Understanding End-of-Life Care in Schizophrenia: Mortality, Stigma, and Innovations
Mary Madrigal, Ph.D.

The past 10 years have seen an increase of awareness regarding provision of quality of care to the terminally ill and a greater emphasis on end-of-life care research. Despite the increase in new research and knowledge, some groups continue to be underserved and understudied, such as persons with serious mental health issues (Baker, 2005; Foti, 2003; McGrath & Jarrett, 2007). In addition, people with serious mental health issues have “long been a disenfranchised minority who access to general medical care has been limited” (Felker, Yazel, & Short, 1996, p. 1356) and have been consistently neglected (Baker, 2005). In particular, people with schizophrenia are often misdiagnosed and many times receive suboptimal medical care (Brown, Inskip, & Barraclough, 2000; Carney, Jones, & Woolson, 2006; Felker et al., 1996). Some of the contributing factors involved in the suboptimal care and lack of discussion about end-of-life care with people who experience schizophrenia are: a fear that the person will have an escalation in psychiatric symptoms, that the person is impaired and cannot comprehend the subject matter, and that the healthcare staff is not educated or trained in facilitating discussions about end-of-life care and advance care planning (Foti et al., 2005).

Compared to that of the general public, mortality of people with schizophrenia is remarkably high, with life expectancy reduced by 8.8 to 10 or more years (Brown et al., 2000; Carney et al., 2006; Dembling, Chen, & Vachon, 1999; Harris & Barraclough, 1998; McGrath & Jarrett, 2007; Mortensen & Juel, 1993). Many homeless persons also experience schizophrenia. “Homeless persons have high rates of mortality with a mean age at death being reported to be 34–47 years and 2.3–4 times higher than the general public” (Podymow, Turnbull, & Coyle, 2006, p. 81).

Natural and Unnatural Mortality of Schizophrenia

The literature on the mortality of schizophrenia exhibits several similarities among studies: there is an excess of mortality from natural and unnatural deaths. In general, natural deaths are related to medical diseases in that many are in the late stages by the time a person is diagnosed with a terminal illness. Many times the care that is provided for comorbidity is suboptimal or worse for persons who experience severe mental conditions. Unnatural deaths are generally related to suicide, homicide, and accidents (Allebeck, 1989; Brown et al., 2000; Carney et al., 2006; Cohen et al., 2002; Dembling et al., 1999; Dickey et al., 2002; Felker et al., 1996; Harris & Barraclough, 1998; Mortensen & Juel, 1993; Simpson & Tsuang, 1996).

Stigma and Schizophrenia

In general, people with schizophrenia are stigmatized. Cohen (2002, as cited in Whitaker, 2002) stated, “We still don’t understand [people who experience severe and chronic illness] and that lack of understanding makes us mean and arrogant, and makes us mislead ourselves, and so we hurt them” (p. 1). Farina, Gliha, Boudreau, Allen, and Sherman (1971) stated, “The mentally ill are disliked and degraded to a surprising degree” (p. 1). Along the same line, Peter Byrne (2001) defined stigma as

Continued on page 2
a “mark of disgrace or discredit that sets a person aside from others” (p. 281). People who experience severe and chronic mental health conditions often report that their questions, concerns, and requests for medical attention or other needs are dismissed and disregarded, leaving the person with a sense of worthlessness and a diminished sense of self and identity (Bromley & Cunningham, 2004). Therefore, it is not surprising that many people with schizophrenia and other chronic mental conditions are diagnosed in the late stages of disease if at all (Brown et al., 2000; Byrne, 2001; McGrath & Jarrett, 2007).

According to James Hawkins, a geriatric psychiatrist who specializes in schizophrenia and palliative care,

If a person with a chronic mental illness such a schizophrenia reaches old age by not dying earlier from suicide, inattention to non-psychiatric medical illness, he or she usually faces death alone and is at least stigmatized in four separate ways; (1) they are dying and dying patients suffer from stigma; (2) they are elderly and in this society, there is a strong stigma against getting old and being elderly; (3) they have a mental illness; (4) commonly, elderly people with schizophrenia experience cognitive and/or memory impairments.

(J. Hawkins, personal communication, March 20, 2008)

Areas of Growth

Though hospices may not provide sufficient care for persons diagnosed with schizophrenia, and health issues of such populations may not be sufficiently addressed, there are some signs that the mental health profession is beginning to improve in these areas. Broadman (2006) created a full service pilot program as part of the study to determine whether persons who were homeless and had access to full service medical and psychiatric care would attend to their medical and psychiatric issues more often. The program included a nurse practitioner that was available 24 hours a day to attend to patient needs and offer education on a variety of issues and topics.

The pilot program provided patients with the opportunity to be seen by a primary care physician for further medical evaluation as needed. The results of the pilot study were very impressive in that the homeless and other participants began to attend to their health and psychiatric issues and utilize health related resources more often. Emergency room visits decreased by 42%. Excess mortality continued, however, and the study acknowledged that more research was needed to develop better, more accessible resources for the homeless and people who suffer from severe and chronic mental health conditions.

One such resource in the community that is providing services to the homeless is called Ottawa Inner City Health Project (OICHP), created by Podymow et al. (2006) as a pilot study as part of a campaign to provide medical services to the homeless who were dying. Podymow et al. asserted that the mortality of the people living in shelters or homeless is high and that many homeless people are found dead in public places; others are found in home dwellings, or arrive dead at the local emergency room. The researchers recognized that many people who experience schizophrenia and other serious mental health conditions do not attend to their medical or physical health issues.

The aim of the study was to demonstrate that medical services could be provided in a shelter-like setting to people with a terminal illness and severe mental health conditions. The participants were 28 homeless, terminally ill patients who were admitted and died at the shelter-based medical facility. The age at death was reported as 34 to 47 years. Many of the participants had “co-existing substance abuse issues along with some that had AIDS and hepatic disease” (p. 81).

The pilot pro- gram successfully demonstrated that effective medical care can be provided in a shelter for the homeless.

Nader Robert Shabahangi, President of AgeSong/Pacific Institute in San Francisco, provides outstanding end-of-life care. AgeSong has its own unique programs in assisted living, dementia, memory improvement training, Alzheimer’s, behavioral health care, and a hospice program. The staff at AgeSong/Pacific

Table of Contents

| Special Features: |
| Understanding End-of-Life Care in Schizophrenia: ....................................................1-6 |
| Mortality, Stigma, and Innovations |
| Impenetrable Shatter: ...............................................................7 |
| Book Review by Daniel Mackler: ..............................................................8 |
| ISPS-US Branch Reports |
| DC/Baltimore Branch: ..............................................................9 |
| Berkshire Branch: ..............................................................9 |
| NYC Branch: ..............................................................9 |
| Michigan Branch ...............................................................10 |
| New Jersey Branch: ..............................................................10 |

Continued on page 3
Institute truly follow the hospice philosophy of providing compassion, palliative care, and support to the individual and family members. In addition, this organization is investing in the next generation by providing ongoing training, education, supervision, and countless workshops for students, staff, and the general public on end-of-life care for people with schizophrenia (N. Shabahangi, personal communication, November 2009).

Foti (2003) created a program called “Do It Your Way: End-of-Life Care for Persons with Serious Mental Illness”. The program was implemented by the Massachusetts Department of Mental Health (MA-DMH). The participants consisted of 47,000 men and women from 58 cities and towns diagnosed with severe and persistent mental health conditions and severe functional impairments. The aim of the study was to build coalitions among healthcare providers, cross-train hospice and mental health workers, educate the community on the importance of advance care planning for people who experience severe and chronic mental health conditions, and more. The study reported an increase in awareness about mental health patient rights and advance care planning. With the success of this program came advancements in research and assessment tools for end-of-life care for people who experience severe and chronic mental health conditions that are paving the way for future programs. In a recent conversation with Foti, she stated that there is still great need to improve end-of-life care to people who experience severe and chronic mental health conditions (M. E. Foti, personal communication, April 17, 2008).

Broadman (2006), Foti (2003), and Podymow et al. (2006) describe three examples of programs that incorporate mental health services and end-of-life care for people with serious mental health conditions. In addition, Angela Baker (2005) of the National Institutes of Health and National Institute of Neurological Disorders and Stroke recognized the great need for mental health professionals to be involved in the end-of-life care, treatment, and mental health process of terminally ill patients, especially the severe and persistent mentally challenged. Baker is an experienced psychiatric nurse practitioner that specialized in psychiatry. She proposed that to add to the quality of life of people who are terminally ill and have a history of schizophrenia, mental health professionals, including mental health nurses and nurse practitioners that specialize in psychiatry, must be part of the end-of-life care team to provide the quality of care received by others.

According to Baker (2005), death “knows no difference between those who suffer from mental illness and those who do not” (p. 302). Baker further asserted that by “providing understanding and compassion, knowledge and expertise, will and hope” (p. 302), the psychiatric team of professionals can greatly enhance the quality of life and death experience of people with schizophrenia and others with a chronic and persistent mental disturbance history.

Foti (2003) also demonstrated that “cross training mental health staff with palliative care and end-of-life service providers with mental health would greatly enhance the quality of life for the terminally ill person, and would also add confidence and quality of work for the staff” (p. 667).

Naomi Feil, M.S., A.C.S.W., the developer of Validation (1992), created a technique for working with people who experience disoriented states and are “trapped in a world of fantasy” (p. 9). Feil also discovered that no matter how disoriented a person may be, “It is a deep human need: to die in peace” (p. 17). Feil developed an effective communication method called validation to assist disoriented people who were living in skilled nursing facilities.

Continued from page 2

Continued on page 4

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She realized that “with no stimulation from the outside world, [disoriented people] become one of the living dead in our nursing homes” (p. 17). Validation method is a developmental theory based on the basic belief that “to validate is to acknowledge the feelings of the person” (p. 10) without judgment. Acknowledgment of the person’s feelings decreases aggressive behavior, reduces stress, and increases the person’s dignity and happiness. Validation staff members are trained to listen, validate the disoriented person’s feelings, and use specific techniques for each of the four stages of disorientation: (1) malorientation; (2) time confusion; (3) repetitive motion; and (4) vegetation. For each stage, validation techniques can be used by trained staff to help the person find resolution.

Finally, these approaches add greatly to the quality of the relationship between the staff and the person. Despite the increase in awareness regarding the availability and quality of end-of-life care, there seems to be barriers for some people with a terminal illness and schizophrenia accessing this care. Some organizations are greatly contributing to quality of life and creating new programs that can offer specialized services needed at the end-of-life for people with schizophrenia. Certainly one solution is by cross training mental health and palliative staff to provide more comprehensive services that will add to the quality of dying a person can experience. I believe this would improve the quality of life and quality of death for countless people who have not received referrals for end-of-life care. Once the patient is admitted for end-of-life care, a comprehensive team such as this could be contracted with or sent to provide the specialized services needed. This would help us move toward a situation in which people would not die alone or in pain because they would be receiving the humane care that many people receive at the end of their lives.

References


Continued from page 3

Continued on page 5

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Mary Madrigal, Ph.D. has worked in the mental health field for well over 20 years in a variety of positions and settings. She has extensive experience working in both the psychosocial/recovery model and in traditional mental health programs. Dr. Madrigal’s behavioral health experience includes, acute inpatient psychiatric, outpatient settings, residential, and partial hospitalization. Dr. Madrigal is a highly effective and skilled clinician working with psychosis and severe psychiatric conditions. She is currently the program director of a clinic that provides mental health services to low-income minorities challenged with substance abuse, mental health conditions, and HIV/AIDS. Dr. Madrigal is the Southern California Branch Coordinator for ISPS-US. She can be contacted at: drmmadrigal@verizon.net.

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Impenetrable Shatter
Michael Eigen
Author, Flames from the Unconscious: Trauma, Madness and Faith, Feeling Matters, and The Psychotic Core.

“Come to my apartment this instant or I’ll throw myself through a window.”

These were the words I heard when I answered the phone. I knew it was Devi and suicide was always a possibility. Sometimes I say or think, “I hope you stay suicidal for a long time.” Where there’s life, there’s …

I was taught not to help people get un-suicidal too quickly. Often a person is used to feeling awful if that is a chronic state. To rush into a better state without inner means to support it can be more harmful than going slow. Not that one has a choice. Things happen, one responds.

My mind instantly saw glass shattering. Shattering again. Continuous shatter. Mind shattering. The words that came out of my mouth were something like, “Ah, to shatter oneself and be free.”

I glanced around my office and saw glass everywhere. A mess to clean up. But comforted myself thinking it could be worse, it could be blood, body parts, brains.

When I came to, Devi was crying. “I can’t. I can’t.” he sobbed over and over. I didn’t know if he meant he couldn’t throw himself through the window or something else, a deeper can’t. People often feel like a coward because they can’t do something they want to do and don’t want to do, like kill themselves or change themselves.

“What is the can’t?” I asked.

“The can’t is I can’t get past myself. I can’t go through myself.”

Long pause, his remarks registering on me and himself as well. I felt he was hearing himself. We worked a long time for the possibility of his saying something he could hear. Often, he would speak and it would go past him, bullets that missed.

There are so many stories of going through something, a rabbit’s hole, a looking glass, a closet. Alice’s going through led to a world of new torments, far from heaven. A bit like Hamlet’s dilemma – would or wouldn’t death free him from pain? What does one have to go through to be free of pain?

“What would it be like to be free of oneself?” I asked. “Free of one’s personality?”

“Where is your hell?” he asked.

“You can’t see or hear it? You can’t feel it?”

Was he tone deaf (tone death) to other peoples’ hell? Maybe in some way. But I knew he could see – whether or not he felt it – he could see it.

“I see hell everywhere, “ Devi said.

“Our appointment is in two hours,” I said. “Our next meeting in hell.”

To say we had a lot to talk about would miss the point. We didn’t say much but we felt the thickness, an impenetrable density. Yet it had weak spots, traces of soft spots, edges, filaments to pull a little. A dense tangle. We sat with it. For me it was a relief to see him – one more time. A relief to feel this thing that doesn’t budge.
Book Review

Daniel Mackler, LCSW
July, 2009

Ordinary Life Therapy, by Carina Håkansson
An Important Book—Shows Us a New Way

With its humblest of titles, this book offers us something quite new—a new way of doing therapy with severely disturbed people. As a therapist who works with this type of client, I am used to reading all sorts of books offering new ways of doing therapy—new methods, new theories, new ideas. In reality, most, however, offer little that is new, and as such are not that inspiring. This book, translated from Swedish, is different. It shines a light in a quite unexpected direction—and for me personally, offered a whole new perspective on my work.

The system is this. Håkansson’s organization places “troubled” people with whom the regular mental health system has failed—people who would mostly be conventionally diagnosed with schizophrenia or bipolar or borderline or drug addiction—with a non-professional host family, where they live for several months to several years. Often, if they have children, their children live with the host family too. This “ordinary” family, in its own way, through its normal life routines and day-to-day patterns and individual personalities, then provides the basic structure of the “therapy.” Meanwhile, Håkansson’s organization provides massive, one-on-one therapeutic support not just to the client but also to the family—and also to both the client and the family at the same time. Basically, it’s the exact opposite of the one-size-fits-all treatment available to the lucky few in the United States—the lucky few who get any “treatment” beyond medication.

The magic of this book is that Håkansson shows again and again just how these “ordinary” families provide a wonderfully rich and therapeutic environment for the clients, but at times, even more so, how the clients provide a wonderfully rich therapeutic experience for the families in return. Similarly, the “professional” therapists and supervisors—and Håkansson herself, who founded and runs the organization—also gain richly from the experience.

As I read this touchingly honest book, I could not help but reflect on my own work. I work in a private practice, I get no support, and at most, if I’m lucky, I get to see a client for a few hours a week—in my office. Although the work can be greatly valuable, and some people are able to make amazing strides as the result of it, I often feel like a therapeutic acrobat, twisting myself this way and that to facilitate the seemingly impossible and often exhausting situations that come my way. Compared to my work, something about Håkansson’s seemed so much more tantalizing—and logical.

As such, I can only hope that more organizations like hers find a home in our world. Although she labels this type of therapy as “ordinary,” at present it is truly unusual.

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Report from ISPS-US-DC/Baltimore
Ann-Louise S. Silver, M.D.

The core group of ISPS-US-DC/Baltimore has been focusing on preparing a book proposal for some of the papers from our ISPS-US meeting in Rockville. On March 17, Edmond de Gaiffier, Ann Silver and Jean Jerardi met at Maurine Kelly’s home, where the four of us worked at organizing a table of contents and deciding on chapter lengths. Additionally, Edmond de Gaiffier has been mastering the technology necessary to take some of the recordings of those talks and has gotten them ready for posting at the ISPS-US website.

We are planning to host regular meetings organized around a topic such as “How do we understand delusions?” On March 5, we convened to attend the lectures by Francoise Davoine and Jean-Max Gaudilliere, hosted by the Washington Center for Psychoanalysis and The George Washington University Departments of English, Human Sciences, and Psychiatry, on the topic of History Beyond Trauma. As always, Francoise and Jean-Max each have something new to bring to this important topic whenever they speak, and the discussions by audience members were positive and thoughtful. Jean-Max closed his talk by recommending that we read or re-read Wilfried Bion’s A Memoir of the Future, and the ISPS-US-DC/Baltimore group has taken up his challenge.

Additionally, we are working with the Washington Center for Psychoanalysis in planning for next year’s Frieda Fromm-Reichmann Lecture. We will soon be able to announce the specifics.

NYC Branch of ISPS-US
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212.533.5687

The New York City Branch of ISPS-US continues to meet monthly to discuss psychosocial therapies and psychotherapies for persons diagnosed with a severe mental disorder. Our ISPS group began meeting in 1996 prior to the establishment of ISPS-US. We began monthly meetings in 1997 and have been meeting at this frequency ever since. We originally met at Dr. Paul Carroll’s apartment on the Upper West Side of Manhattan and then, due to the growth of our group, re-located to our current institutional sponsor, New York University. Specifically, it is the Postdoctoral Program in Psychotherapy and Psychoanalysis that sponsors us as an NYU-based group.

This academic year (2009-2010) we began with a panel on spirituality and psychosis. Nancy Kehoe PhD (author of “Wrestling with our Inner Angels: Faith, Mental Illness, and the Journey to Wholeness”) from Harvard Medical School presented and her work was discussed by psychoanalysts Mark Finn PhD (author of “Tibetan Buddhism in Comparative Psychoanalysis”) and Tony Stern MD (author of “Everything Starts from Prayer”). We also had a panel on CBT and Psychoanalysis-Differences and Similarities. Brian Koehler PhD (New York University) presented a current case of 10 years duration and this was discussed by two CBT clinicians/researchers, Yulia Landa PhD (Cornell Medical School) and psychoanalyst Michael Garrett MD (Downstate Medical School). The case was also discussed by two senior psychoanalysts from Columbia University, Eric Marcus MD and Andy Lotterman MD. Next we had Ira Steinman MD from San Francisco present from his new book “Treating the Untreatable: Healing in the Realms of Madness” published in 2009 by Karnac. Afterwards, Ira moderated a panel discussion on psychotherapy in the age of neuroscience with Charles Marmor MD, Ze’ev Levin MD and Brian Koehler PhD at the Philoctetes Center housed at the NY Psychoanalytic Institute (the video can be watched at http://philoctetes.org/Past_Programs/The_Role_of_Psychotherapy_in_the_Age_of_Neuroreceptors_and_Genes). In the following month Daniel Mackler LCSW gave his paper on non-coercive therapy of persons with psychotic symptoms. At this meeting, Daniel noted that he was embarking on a new film project (nationally and internationally) of current innovative psychotherapies for persons with psychosis.

In the near future, we will hear from Zvi Lothane MD on psychotherapy and psychosis, David Wilson PhD on substance misuse disorders and psychosis, James Ogilvie PhD (talk to be determined), Sharon Farber PhD on cults and psychosis, and Patricia Thackray, Founder/Director of The Bridge Poetry Program (this will be the second Elaine Schwager Poetry Presentation in honor of our deceased colleague, psychoanalyst and poet, Elaine Schwager, wife of our esteemed colleague Marvin Hurvich PhD).

Our proceedings are now being recorded by Julie Kipp PhD with the permission of presenters for educational and archival purposes. Our group continues to grow, as we have almost 300 persons on our email list. Jessica Arenella PhD is working towards having all of these persons officially join ISPS-US. It is very gratifying when we hear of people signing on with our group, e.g., just yesterday I received an email from a student of mine saying that he just sent in his dues and officially joined ISPS-US. This helps make our group a more significant voice for the development of psychotherapies for persons struggling with psychosis. Thank you to everyone for supporting this worthwhile group over the many years we have been meeting.
Michigan Branch of ISPS-US, Patricia L. Gibbs, Ph.D.
22731 Newman St., #235   Dearborn, MI 48124   (313) 274-5490

The ISPS-US Michigan members do not hold meetings. Members keep in touch through the Michigan Listserv, by attending local professional meetings, and attending the yearly ISPS-US Annual Conference.

Rebecca Hatton, Psy.D., LP completed an 8 week seminar on "Psychotherapy for People with Schizophrenia." Dr. Hatton is developing an in-service training on "(Real) Recovery from Psychosis" for the Washtenaw County Community Support and Treatment Services, where she is currently employed.


Elizabeth Waiess, Psy. D., presented her paper "Who the Dickens is Miss Havisham?" to the February meeting of the Michigan Psychoanalytic Council. Bertram Karon, Ph.D., was the formal discussant.


Clio's Psyche.

New Jersey Branch of ISPS-US

The New Jersey Branch of ISPS was launched on November 15, 2009 with a presentation by Murphy Halliburton, tenured assistant professor in the Graduate Center and Department of Anthropology, Queens College CUNY. Halliburton discussed his new book, Mudpacks and Prozac: Experiencing Ayurvedic, Biomedical, and Religious Healing (2009) Left Coast Press. Based on several years of field research in Kerala, India, the text is a fascinating comparative analysis of how patients choose among the therapies of Western biomedical (allopathic), Ayurvedic, and religious healing systems, and how they experience each of these treatments. According to Prof. Halliburton, the Indian state of Kerala presents special opportunities for research. It is a region with an extremely high literacy rate, allowing for dissemination of information about healing systems; and it is home to a number of distinct, institutionalized alternatives for the alleviation of human distress – a western style psychiatric facility, an Ayurvedic institute, and several religious shrines. Despite the fact that these several models draw on entirely different explanatory models of treatment, and hence could be seen as epistemological competitors, Halliburton found a widespread pluralism in his interviews with the people receiving the treatments. Many were able to discuss their experience with several treatment modalities in personal, familial, religious, and societal terms, generally untroubled by the competing explanations for their conditions as, for example, “schizophrenia” or “possession.”

Another focus of Halliburton’s research as a medical anthropologist had to do with the aesthetics of healing. Here he found striking contrasts, between for example the Ayurvedic system-- in which the pleasurable experience of the medical treatments was coextensive with the favorable outcome-- and the allopathic model-- in which treatments are widely considered unpleasurable experiences to be endured in order to achieve improvement. While outcome as such was not a main focus of the research, Halliburton noted that the reported ‘cure rate’ for all the methods was about the same- about one third of cases. And, not surprisingly, he found that a number of respondents had been to several of the treatment systems, moving to one from another until finding some relief.

The meeting, held in the home of Ross Tappen and Jessica Arenella in Montville, NJ was attended by a mix of professionals including ISPS members from NY and NJ, professionals from the South Asian Mental Health association of NJ, academicians, and lay people interested to hear about ways to help an afflicted loved one. The “aesthetics” of the meeting featured a special gift for the attendee who traveled the farthest distance, made by Ross’ daughter Eleanor, and chocolate chip cookies made by Jessica. ISPS-US New Jersey branch meets next in March, and looks forward to welcoming Alice Lombardo Maher, M.D., director and founder of Changing Our Consciousness (http://www.changingourconsciousness.org) to discuss the forthcoming documentary, “How to Touch a Hot Stove,” which addresses de-stigmatizing mental illness. We will have an opportunity for a lively discussion about the process of making the film and the narratives that unfold. For information contact: Jessica Arenella at jessarenella@yahoo.com or Ross Tappen at rtappen@mindspring.com.
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