).

Because family support is so crucial, it is necessary that assessment and involvement of the family is always considered. A necessary first step is an evaluation of the family history and dynamics. At times, children or spouses are angry or have conflicted feelings about the elder with CMI. A history in which neglect, abandonment or abuse by the elder occurred during the active phases of their disease may have left scars on family members that need to be addressed before increased involvement is possible (Patterson, Semple, Shaw, Grant, & Jeste, 1996). Family members who have a long history of involvement with the elder may require education about the impact that aging is having on their ill relative. Family members, for example, often confuse symptoms related to a medical condition or dementia with the symptoms of mental illness. As a result, the effects of medical or cognitive deterioration are often misunderstood and, at times, ignored. Family members with past experience dealing with the mental health system may adopt an adversarial role if their past experiences with the system were negative. Affirming the value of their knowledge and their input into the treatment of their relative can be critical. Educating family members about agency operations and about treatment processes and methods can be critical in relieving family distrust and securing their involvement.

A variety of resources and community services may be required in order to promote optimal functioning of an elderly person with CMI. A focus on ECMI provides students with an excellent example of the importance of the referral specialist, broker and advocate roles in securing needed resources for vulnerable clients. ECMI represent a social work constituency that requires an extensive knowledge by the professional of two separate service sectors and of how these

service sectors intersect. Often an information exchange does not exist between aging and mental health-related agencies. Social workers dealing with ECMI, therefore, must pro-actively seek out and link such agencies to develop adequate and coordinated service delivery. Many mental health agencies assist younger clients with vocational rehabilitation, housing and recreational opportunities. Such services may not meet the needs of elders with CMI. Other mental health agencies whose services do benefit elders may have physical barriers, such as stairways, which prohibit elders' participation. Such cases exemplify the need for students to move beyond the referral specialist role and become a broker, defined as an intermediary who actively works to connect people with needed resources (Hepworth, Rooney, & Larsen, 1997). To perform a broker role, a thorough knowledge of community resources, including solid working relationships with key contact people, is necessary.

Social welfare policy

The foundation social welfare policy course focuses on the history and current patterns of social welfare policies and programs and highlights how these may promote or hinder optimal functioning and well-being. The history of mental health and aging policy clearly demonstrates how governmental policies reflect prevailing culture, values and knowledge and how such policies positively or negatively affect the lives of vulnerable members of our society.

In the early part of this country's history, the family was seen as the system with primary responsibility for meeting the needs of the disabled, including the elderly and mentally ill. Federal and state monies were not directed toward the provision of services to support families in the care of their mentally ill or frail elderly relatives. In the early part of the 19th century, sentiment began to change about the government's role in addressing the basic needs of the most vulnerable citizens. Local governments assumed greater responsibility for the indigent elderly through the development of poorhouses, while state-operated asylums addressed the needs of the mentally ill. While some mentally ill elders were admitted to the state-run asylums, most indigent elders, regardless of their condition, were placed in local poorhouses. Although the poorhouses represented an improvement over the neglect that ECMI previously had experienced, no psychiatric or medical treatment was provided. In the beginning of the 20th century, however, an emphasis on the medical model to treat both the elderly and the mentally ill resulted in a change in this system. The passage of the State Care Act at the turn of the century shifted responsibility for insane and demented elders to the states (Goldman & Frank, 1990). Local communities, which were interested in reducing their own financial burdens, readily sent elders and the mentally ill to the state-run mental hospitals.

The housing of dependent elders and the mentally ill in state-run institutions continued until the middle of the century. During the late 1950's, the introduction of psychotropic medications as a method to treat chronic mental illness, combined

with a service emphasis on treating persons in the "least restrictive environments" created the impetus for the de-institutionalization movement, shifting care for the mentally ill back to the local community. Insufficient planning and funding, however, resulted in a dearth of adequate resources to meet the needs of de-institutionalized patients. As a result, families have once again become the primary caregivers of persons with CMI. Today, 50% - 73% of the mentally ill live with family members (Johnson, 1990).

The introduction of Medicaid in 1965, which funded nursing home residence for indigent elders, enabled the "trans-institutionalization" of older persons with CMI from state-run mental hospitals to nursing homes where the federal government shared the financial burden for their care (Sherrell, Anderson & Buckwalter, 1998). Just as de-institutionalization did not translate into the adequate provision of community-based services for younger persons with CMI, inadequate arrangements existed for the treatment of ECMI within the nursing home environment. Research indicates that while trans-institutionalized elders did receive psychotropic medications to treat psychotic symptoms, less than 10% received any type of psychosocial therapy (Aiken, 1990). As time went on, concerns about increased federal spending led to the passage of the 1987 Omnibus Budget Reconciliation Act (OBRA). This act requires that persons with mental illness only be admitted to Medicaid-funded nursing home beds if they also have a medical illness or disability that necessitates nursing home care. Therefore, elders who require a structured living environment and supervision due to a mental illness alone cannot be admitted to a federally supported nursing home. At the time the act was passed, elder nursing home residents who had a chronic mental illness but lacked a medical illness or disability were discharged from their nursing homes. Unfortunately, few housing and service alternatives for mentally ill elders have been developed by local or state governments. While community-based services for younger persons with CMI are widely recognized as inadequate and many states are experimenting with new service delivery systems, little attention has been focused on the paucity of services for ECMI.

Medicare, which was introduced in 1965 along with the Medicaid program, greatly increased elders' access to affordable health care services and significantly decreased the number of elders forced into poverty by health care bills (Hooyman & Kiyak, 1996). Medicare, however, focuses on services to meet elders' acute care needs. Funding is not provided for continuing care services to address chronic conditions, such as schizophrenia. Additionally, while Medicare covers 80% of elders' outpatient medical costs, it only funds 50% of their outpatient mental health costs (Aiken, 1990). Such a system can act as a deterrent to elders who seek mental health care treatment. Lack of adequate insurance coverage and a dearth of appropriate programs contribute to the high numbers of elders with mental health needs who do not receive services. Studies estimate that between 37% and 60% of elders with mental health care needs do not receive treatment (Wetle & Mark, 1990).

Social welfare policies have considerably improved the treatment and living conditions of elders with CMI. However, many gaps in services still exist. Currently, there is no one comprehensive policy covering geriatric mental health care. The existing system of finance for psychiatric services is fragmented and confusing. Current congressional discussions on the future shape of Medicare reflect societal concerns about the rapid growth of the elderly population, the size of the federal budget and generational equity. The future shape of both Medicare and Medicaid will inevitably affect elders with CMI. A classroom examination of how values, priorities and beliefs have influenced the development of policies that impact ECMI and how these policies have been translated into programs could provide students with a deeper understanding of why and how social welfare policies are developed and implemented.

Research methods

The foundation social work research course teaches students to understand, appreciate, and use diverse research methods in order to conduct ethical, efficacious and accountable practice. Additionally, students are taught to understand and avoid potential biases in research with minority and disadvantaged groups. Information about ECMI can be infused into this content to demonstrate issues related to the adequate definition of study populations, appropriate measurement selection and study design.

Prevalence studies on chronic mental illness among elders face many challenges and have resulted in widely varying estimates of the current number of EMCI and the projected number of such elders as the baby boomers age (Nordhus, Nielsen & Kvale, 1998). These challenges include varying definitions of key terms. Students should be advised that when investigating community-dwelling elders with chronic mental illness, several terms must be carefully defined. First, a decision must be made regarding the term "elderly". The required age for Social Security partial benefits (62 years) or full benefits (65 years) could be selected. Some researchers choose a younger age, such as 50 or 55 years, especially when studying persons, such as those with CMI or developmental disabilities, whose conditions and resultant lifestyle may lead to early disability and illness (Cohen, 1991; Seltzer, 1992). Next, the term "mental illness" must be considered. Some researchers include all DSM-IV axis I diagnoses, including substance abuse and dementia, while others exclude the latter two diagnoses. Still others include Axis II personality disorders (Neugebauer, 1980). The term "chronic" may refer to ongoing illness that began in younger years and persists into later life. Alternately, "chronic" could apply to late-onset mental disorders which then continue throughout the later years. Lastly, the term "community-dwelling" could be used to mean only those ECMI who live alone or with their families, or may also include those dwelling in assisted living facilities or in nursing homes.

Students need to understand the implications of operational concepts when designing or evaluating a research study involving elderly with CMI.

Once the study population has been suitably defined, issues related to data collection arise. A wide variety of instruments has been developed to measure various aspects of mental health and functioning. Many of these instruments, however, were originally designed for younger populations and, therefore, may lack validity with the elderly (Schulz & Visintainer, 1991). When designing a research study of elders with CMI, students should carefully examine potential instruments and determine the populations on which the instruments were used. The appropriate source of the data to be collected must also be carefully considered. Although, at first glance, the natural data source may appear to be the persons with CMI, when the subjects are elderly the possibility of cognitive impairment must be considered. Cognitive deficits that compromise the reliability of self-reports may exist in some subjects. In such cases a primary caregiver or surrogate may be asked to provide the needed information. Issues regarding the accuracy of information provided by proxies must be taken into consideration, however. Research suggests that information obtained from proxied responses may be systematically biased (Allen & Mor, 1997).

Many studies of community-dwelling persons with CMI and of their family members have been conducted since the introduction of de-institutionalization. There is increasing research on both the chronically mentally ill and on the elderly. However, very little research has focused on ECMI. Additionally, studies that examine the impact of caregiving among family members of older persons with CMI are scarce (Abramson, Quam, & Wasow, 1986; Patterson, Semple, Shaw, Grant, & Jeste, 1996). Students should be cautioned about applying the results of studies about CMI to the elderly population. Similarly, the results of studies focusing on elders with dementia or late-onset psychiatric disorders should not be applied to ECMI. Students may be helped to appreciate the reality of such threats to external validity by considering the following questions: In what ways are ECMI and their families similar to or different from younger persons with CMI and their family members? In what ways are ECMI and their families similar to or different from other elderly populations, such as those with Alzheimer's Disease, and their caregivers?

LEARNING ACTIVITIES AND RESOURCES

In addition to including content in social work courses, learning activities can increase students' awareness of the complexity in working with older adults with CMI and heighten their sensitivity to the impact of chronic mental illness on elders' experiences, relationships and resources. In-class exercises contrasting case management situations for older and younger adults with chronic mental illness serve to highlight the differential impact that CMI has on young vs. older adults and on the resources that are (or are not) available in the community for these two

populations. Case studies focused on the experience of family members of an elder with CMI can help sensitize students to the personal and practical challenges that families encounter as they struggle to secure needed services and supports for older members with complex and multifaceted needs. Class assignments that encourage students' interaction with professionals in the mental health field who serve older clients can help sharpen the students' understanding of the special skills needed to work with this client population.[1] In practice and human behavior classes, these types of activities can refine assessment skills, and highlight the developmental issues for the individuals' and the family. In a policy class, the activity can highlight fragmentation between various service sectors (e.g. mental health, health, aging). The research classes can use these exercises to develop a needs assessment for the community. Instructors including ECMI content in their courses can find additional information and resources at the National Alliance for the Mentally Ill website (www.nami.org)

CONCLUSION

This model provides an infusion strategy to assist faculty in including more content about a vulnerable segment of the older population–elders with chronic mental illness. For teaching content on ECMI, this framework exposes students to the multi-level issues in service provision, including how the aging process effects the older person with mental illness, family dynamics that affect care provision, interfaces within the service system and various methods of understanding and treating mental illness in the current cohort of older adults.

This model cannot exhaustively cover all of the material that is relevant to providing service to ECMI. However, it does provide a foundation for including content on this population that is traditionally omitted in the curriculum. As advances in health and mental health fields continue to extend the life expectancy rates, social workers will continue to see increased numbers of ECMI in various service settings. Social workers who receive foundational information about salient issues facing this population will be better prepared to offer quality service. The infusion model presented here provides faculty with relevant content on ECMI to include in case examples, lecture content or experiential activities.

NOTE:

[1] Contact the primary author for copies of case studies and exercises

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