

Soteria-Alaska

A Pilot Project Proposal

August 8, 2004

I. Background

This proposal is the result of a process that began with Robert Whitaker's December 13, 2002, presentation to the Alaska Mental Health Board regarding his findings as revealed in *Mad in America*¹ and the growing consensus that a pilot project along the lines of the successful Soteria House project² should be initiated for Alaska.³ This project has also garnered offers of help to make it a success from prominent psychiatrists experienced in working with people under Soteria concepts.

The 1971-1983 National Institute of Mental Health funded Soteria House Research Project, by Loren R. Mosher, M.D., demonstrated that many people suffering from acute psychiatric difficulties could be successfully treated with no or little psychotropic medication and, that people who responded well to such treatment had substantially better outcomes than those treated and then maintained on such drugs. These findings, however, were overwhelmed by the psychiatric medication juggernaut and have yet to significantly impact public mental health policy development in this country.⁴

Mr. Whitaker, in his presentation to the Board, suggested it would be very desirable for Alaska to initiate a non-traditional alternative, such as a Soteria House, for people in acute psychiatric crises. In such a program, while psychiatric drugs could play a role, they would be used minimally, and for short periods if at all possible. This was receptively received by the Board and recent indications are that the Alaska Mental Health Trust Authority (Trust) may be willing to favorably entertain funding such a proposal.

The Soteria-Alaska Pilot Project would go a long way in enhancing the choices that are available for patients in the Alaska community. This program would certainly enhance the patient's ability to have not only a choice in the focus of programs, but would also

¹ Earlier this year, Mr. Whitaker published, "The case against antipsychotic drugs: a 50-year record of doing more harm than good," in *Medical Hypotheses*, Volume 62, Issue 1, 2004, Pages 5-13, (Appendix A) which was reviewed in the *British Medical Journal*, Vol. 328/414, February, 2004 as follows:

Maintaining people with schizophrenia on neuroleptics (the accepted standard care) may actually be doing them a disservice. According to a 50 year review, long term treatment worsens long term outcomes, and up to 40% of people would do better without neuroleptics. Initiation of treatment only after a subsequent episode and helping patients who are stabilised on neuroleptics to gradually withdraw from them would increase recovery rates and reduce the proportion of patients who become chronically ill (*Medical Hypotheses* 2004;62:5-13).

² See, e.g., Soteria and Other Alternatives to Acute Psychiatric Hospitalization A Personal and Professional Review, by Loren R. Mosher, M.D., *The Journal of Nervous and Mental Disease*, 187:142-149, 1999, Appendix B.

³ The availability of such an alternative has been endorsed by the CEO of API. See Appendix C.

⁴ There are, however, very successful Soteria and Soteria-like programs in other countries.

enhance their informed choice of whether to take medications as a part of their treatment. Such a choice would be in concert with a possible decision by the Alaska supreme court requiring a less restrictive alternative to the involuntary administration of psychotropic medications when possible.⁵

The Consumers Consortium has also felt so strongly about the need for such a program that it has engaged Dr. Aron Wolf to write a preliminary business plan for a Soteria like project and an alternative community program. Dr. wolf is currently working on this project and plans to have it accomplished by September 15, 2004.

All of these factors augur for the implementation of a Soteria or Soteria-like alternative to acute hospitalization in Alaska.

II. Population to be Served

The Soteria-Alaska Pilot Project would be a direct alternative to hospitalization at the Alaska Psychiatric Institute (API). Subject to availability of beds and eligibility, prospective clients would be given the option of going to the Soteria-Alaska Pilot Project rather than API. All admissions must be voluntary. In addition to people being faced with involuntary commitment at API, people who have been hospitalized in the past and feel they are spiraling down and need somewhere to go to prevent hospitalization would also be eligible on a space available basis.

III. The Soteria-Alaska Pilot Project

The proposal is for a Soteria⁶ or Soteria-like alternative to acute hospitalization operating under the principles enunciated by Dr. Mosher in "Soteria and Other Alternatives to Acute Psychiatric Hospitalization." Prior to his passing last month, Dr. Mosher e-mailed what resources it would take (edited somewhat as to form):

What is needed is a house that can get a license to "treat acutely mentally ill" persons. It needs to be zoned so 6-8 unrelated persons can live there. Detached houses are best as there is then space to allow for noise and some odd goings on. As for a budget you need 2 staff on at all times-we were able to use non-mental health trained staff supervised by a licensed social worker or psychologist. These are all full time positions although the supervisor need only work 40 hours (i.e. no back up), so you need 2 X 52 X 168 hours of line staff money plus vacation and sick leave time at whatever the going rate is up there for college grads with no specialized training in mental health.

We always got by with 10 hours a week of psychiatric time to do admission workups and discharge notes (usually required by law if you

⁵ See, website on *Myers v. Alaska Psychiatric Institute*, S-11021 in the Alaska Supreme Court, <http://psychrights.org/States/Alaska/CaseOne.htm>.

⁶ Soteria is a Greek word meaning salvation or deliverance.

want to operate as an alternative to hospitalization). The last one we ran cost about \$150/person/day in 1994 dollars. This included everything-rent, food, utilities and staff cost etc. That came to about \$ 300,000 per year so I guess you'd need about \$400,000 as an annual budget. Several states have Medicaid rehab waivers by which they've established per diem rates for alternatives. The current one for places here in San Diego is \$215/day. The problem is, sometimes getting involved with Medicaid forces you to have nurses as part of the staff and they add lots to the cost.

To reassure the powers that be you should have a staff training budget in addition to what the house director/supervisor can provide. The chapter in our book, Community Mental Health: a Practical Guide, on staffing-chap 10 as I recall-we give some criteria for staff selection and deselection for working in Soteria like places. I used them successfully with 3 different house director social workers. We also have a training manual that will be contained in a new Soteria book that should appear this year. The problem is of course that there are not many folks around who have actually done this work. There is no "cook book" because each place has to differ according to the context in which it will exist.

IV. Budget

The Budget (in thousands) for the Soteria-Alaska Pilot Project, starting in FY 06, is as follows:

Fund Source	FY06	FY07	FY08	FY09	FY10
Authority Grants - Capital	\$500				
Authority Grants - Operating	\$300	\$350	\$300	\$250	\$200

It is essential that these be Authority Grants rather than Mental Health Trust Authority Authorized Receipts (MHTAAR) funds in order to ensure fidelity to the Soteria principles in implementation.

The one time capital grant of \$500,000 is to acquire a suitable residential property.

The \$300,000 in operating funds for FY 06 assumes an annualized budget of \$400,000 and that it will take one quarter to begin operations.⁷ Thereafter the Authority Grants requirements goes down to half of the anticipated annual cost through use of other payers, such as Medicaid and even private insurers.⁸ This very well could be improved by changing the Medicaid Regulations and/or obtaining a waiver(s) so that the Soteria

⁷ It also assumes that it does not have to be staffed by nurses.

⁸ Dr. Wolf, who is consulting on this project has indicated he is in a position to try to negotiate this with the four main private insurers in Alaska.

services can access these sources of funds. The great reduction in costs should be grounds enough to for such payers to agree.

V. Implementation

Implementation is critical to the success of this project and the key to implementation for the Soteria-Alaska Pilot Project is having people experienced in Soteria-like programs involved. Before his untimely death last month, Dr. Mosher had agreed to come to Alaska for three months to help get Soteria-Alaska off the ground and on the right direction in funding was obtained. There are, however, other psychiatrists with appropriate experience who have expressed willingness to help.

Dr. Peter Stastny is Associate Professor of Psychiatry at Albert Einstein College of Medicine, and Senior Psychiatrist at Bronx Psychiatric Center. Dr. Stastny is the author of numerous scholarly papers on psychosocial treatments, advance directives, self-help and empowerment, film history and mental health and subjective experiences. He has spearheaded innovative programs, such as peer specialist services, consumer-run businesses, and transitional living groups. Dr. Stastny is convening a working-conference this fall in New England of the key people involved in alternatives such as Soteria-type programs from around the world.

Dr. Ann-Louise Silver practiced psychiatry for 25 years at Chestnut Lodge Hospital, from 1976 to the time of its closing in April, 2001. She worked with patients both in the non-medication and the medication phases of the history of this famous institution and found that the patients with whom she worked during the non-medication phase did far better than did those who were chronically medicated.⁹ Dr. Silver is currently the president of the US Chapter of the International Society for the Psychological treatments of the Schizophrenias and other psychoses (ISPS-US). Dr. Silver also practiced for over two years at the Northern Region of Alaska in the late 1960's while her husband served a tour of duty at Fort Wainwright and has maintained her Alaska medical license on an inactive basis since then.

Dr. Dan Dorman is Assistant Clinical Professor of Psychiatry at the UCLA School of Medicine. He has a background in family medicine, psychoanalysis and research in neurophysiology. Dr. Dorman has practiced and taught psychotherapy for over thirty years. His recently published and acclaimed book "Dante's Cure" chronicles his work with Catherine Penney, who was considered a hopeless case, but with Dr. Dorman's help, fully recovered from her descent into madness and is now a psychiatric nurse in southern California.

Jim Gottstein has made arrangements to meet with both Drs. Silver and Dorman on an upcoming trip to Chicago in September.

As mentioned above, Aron S. Wolf M.D., M.M.M., of Wolf Healthcare P.C., is currently working on developing a model using both Soteria modules as well as community type

⁹ See, e.g., http://www.isps-us.org/articles/ISPS_Debate/I_Oppose/i_oppose.html.

models as demonstrated by the Ionia community in Kasilof. Dr. Wolf is a well known, longtime Alaskan psychiatrist. Dr. Wolf accomplished his psychiatric training in Baltimore. One of his principal mentors was Otto Will of Chestnut Lodge and later the Director of the Institute of Living. As a part of his mentoring, Dr. Wolf spent considerable time at Chestnut Lodge learning their interactive ways of relating to severely psychotic individuals. Dr. Wolf more recently obtained a Master of Medical Management Degree from Tulane University and used his administrative knowledge as the first Regional Medical Director for the Providence Health System in Alaska prior to opening his own consulting practice.

Appendix A

"The case against antipsychotic drugs: a 50-year record of doing more than good," in *Medical Hypotheses*, Volume 62, Issue 1 , 2004, Pages 5-13



ELSEVIER

The case against antipsychotic drugs: a 50-year record of doing more harm than good[☆]

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Summary Although the standard of care in developed countries is to maintain schizophrenia patients on neuroleptics, this practice is not supported by the 50-year research record for the drugs. A critical review reveals that this paradigm of care worsens long-term outcomes, at least in the aggregate, and that 40% or more of all schizophrenia patients would fare better if they were not so medicated. Evidence-based care would require the selective use of antipsychotics, based on two principles: (a) no immediate neuroleptisation of first-episode patients; (b) every patient stabilized on neuroleptics should be given an opportunity to gradually withdraw from them. This model would dramatically increase recovery rates and decrease the percentage of patients who become chronically ill.

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Introduction

The standard of care for schizophrenia calls for patients to be maintained indefinitely on antipsychotic drugs. The evidence for this practice comes from research showing the drugs are effective in treating acute psychotic symptoms and in preventing relapse [1,2]. Historians also argue that the introduction of neuroleptics in the 1950s made it possible to empty the mental hospitals, and that this is further proof of the drugs' merits [3]. Yet, long-term outcomes with schizophrenia remain poor, and may be no better than they were 100 years ago, when water therapies and fresh air were the treatment of the day [4–7].

There is an evident paradox in the research record. The efficacy of neuroleptics appears to be well established, yet there is a lack of evidence showing that these drugs have improved patients' lives over the long-term. That paradox recently stirred an unusual editorial in *Eur. Psychiatry*,

which posed this question: "After fifty years of neuroleptic drugs, are we able to answer the following simple question: Are neuroleptics effective in treating schizophrenia?" [8] A close review of the research literature provides a surprising answer. The preponderance of evidence shows that the current standard of care – continual medication therapy for all patients so diagnosed – does more harm than good.

Did neuroleptics enable deinstitutionalization?

The belief that the introduction of chlorpromazine, marketed in the US as Thorazine, made it possible to empty state hospitals stems from research by Brill and Patton. In the early 1960s, they reported that the patient census at state mental hospitals in the US declined from 558,600 in 1955 to 528,800 in 1961. Although they did not compare discharge rates for drug-treated versus placebo-treated patients, they nevertheless concluded that neuroleptics must have played a role in the decline since it coincided with their introduction. The fact that the two occurred at the same time was seen as the proof [9,10].

[☆] Mad in America: Bad Science, Bad Medicine, and the Enduring Mistreatment of the Mentally Ill (Perseus Publishing, 2002).

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However, there were obvious confounding factors. In the early 1950s, the Council of State Governments in the US urged the federal government to share the fiscal burden of caring for the mentally ill, and proposed that “out-patient clinics should be extended and other community resources developed to care for persons in need of help, but not of hospitalization” [11,12]. As part of this agenda, states began developing community care initiatives, funneling the mentally ill into nursing homes and halfway houses. This change in social policy could easily have been responsible for the slight drop in patient numbers observed by Brill and Patton.

Moreover, there was one state that did compare discharge rates for schizophrenia patients treated with and without drugs, and its results do not support the historical claim made for neuroleptics. In a study of 1413 first-episode male schizophrenics admitted to California hospitals in 1956 and 1957, researchers found that “drug-treated patients tend to have longer periods of hospitalization... furthermore, the hospitals wherein a higher percentage of first-admission schizophrenic patients are treated with these drugs tend to have somewhat higher retention rates for this group as a whole”. In short, the California investigators determined that neuroleptics, rather than speed patients’ return to the community, apparently *hindered* recovery [13].

The true period of deinstitutionalization in the US was from 1963 to the late 1970s, the exodus of patients driven by social and fiscal policies. In 1963, federal government began picking up some of the costs of care for the mentally ill not in state institutions, and two years later, Medicare and Medicaid legislation increased federal funding for care of mental patients provided they were not housed in state hospitals. Naturally, states responded by discharging their hospital patients to private nursing homes and shelters. In 1972, an amendment to the Social Security act authorized disability payments to the mentally ill, which accelerated the transfer of hospitalized patients into private facilities. As a result of these changes in *fiscal* policies, the number of patients in state mental hospitals dropped from 504,600 to 153,544 over a 15-year period (1963–1978) [14].

Establishing efficacy: the pivotal NIMH trial

The study that is still cited today as proving the efficacy of neuroleptics for curbing acute episodes of schizophrenia was a nine-hospital trial of 344 patients conducted by the National Institute of Mental Health in the early 1960s. At the end of six weeks,

75% of the drug-treated patients were “much improved” or “very much improved” compared to 23% of the placebo patients. The researchers concluded that neuroleptics should no longer be considered mere “tranquilizers” but “antischizophrenic” agents. A magic bullet had apparently been found for this devastating disorder [1].

However, three years later, the NIMH researchers reported on one-year outcomes for the patients. Much to their surprise, they found that “patients who received placebo treatment were less likely to be rehospitalized than those who received any of the three active phenothiazines” [15]. This result raised an unsettling possibility: While the drugs were effective over the short-term, perhaps they made people more biologically vulnerable to psychosis over the long run, and thus the higher rehospitalization rates at the end of one year.

The NIMH withdrawal studies

In the wake of that disturbing report, the NIMH conducted two medication-withdrawal studies. In each one, relapse rates *rose* in correlation with neuroleptic dosage before withdrawal. In the two trials, only 7% of patients who were on placebo relapsed during the following six months. Twenty-three percent of the patients on less than 300 mg of chlorpromazine daily relapsed following drug withdrawal; this rate climbed to 54% for those receiving 300–500 mg and to 65% for patients taking more than 500 mg. The researchers concluded: “Relapse was found to be significantly related to the dose of the tranquilizing medication the patient was receiving before he was put on placebo – the higher the dose, the greater the probability of relapse” [16].

Once more, the results suggested that neuroleptics increased the patients’ biological vulnerability to psychosis. Other reports soon deepened this suspicion. Even when patients reliably took their medications, relapse was common, and researchers reported in 1976 that it appeared that “relapse during drug administration is greater in severity than when no drugs are given” [17]. A retrospective study by Bockoven also indicated that the drugs were making patients chronically ill. He reported that 45% of patients treated at Boston Psychopathic Hospital in 1947 with a progressive model of care did not relapse in the five years following discharge, and that 76% were successfully living in the community at the end of that follow-up period. In contrast, only 31% of patients treated in 1967 with neuroleptics at a community health center remained relapse-free over the next five years, and as a group they were much more “socially dependent” – on welfare and

needing other forms of support – than those in the 1947 cohort [18].

Drug treatment versus experimental forms of care

With debate over the merits of neuroleptics rising, the NIMH revisited the question of whether newly admitted schizophrenia patients could be successfully treated without drugs. There were three NIMH-funded studies conducted during the 1970s that examined this possibility, and in each instance, the newly admitted patients treated without drugs did better than those treated in a conventional manner.¹

In 1977, Carpenter reported that only 35% of the nonmedicated patients in his study relapsed within a year after discharge, compared to 45% of those treated with neuroleptics. The non-medicated patients also suffered less from depression, blunted emotions, and retarded movements [20]. A year later, Rappaport et al. [21] reported that in a trial of 80 young male schizophrenics admitted to a state hospital, only 27% of patients treated without neuroleptics relapsed in the three years following discharge, compared to 62% of the medicated group. The final study came from Mosher, head of schizophrenia research at the NIMH. In 1979, he reported that patients who were treated without neuroleptics in an experimental home staffed by nonprofessionals had lower relapse rates over a two-year period than a control group treated with drugs in a hospital. As in the other studies, Mosher reported that the patients treated without drugs were the better functioning group as well [22,23].

The three studies all pointed to the same conclusion: Exposure to neuroleptics increased the long-term incidence of relapse. Carpenter's group defined the conundrum

There is no question that, once patients are placed on medication, they are less vulnerable

¹ In the early 1960s, May conducted a study that compared five forms of treatment: drug, ECT, psychotherapy, psychotherapy plus drug, and milieu therapy. Over the short-term, the drug-treated patients did best. As a result, it came to be cited as proof that schizophrenia patients could not be treated with psychotherapy. However, the long-term results told a more nuanced story. Fifty-nine percent of patients initially treated with milieu therapy but no drugs were successfully discharged in the initial study period, and this group "functioned over the follow-up (period) at least as well, if not better, than the successes from the other treatments". Thus, the May study suggested that a majority of first-episode patients would fare best over the long-term if initially treated with "milieu therapy" rather than drugs [19].

to relapse if maintained on neuroleptics. But what if these patients had never been treated with drugs to begin with? . . . We raise the possibility that antipsychotic medication may make some schizophrenic patients more vulnerable to future relapse than would be the case in the natural course of the illness [20].

In the late 1970s, two physicians at McGill University in Montreal, Guy Chouinard and Barry Jones, offered a biological explanation for why this was so. The brain responds to neuroleptics – which block 70–90% of all D₂ dopamine receptors in the brain – as though they are a pathological insult. To compensate, dopaminergic brain cells increase the density of their D₂ receptors by 30% or more. The brain is now "supersensitive" to dopamine, and this neurotransmitter is thought to be a mediator of psychosis. The person has become more biologically vulnerable to psychosis and is at particularly high risk of severe relapse should he or she abruptly quit taking the drugs. The two Canadian researchers concluded:

Neuroleptics can produce a dopamine supersensitivity that leads to both dyskinetic and psychotic symptoms. An implication is that the tendency toward psychotic relapse in a patient who has developed such a supersensitivity is determined by more than just the normal course of the illness. . . the need for continued neuroleptic treatment may itself be drug induced [24,25].

Together, the various studies painted a compelling picture of how neuroleptics shifted outcomes away from recovery. Bockoven's retrospective and the other experiments all suggested that with minimal or no exposure to neuroleptics, at least 40% of people who suffered a psychotic break and were diagnosed with schizophrenia would not relapse after leaving the hospital, and perhaps as many as 65% would function fairly well over the long-term. However, once first-episode patients were treated with neuroleptics, a different fate awaited them. Their brains would undergo drug-induced changes that would increase their biological vulnerability to psychosis, and this would increase the likelihood that they would become chronically ill.

The world health organization studies

In 1969, the World Health Organization initiated a study to compare outcomes for schizophrenia in "developed" countries with outcomes in "undeveloped" countries. Once again, the results were surprising. Patients in the three poor countries –

India, Nigeria and Colombia – were doing dramatically better at two-year and five-year follow-ups than patients in the US and four other developed countries. They were more likely to be fully recovered and faring well in society – “an exceptionally good social outcome characterized these patients”, the WHO researchers wrote – and only a small minority had become chronically sick. At five years, about 64% of the patients in the poor countries were asymptomatic and functioning well. In contrast only 18% of patients in the rich countries were in this best-outcomes category. The difference in outcomes was such that the WHO researchers concluded living in a developed nation was a “strong predictor” that a schizophrenic patient would never fully recover [26].

These findings naturally stung psychiatrists in the US and other rich countries. Faced with such dismal results, many argued the WHO study was flawed and that a number of the patients in the poor countries must not have been schizophrenic but ill with a milder form of psychosis. With that criticism in mind, the WHO conducted a study that compared two-year outcomes in 10 countries, and it focused on first-episode schizophrenics all diagnosed by Western criteria. The results were the same. “The findings of a better outcome of patients in developing countries was confirmed”, the WHO investigators wrote. In the poor countries, 63% of schizophrenics had good outcomes. Only slightly more than one-third became chronically ill. In the rich countries, the ratio of good-to-bad outcomes was almost precisely the reverse. Only 37% had good outcomes, and the remaining patients did not fare so well [27].

The WHO investigators did not identify a cause for the stark disparity in outcomes. However, they did note there was a difference in the medical care that was provided. Doctors in the poor countries generally did not keep their patients on neuroleptics, while doctors in the rich countries did. In the poor countries, only 16% of the patients were maintained on neuroleptics. In the developed countries, 61% of the patients were kept on such drugs.

Once again, the research record told the same story. In the WHO studies, there was a correlation between use of the medications on a continual basis and poor long-term outcomes.

MRI studies

While most researchers have used MRIs to investigate possible causes of schizophrenia, a small number have employed this technology to study the effects of neuroleptics on the brain. These

investigators have found that the drugs cause atrophy of the cerebral cortex and an enlargement of the basal ganglia [28–30]. Moreover, researchers at the University of Pennsylvania reported in 1998 that the drug-induced enlargement of the basal ganglia is “associated with greater severity of both negative and positive symptoms” [31]. In other words, they found that the drugs cause changes in the brain associated with a *worsening* of the very symptoms the drugs are supposed to alleviate.

Relapse studies

As discussed earlier, evidence for the efficacy of neuroleptics is stated to be two-fold. First, the NIMH trial in the 1960s found that neuroleptics are more effective than placebo in curbing acute episodes of psychosis. Second, the drugs have been shown to prevent relapse. In 1995, Gilbert reviewed 66 relapse studies, involving 4365 patients, and summed up the collective evidence: Fifty-three percent of patients withdrawn from neuroleptics relapsed within 10 months, versus 16% of those maintained on the drugs. “The efficacy of these medications in reducing the risk of psychotic relapse has been well documented,” she wrote [2].

At first glance, this conclusion seems to contradict the research showing that the drugs made patients chronically ill. There is an answer to this puzzle however, and it is a revealing one. The studies by Rappaport, Mosher and Carpenter involved patients who, at the start of the experiment, were not on neuroleptics but were then treated either with placebo or a neuroleptic. And in those studies, relapse rates were lower for the placebo group. In contrast, the 66 studies reviewed by Gilbert were *drug-withdrawal* studies. In the studies she analyzed, patients who had been stabilized on neuroleptics were divided into two cohorts: One would keep on taking the drugs and the other would not, and the studies reliably found that people withdrawn from their neuroleptics were more likely to become sick again.

Thus, the literature suggests that relapse rates fall into three groups: lowest for those not placed on neuroleptics in the first place, higher for those who take the drugs continuously, and highest of all for those withdrawn from the drugs. Yet even that picture is misleading.

First, for the most part, the drug-withdrawal studies were conducted in a select group of “good responders” to neuroleptics, rather than in the general patient population. In the real world, up

to 30% of hospitalized patients do not respond to neuroleptics. Among those who do and are discharged, more than one-third relapse within the next 12 months and need to be rehospitalized, even though they reliably take their medications. Thus, fewer than 50% of people who suffer a schizophrenic break respond to standard neuroleptics and remain relapse-free for as long as a year, but the relapse studies, to a large degree, were conducted in this group of good responders. In 1998, Hogarty pointed out how this study design led to a mistaken understanding of true relapse rates with antipsychotics: “A reappraisal of the literature suggests a one-year, post-hospital, relapse rate of 40% on medication, and a substantially higher rate among patients who live in stressful environments, rather than earlier estimates of 16%” [32].

At the same time, the relapse studies were designed in ways that exaggerated the risk of relapse in the drug-withdrawn groups. In response to Gilbert, Baldessarini reanalyzed the same 66 studies, only he divided the drug-withdrawn cohort into “abrupt-withdrawal” and “gradual-withdrawal” groups. He determined that the relapse rate in the abruptly withdrawn group was *three times higher* than in the gradual group [33]. In other words, it was the abrupt cessation that caused much of the excess relapse risk. Indeed, in a further review of the relapse literature, Baldessarini found that only one-third of schizophrenia patients gradually withdrawn from their drugs relapsed within six months and that those who reached this six-month point without become sick again had a good chance of remaining well indefinitely. “The later risk of relapsing was remarkably limited,” he concluded [34].

The relapse studies are cited to support a paradigm of care that emphasizes continual drug therapy for schizophrenia patients. But upon closer examination, a new picture emerges. The real-world first-year relapse rate for patients maintained on neuroleptics is understood to be 40%, while the rate for patients gradually withdrawn from the drugs is 33%. Thus, once bad trial design is eliminated, the evidence for continual medication disappears. At the same time, evidence appears showing that a majority of patients – two-thirds in the gradual withdrawal studies – can do fairly well without the drugs.

Doing more harm than good

Although this review of neuroleptics may seem surprising, the research record actually is quite

consistent. The pivotal NIMH study in the early 1960s found that the drugs had a short-term benefit, but that over the long-term the drug-treated patients had higher relapse rates. Similarly, in his retrospective study, Bockoven found that patients treated with neuroleptics were more likely to become chronically ill. The experiments by Carpenter, Mosher, and Rappaport all showed higher relapse rates for drug-treated patients, and in 1979, Canadian investigators put together a biological explanation for why this would be so. The World Health Organization reported higher recovery rates in poor countries where patients were not regularly maintained on the drugs. Finally, the MRI studies by investigators at the University of Pennsylvania confirmed the problem of drug-induced chronicity in a compelling way. The drug treatment caused a pathological change in the brain associated with a worsening of symptoms – that is a convincing example of cause and effect.

Thus, there is a preponderance of evidence showing that standard neuroleptics, over the long-term, increase the likelihood that a person will become chronically ill. This outcome is particularly problematic when one considers that the drugs also cause a wide range of troubling side effects, including neuroleptic malignant syndrome, Parkinsonian symptoms, and tardive dyskinesia. Patients maintained on standard neuroleptics also have to worry about blindness, fatal blood clots, heat stroke, swollen breasts, leaking breasts, impotence, obesity, sexual dysfunction, blood disorders, painful skin rashes, seizures, diabetes, and early death [35–40].

Once all these factors are considered, it is hard to conclude that standard neuroleptics are therapeutically neutral. Instead, the research record shows harm done, and the record is consistent across nearly 50 years of research. [See “Timeline to Failure” in Appendix A.]

A better model: the selective use of neuroleptics

At the very least, this history argues that the best model of care would involve selective use of neuroleptics. The goal would be to minimize their use. Several investigators in Europe have developed programs based on that goal, and in every instance they have reported good results. In Switzerland, Ciompi established a house modeled on Mosher’s Soteria Project, and in 1992 he concluded that first-episode patients treated with no or very low doses of medication “demonstrated

significantly better results” than patients treated conventionally [41]. In Sweden, Cullberg reported that 55% of first-episode patients treated in an experimental program were successfully off neuroleptics at the end of three years, and the others were being maintained on extremely low doses of chlorpromazine. Moreover, patients treated in this manner spent fewer days in the hospital than conventionally treated patients during the follow-up period [42,43]. Lehtinen and his colleagues in Finland now have five-year results from a study that involved treating first-episode patients without neuroleptics for the initial three weeks and then initiating drug treatment only when “absolutely necessary”. At the end of five years, 37% of the experimental group had never been exposed to neuroleptics, and 88% had never been rehospitalized during the two-to-five-year follow-up period [44,45].

Those results are much better than any achieved in the US following the standard model of continual medication. Indeed, in his meta-analysis of such experimental studies, John Bola at the University of Southern California concluded that most “show better long-term outcomes for the unmedicated subjects” [23].

The atypicals: dawn of a new era?

Admittedly, the record of poor long-term results reviewed here was produced by standard neuroleptics. The poor outcomes may also reflect prescribing practices in the US that, until the late 1980s, involved putting patients on high dosages. The long-term research record for clozapine and other atypicals like risperidone and olanzapine has yet to be written.

One hopes that these newer drugs will lead to better outcomes, but there are reasons to be skeptical. As is now widely acknowledged, the clinical trials of the atypicals were biased by design against the old ones, and thus there is no compelling evidence that the new ones are truly better [46]. While the risk of tardive dyskinesia may be reduced with the atypicals, they bring their own set of new problems, such as an increased risk of obesity, hyperglycemia, diabetes, and pancreatitis [47–49]. Together, these side effects raise the concern that the atypicals regularly induce metabolic dysfunction of some kind, and thus their long-term use will lead to early death. The atypicals also have been shown to cause an increase in D2 receptors, just like the old ones do, and that is believed to be the mechanism that makes medicated patients more biologically vulnerable to psychosis [50].

Summary

The history of medicine is replete with examples of therapies that were eagerly embraced for a period and then later discarded as harmful. A scientific examination of the evidence is supposed to save us from such folly today. And science has in fact provided research data to guide prescribing practices. The evidence consistently reveals that maintaining all schizophrenia patients on antipsychotics produces poor long-term outcomes, and that there is a large group of patients – at least 40% of all people so diagnosed – who would do better if they were never exposed to neuroleptics, or, in the alternative, were encouraged to gradually withdraw from the drugs. (The percentage of patients diagnosed with schizoaffective disorder, or some milder form of psychosis, that could do well without the drugs is undoubtedly much higher.)

This conclusion is not a new one, either. Nearly 25 years ago, Jonathan Cole, one of the pioneering figures in psychopharmacology, published a paper provocatively titled “Maintenance Antipsychotic Therapy: Is the Cure Worse than the Disease?” After reviewing the research data, he concluded that “an attempt should be made to determine the feasibility of drug discontinuance in every patient” [17]. The evidence supported a standard of care that involved gradual withdrawal. The research record of neuroleptics since that time – most notably the WHO studies and the MRI study by investigators at the University of Pennsylvania – confirms the wisdom of his advice.

Indeed, Harding’s long-term study shows that gradual withdrawal is an essential step on the path to full recovery. She found that one-third of the schizophrenia patients on the back wards of a Vermont state hospital in the 1950s were completely recovered thirty years later, and that this group shared one characteristic: all had long since stopped taking neuroleptics [51]. She concluded that it was a “myth” that patients must be on medication all their lives, and that in “reality it may be a small percentage who need medication indefinitely” [52].

Yet, in spite of all this evidence, today there is almost no discussion within psychiatry of adopting practices that would involve using neuroleptics in a selective manner, and that would integrate gradual withdrawal into the standard of care. Instead, psychiatry is moving in the opposite direction and prescribing antipsychotics to an ever larger patient population, including those said simply to be “at risk” of developing schizophrenia. While this expansion of the use of antipsychotics serves obvious financial interests, it is treatment that is certain to harm many.

Appendix A

A timeline for neuroleptics.

Preclinical

- 1883 Phenothiazines developed as synthetic dyes.
- 1934 USDA develops phenothiazines as insecticide.
- 1949 Phenothiazines shown to hinder rope-climbing abilities in rats.
- 1950 Rhone Poulenc synthesizes chlorpromazine, a phenothiazine, for use as an anesthetic.

Clinical history/standard neuroleptics

- 1954 Chlorpromazine, marketed in the US as Thorazine, found to induce symptoms of Parkinson's disease.
- 1955 Chlorpromazine said to induce symptoms similar to encephalitis lethargica.
- 1959 First reports of permanent motor dysfunction linked to neuroleptics, later named tardive dyskinesia.
- 1960 French physicians describe a potentially fatal toxic reaction to neuroleptics, later named neuroleptic malignant syndrome.
- 1962 California Mental Hygiene Department determines that chlorpromazine and other neuroleptics prolong hospitalization.
- 1963 Six-week NIMH collaborative study concludes that neuroleptics are safe and effective "antischizophrenic" drugs.
- 1964 Neuroleptics found to impair learning in animals and humans.
- 1965 One-year followup of NIMH collaborative study finds drug-treated patients more likely than placebo patients to be rehospitalized.
- 1968 In a drug withdrawal study, the NIMH finds that relapse rates rise in direct relation to dosage. The higher the dosage that patients are on before withdrawal, the higher the relapse rate.
- 1972 Tardive dyskinesia is said to resemble Huntington's disease, or "postencephalitic brain damage".
- 1974 Boston researchers report that relapse rates were lower in pre-neuroleptic era, and that drug-treated patients are more likely to be socially dependent.
- 1977 A NIMH study that randomizes schizophrenia patients into drug and non-drug arms reports that only 35% of the non-medicated patients relapsed within a year after discharge, compared to 45% of those treated with medication.
- 1978 California investigator Maurice Rappaport reports markedly superior three-year outcomes for patients treated without neuroleptics. Only 27% of the drug-free patients relapsed in the three years following discharge, compared to 62% of the medicated patients.
- 1978 Canadian researchers describe drug-induced changes in the brain that make a patient more vulnerable to relapse, which they dub "neuroleptic induced supersensitive psychosis".
- 1978 Neuroleptics found to cause 10% cellular loss in brains of rats.
- 1979 Prevalence of tardive dyskinesia in drug-treated patients is reported to range from 24% to 56%.
- 1979 Tardive dyskinesia found to be associated with cognitive impairment.
- 1979 Loren Mosher, chief of schizophrenia studies at the NIMH, reports superior one-year and two-year outcomes for Soteria patients treated without neuroleptics.
- 1980 NIMH researchers find an increase in "blunted effect" and "emotional withdrawal" in drug-treated patients who don't relapse, and that neuroleptics do not improve "social and role performance" in non-relapsers.
- 1982 Anticholinergic medications used to treat Parkinsonian symptoms induced by neuroleptics reported to cause cognitive impairment.
- 1985 Drug-induced akathisia is linked to suicide.
- 1985 Case reports link drug-induced akathisia to violent homicides.
- 1987 Tardive dyskinesia is linked to worsening of negative symptoms, gait difficulties, speech impairment, psychosocial deterioration, and memory deficits. They conclude it may be both a "motor and dementing disorder".
- 1992 World Health Organization reports that schizophrenia outcomes are much superior in poor countries, where only 16% of patients are kept continuously on neuroleptics. The WHO concludes that living in a developed nation is a "strong predictor" that a patient will never fully recover.

Appendix A (continued)

Clinical history/standard neuroleptics

- 1992 Researchers acknowledge that neuroleptics cause a recognizable pathology, which they name neuroleptic induced deficit syndrome. In addition to Parkinson's, akathisia, blunted emotions and tardive dyskinesia, patients treated with neuroleptics suffer from an increased incidence of blindness, fatal blood clots, arrhythmia, heat stroke, swollen breasts, leaking breasts, impotence, obesity, sexual dysfunction, blood disorders, skin rashes, seizures, and early death.
- 1994 Neuroleptics found to cause an increase in the volume of the caudate region in the brain.
- 1994 Harvard investigators report that schizophrenia outcomes in the US appear to have worsened over past 20 years, and are now no better than in first decades of 20th century.
- 1995 "Real world" relapse rates for schizophrenia patients treated with neuroleptics said to be above 80% in the two years following hospital discharge, which is much higher than in pre-neuroleptic era.
- 1995 "Quality of life" in drug-treated patients reported to be "very poor".
- 1998 MRI studies show that neuroleptics cause hypertrophy of the caudate, putamen and thalamus, with the increase "associated with *greater* severity of both negative and positive symptoms".
- 1998 Neuroleptic use is found to be associated with atrophy of cerebral cortex.
- 1998 Harvard researchers conclude that "oxidative stress" may be the process by which neuroleptics cause neuronal damage in the brain.
- 1998 Treatment with two or more neuroleptics is found to increase risk of early death.
- 2000 Neuroleptics linked to fatal blood clots.
- 2003 Atypicals linked to an increased risk of obesity, hyperglycemia, diabetes, and pancreatitis.

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Appendix B

Soteria and Other Alternatives to Acute Psychiatric Hospitalization A
Personal and Professional Review, by Loren R. Mosher, M.D., *The
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Soteria and Other Alternatives to Acute Psychiatric Hospitalization

A Personal and Professional Review

LOREN R MOSHER, M.D.^{1,2}

ABSTRACT: The author reviews the clinical and special social environmental data from the Soteria Project and its direct successors. Two random assignment studies of the Soteria model and its modification for long-term system clients reveal that roughly 85% to 90% of acute and long-term clients deemed in need of acute hospitalization can be returned to the community without use of conventional hospital treatment. Soteria, designed as a drugfree treatment environment, was as successful as anti-psychotic drug treatment in reducing psychotic symptoms in 6 weeks. In its modified form, in facilities called Crossing Place and McAuliffe House where so-called long-term "frequent flyers" were treated, alternative-treated subjects were found to be as clinically improved as hospital-treated patients, at considerably lower cost. Taken as a body of scientific evidence, it is clear that alternatives to acute psychiatric hospitalization are as, or more, effective than traditional hospital care in short-term reduction of psychopathology and longer- social adjustment. Data from the original drug-free, home-like, nonprofessionally staffed Soteria Project and its Bern, Switzerland, replication indicate that persons without extensive hospitalizations (<30 days) are especially responsive to the positive therapeutic effects of the well-defined, replicable Soteria-type special social environments. Reviews of other studies of diversion of persons deemed in need of hospitalization to "alternative" programs have consistently shown equivalent or better program clinical results, at lower cost, from alternatives. Despite these clinical and cost data, alternatives to psychiatric hospitalization have not been widely implemented, indicative of a remarkable gap between available evidence and clinical practice. J Nerv Ment Dis 187:142-149, 1999

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Introduction

In 1961, while serving as a medical intern, knowing I was soon to embark on a career as a psychiatrist, I suffered what retrospectively could be labeled an existential crisis. For the first time I experienced the responsibility of caring for persons who would soon die-and I was powerless to do anything about it-except to try to understand their experience of it. They frequently expressed how helpless and depersonalized they felt, "I'm just the one with lung cancer" or "Why can't you do something so I can breathe-- drowning" or "All this place has done is to make me into a nobody-you can't do anything for me so you steer clear." For the first time I faced my own mortality and with it the degrading, dehumanizing and helplessness of the process that could accompany it-particularly if I had the misfortune of being in a hospital like the one in which I worked.

Previous intensive psychotherapy as a medical student had obviously not prepared me to face mortality compounded by the degradation ceremonies I presided over within the institution. As a sometime intellectual, I sought help with my conundrum in the library. Rollo May's *Existence* (1958) was the beginning of a quest for an intellectual foundation for the depth of what I was experiencing personally. With the help of May's book and an existential analytic tutor (Dr. Ludwig Lefebre), I studied the writings of a number of the phenomenologic/existential thinkers (e.g., Allers, 1961; Boss, 1963; Hegel, 1967; Husserl, 1967; Sartre, 1956; Tillich, 1952; and others) in greater depth. I concluded that their open minded, noncategorizing, no preconceptions approach was a breath of fresh air in the era of rationalistic theory driven approaches (such as psychoanalysis) to disturbed and disturbing persons.

So, I brought to my psychiatric residency a phenomenology-based "what you see is what you've got" bias to my interactions with patients and a sensitivity to the issues of a degradation and power especially as embodied in conventional institutional practices. The good mentors (e.g., Drs. Elvin Semrad and Norman Paul) in my psychiatric training

taught me how to listen and attempt to find meaning in the distorted communications of my patients and their families (in 1962!) by doing my best to put my feet into their shoes. Harry Stack Sullivan (1962) and the double bind theory (Bateson et al., 1956) provided intellectual support. I also learned how to ask and look for answers to questions of interest from research gods (e.g., Dr. Martin Orne). On the other hand, the institution itself gave me master classes in the art of the "total institution" (Goffman, 1961); authoritarianism, the degradation ceremony, the induction and perpetuation of powerlessness, unnecessary dependency, labeling, and the primacy of institutional needs over those of the persons it was ostensibly there to serve--the patients. These institutional lessons were not part of the training program. In fact, my efforts to be helpful to my patients were interrupted by these institutional needs. When brought up they were denied, rationalized, or simply invalidated, "You're just a resident and aren't yet able to understand why these processes are not as you see them." From a series of such experiences, I began to believe that psychiatric hospitals were not usually very good places in which to be insane.

Although the Thorazine assault troops (Smith, Klein, and French's own terminology for its 1956 charge to the company's detail men--see BradenJohnson [1990]) had already successfully done their job --selling the neuroleptics -- never became a true believer in the "magic bullet" attribution commonly ascribed the neuroleptic drugs. Despite being trained by psychopharmacologic icons (e.g., Dr. Gerald Klerman), I somehow never found a Lazarus among those I treated with the major tranquilizers. Again, my experience led me to question the emerging psychopharmacologic domination of the treatment of very disturbed and disturbing persons. Actually those persons seemed to appreciate my sometimes clumsy attempts to understand them and their lives. Because I hadn't found a large role for drugs in the helping process, I was led to believe more in interpersonal than neuroleptic "cures." I did worry about what went on in the 164 hours a week when my patients were not with me -- was the rest of their world trying to understand and relate meaningfully to them?

So, as a career unfolded, the questioning of conventional wisdom remained part of me, albeit not always acted upon in a way that would bring undue attention and consequent retribution. To interests in the meaningfulness of madness, understanding families, and the conduct of research, I added one from my institutional experience; if places called hospitals were not good for disturbed and disturbing behavior, what kinds of social environments were? In 1966-1967, this interest was nourished by R.D. Laing and his colleagues in the Philadelphia Association's Kingsley Hall in London. The deconstruction of madness and the madhouse that took place there generated ideas about how a community-based, supportive, protective, normalizing environment might facilitate reintegration of psychologically disintegrated persons without artificial institutional disruptions of the process. This, combined with my existential/phenomenologic-psychotherapy and anti-neuroleptic drug biases resulted, in 1969-1971, in the design and implementation of the Soteria Research Project. Soteria is a Greek word meaning salvation or deliverance. In addition to my interests, the project included ideas from the era of "moral treatment" in American psychiatry (Bockhoven, 1963), Sullivan's (1962) interpersonal theory and his specially designed milieu for persons with schizophrenia at

Sheppard and Enoch Pratt Hospital in the 1920s, labeling theory (Scheff, 1966), intensive individual therapy based on Jungian theory (Perry, 1974) and Freudian psychoanalysis (Fromm-Reichman, 1948; Searles, 1965), the notion of growth from psychosis (Laing, 1967; Menninger, 1959), and examples of community-based treatment such as the Fairweather Lodges (Fairweather et al., 1969).

The Soteria Project (1971-1983)

This project's design was a random assignment, 2-year follow-up study comparing the Soteria method of treatment with "usual" general hospital psychiatric ward interventions for persons *newly diagnosed as having schizophrenia* and deemed in need of hospitalization. It has been extensively reported (see especially Mosher et al., 1978, 1995). In addition to less than 30 days previous hospitalization (i.e., "newly diagnosed"), the Soteria study selected 18- to 30- unmarried subjects about whom three independent raters could agree met DSM-11 criteria for schizophrenia and who were experiencing at least four of seven Bleulerian symptoms of the disorder (Table 1). The early onset (18 to 30 years) and marital status criteria were designed to identify a subgroup of persons diagnosed with schizophrenia who were at statistically high risk for long- disability. We believed that an experimental treatment should be provided to those individuals most likely to have high service needs over the long term. All subjects were public sector clients screened at the psychiatric emergency room of a suburban San Francisco Bay Area county hospital.

TABLE 1: The Soteria Project: research admission/selection criteria

1. Diagnosis: DSM II schizophrenia (3 independent clinicians)
2. Deemed in need of hospitalization
3. Four of seven Bleulerian diagnostic symptoms (2 independent clinicians)
4. Not more than one previous hospitalization for 30 d or less
5. Age: 18-30
6. Marital status: single

Basically, the Soteria method can be characterized as the 24 hour a day application of interpersonal phenomenologic interventions by a nonprofessional staff, usually without neuroleptic drug treatment, in the context of a small, homelike, quiet, supportive,

protective, and tolerant social environment. The core practice of interpersonal phenomenology focuses on the development of a nonintrusive, noncontrolling but actively empathetic relationship with the psychotic person without having *to do* anything explicitly therapeutic or controlling. In shorthand, it can be characterized as "being with," "standing by attentively," "trying to put your feet into the other person's shoes," or "being an LSD trip guide" (remember, this was the early 1970s in California). The aim is to develop, over time, a shared experience of the meaningfulness of the client's individual social context-current and historical. Note, there were no therapeutic "sessions" at Soteria. However, a great deal of "therapy" took place there as staff worked gently to build bridges, over time, between individuals' emotionally disorganized states to the life events that seemed to have precipitated their psychological disintegration. The context within the house was one of positive expectations that reorganization and reintegration would occur as a result of these seemingly minimalist interventions.

The original Soteria House opened in 1971. A replication facility ("Emanon") opened in 1974 in another suburban San Francisco Bay Area city. This was done because clinically we soon saw that the Soteria method "worked." Immediate replication would address the potential criticism that our results were a one-time product of a unique group of persons and expectation effects. The project first published systematic 1-year outcome data in 1974 and 1975 (Mosher and Menn, 1974; Mosher et al., 1975). Despite the publication of consistently positive results (Mosher and Menn, 1978; Matthews et al., 1979) for this subgroup of newly diagnosed psychotic persons from the first cohort of subjects (1971-1976), the Soteria Project ended in 1983. Because of administrative problems and lack of funding, data from the 1976-1983 cohort were not analyzed until 1992. Because of our selection criteria and the suburban location of the intake facilities, both Soteria-treated and control subjects were young (age 21), mostly white (10% minority), relatively well educated (high school graduates) men and women raised in typical lower middle class, blue-collar suburban families.

Results

Cohort 1 (1971-1976)

Briefly summarized, the significant results from the initial, Soteria House only, cohort were:

Admission Characteristics. Experimental and control subjects were remarkably similar on 10 demographic, 5 psychopathology, 7 prognostic, and 7 psychosocial preadmission (independent) variables.

Six-Week Outcome. In terms of psychopathology, subjects in both groups improved significantly and comparably, despite Soteria subjects not having received neuroleptic drugs. All control patients received adequate anti-psychotic drug treatment in hospital and were discharged on maintenance dosages. More than half stopped medications over

the 2-year follow-up period. Three percent of Soteria subjects were maintained on neuroleptics.

Milieu Assessment. Because we conceived the Soteria program as a recovery-facilitating social environment, systematic study and comparison with the CMHC were particularly important. We used Moos' Ward Atmosphere Scale (WAS) and COPES scale for this purpose (Moos, 1974, 1975). The differences between the programs were remarkable in their magnitude and stability over 10 years. COPES data from the experimental replication facility, Emanon, was remarkably similar to its older sibling, Soteria House. Thus, we concluded that the Soteria Project and CMHC environments were, in fact, very different and that the Soteria and Emanon milieus conformed closely to our predictions (Wendt et al., 1983).

Community Adjustment. Two psychopathology, three treatment, and seven psychosocial variables were analyzed. At 2 years postadmission, Soteriatreated subjects from the 1971-1976 cohort were working at significantly higher occupational levels, were significantly more often living independently or with peers, and had fewer readmissions; 571/16 had never received a single dose of neuroleptic medication during the entire 2-year study period.

Cost. In the first cohort, despite the large differences in lengths of stay during the initial admissions (about 1 month versus 5 months), the cost of the first 6 months of care for both groups was approximately \$4000. Costs were similar despite 5-month Soteria and 1-month hospital initial lengths of stay because of Soteria's low per them cost and extensive use of day care, group, individual, and medication therapy by the discharged hospital control clients. (Matthews et al., 1979; Mosher et al., 1978).

Cohort II (1976-1982; includes all Emanon-treated subjects)

Admission, 6-week, and milieu assessments replicated almost exactly the findings of the initial cohort. Nearly 25% of experimental clients in this cohort received some neuroleptic drug treatment during their initial 6 weeks of care. Again, all hospital-treated subjects received anti- drugs during their index admission episode. In this cohort, half of the experimental and 70% of control subjects received postdischarge maintenance drug treatment. However, in contrast to Cohort 1, after 2 years, no significant differences existed between the experimental and control groups in symptom levels, treatment received (including medication and rehospitalization), or global good versus poor outcomes. Consistent with the psychosocial outcomes in Cohort I, Cohort II experimental subjects, as compared with control subjects, were more independent in their living arrangements after 2 years.

Interestingly, independent of treatment group, good or poor outcome is predicted by four measures of preadmission psychosocial competence (Mosher et al., 1992): level of education (higher), precipitating events (present), living situation (independent), and

work (successful). Good outcome was narrowly defined as having no more than mild symptoms *and* either living independently or working or going to school at both 1- and 2-year follow-up (Mosher et al., 1995).

The Second Generation

Although closely involved in the California-based Soteria Project throughout the study's life, I lived in Washington, D.C., while working for the NIMH. In 1972, I became psychiatric consultant to Woodley House, a half-way house founded in Washington, D.C., in 1958. In consultation, staff were often distressed when describing house residents who went into crisis, and there was no option but to hospitalize them. Recovery from such institutionalizations they saw as taking nearly 18 months. So, in 1977, a Soteria-like facility (called "Crossing Place") was opened by Woodley House Programs that differed from its conceptual parent in that it:

- 1) admitted any nonmedically ill client deemed in need of psychiatric hospitalization regardless of diagnosis, length of illness, severity of psychopathology, or level of functional impairment;
- 2) was an integral part of the local public community mental health system, which meant that most patients who came to Crossing Place were receiving psychotropic medications; and
- 3) had an informal length of stay restriction of about 30 days to make it economically appealing.

So, beginning in 1977, a modified Soteria method was applied to a much broader patient base, the so-called "seriously and persistently mentally ill". Although a random assignment study of a Crossing Place model has only recently been published (Fenton et al., 1998), it was clear from early on that the Soteria method "worked" with this nonresearchcriteria-derived heterogeneous client group. Because of its location and "open" admissions Crossing Place clients, as compared with Soteria subjects, were older (37), more nonwhite (70%), multiadmission, long-term system users (averaging 14 years) who were raised in poor urban ghetto families. From the outset, Crossing Place was able to return 90% or more of its 2000 plus (by 1997) admissions directly to the community-completely avoiding hospitalization (Kresky-Wolff et al., 1984). In its more than 20 years of operation, there have been no suicides among clients in residence, and no serious staff injuries have occurred. Although the clients were different, as noted above, the two settings (Soteria and Crossing Place) shared staff selection processes (Hirschfeld et al., 1977; Mosher et al., 1973), philosophy, institutional and social structure characteristics, and the culture of positive expectations.

In 1986 the social environments at Soteria and Crossing Place were compared and contrasted as follows:

In their presentations to the world, Crossing Place is conventional and Soteria unconventional. Despite this major difference, the actual in-house interpersonal interactions are similar in their informality, earthiness, honesty, and lack of professional jargon. These similarities arise partially from the fact that neither program ascribes the usual patient role to the clientele. Crossing Place admits "chronic" patients, and its public funding contains broad length-of-stay standards (1 to 2 months). Soteria's research focus views length of stay as a dependent variable, allowing it to vary according to the clinical needs of the newly diagnosed patients. Hence, the initial focus of the Crossing Place staff is: What do the clients need to accomplish relatively quickly so they can resume living in the community?

This empowering focus on the client's responsibility to accomplish a goal(s) is a technique that Woodley House has used successfully for many years. At Soteria, such questions were not ordinarily raised until the acutely psychotic state had subsided-usually 4 to 6 weeks after entry. This span exceeds the average length of stay at Crossing Place. In part, the shorter average length of stay at Crossing Place is made possible by the almost routine use of neuroleptics to control the most flagrant symptoms of its clientele. At Soteria, neuroleptics were almost never used during the first 6 weeks of a patient's stay. Time constraints also dictate that Crossing Place will have a more formalized social structure than Soteria. Each day there is a morning meeting on "what are you doing to fix your life today" and there are also one or two evening community meetings.

The two Crossing Place consulting psychiatrists each spend an hour a week with the staff members reviewing each client's progress, addressing particularly difficult issues, and helping develop a consensus on initial and revised treatment plans. Soteria had a variety of ad-hoc crisis meetings, but only one regularly scheduled house meeting per week. The role of the consulting psychiatrist was more peripheral at Soteria than at Crossing Place: He was not ordinarily involved in treatment planning and no regular treatment mee

In summary, compared to Soteria, Crossing Place is more organized, has a tighter structure, and is more oriented toward practical goals. Expectations of Crossing Place staff members are positive but more limited than those of Soteria staff. At Crossing Place, psychosis is frequently not addressed directly by staff members, while at Soteria the client's experience of acute psychosis is often a central subject of interpersonal communication. At Crossing Place, the use of neuroleptics restricts psychotic episodes. The immediate social problems of Crossing Place clients (secondary to being system "veterans" and also because of having come mostly from urban lower social class minority families) must be addressed quickly: no money, no place to live, no one with whom to talk. Basic survival is often

the issue. Among the new to the system, young, lower class, suburban, mostly white Soteria clients, these problems were present but much less pressing because basic survival was usually not yet an issue.

Crossing Place staff members spend a lot of time keeping other parts of the mental health community involved in the process of addressing client needs. The clients are known to many other players in Lite system. Just contacting everyone with a role in the life of any given client can be an all-day process for a staff member. In contrast, Soteria clients, being new to the system, had no such cadre of involved mental health workers. While in residence, Crossing Place clients continue their involvement with their other programs if clinically possible. At Soteria, only the project director and house director worked with both the house and the community mental health system. At Crossing Place, all staff members negotiate with the system. Because of the shorter lengths of stay, the focus on immediate practical problem solving, and the absence of clients from the house during the daytime, Crossing Place tends to be less consistently intimate in feeling than Soteria. Although individual relationships between staff members and clients can be very intimate at Crossing Place, especially with returning clients ... it is easier to get in and out of Crossing Place without having a significant relationship (Mosher et al., 1986, pp. 262-264).

A Second Generation Sibling

In 1990, McAuliffe House, a Crossing Place replication, was established in Montgomery County, Maryland. This county's southern boundary borders Washington, D.C. Crossing Place helped train its staff; for didactic instruction there were numerous articles describing the philosophy, institutional characteristics, social structure, and staff attitudes of Crossing Place and Soteria and a treatment manual from Soteria. My own continuing influence as philosopher/clinician/godfather/supervisor is certain to have made replicability of these special social environments easier. In Montgomery County, it was possible to implement the first random assignment study of a residential alternative to hospitalization that was focused on the seriously mentally ill "frequent flyers" in a living, breathing, never before researched, "public" system of care. Because of this well funded system's early crisis-intervention focus, it hospitalized only about 10% of its more than 1500 long-term clients each year. Again, because of a well-developed crisis system, less than 10% of hospitalizations were involuntary- our voluntary research sample was representative of even the most difficult multi-problem clients. The study excluded *no one* deemed in need of acute hospitalization except those with complicating medical conditions or who were acutely intoxicated. The subjects were as representative of suburban Montgomery County's public clients as Crossing Place's were of urban Washington, D.C.; mid-thirties, poor, 25% minority, long durations of illness, and multiple previous hospitalizations. However, many of the Montgomery County

nonminority clients came from well-educated affluent families. The results (Fenton et al., 1998) were not surprising. The alternative and acute general hospital psychiatric wards were clinically equal in effectiveness, but the alternative cost about 40% less. For a system, this means a savings of roughly \$19,000 per year for each seriously and persistently mentally ill person who uses acute alternative care exclusively (instead of a hospital). Based on 1993 dollars, total costs for the hospital in this study were about \$500 per day (including ancillary costs) and the alternative about \$150 (including extramural treatment and ancillary costs).

Important Therapeutic Ingredients

Descriptively, the therapeutic ingredients of these residential alternatives, ones that clearly distinguish them from psychiatric hospitals, in the order they are likely to be experienced by a newly admitted client, are:

- 1) The setting is indistinguishable from other residences in the community, and it interacts with its community.
- 2) The facility is small, with space for no more than 10 persons to sleep (6 to 8 clients, 2 staff). It is experienced as home-like. Admission procedures are informal and individualized, based on the client's ability to participate meaningfully.
- 3) A primary task of the staff is to understand the immediate circumstances and relevant background that precipitated the crisis necessitating admission. It is anticipated this will lead to a relationship based on shared knowledge that will, in turn, enable staff to put themselves into the client's shoes. Thus, they will share the client's perception of their social context and what needs to change to enable them to return to it. The relative paucity of paperwork allows time for the interaction necessary to form a relationship.
- 4) Within this relationship the client will find staff carrying out multiple roles: companion, advocate, case worker, and therapist-although no therapeutic sessions are held in the house. Staff have the authority to make, in conjunction with the client, and be responsible for, on-the-spot decisions. Staff are mostly in their mid-20s, college graduates, selected on the basis of their interest in working in this special setting with a clientele in psychotic crisis. Most use the work as a transitional step on their way to advanced mentalhealth-related degrees. They are usually psychologically tough, tolerant, and flexible and come from lower middle class families with a "Problem" member. (Hirschfeld et al., 1977; Mosher et al., 1973, 1992) In contrast to psychiatric ward staff, they are trained and closely supervised in the adoption and validation of the clients' perceptions. Problem solving and supervision focused on relational difficulties (*e.g.*, "transference" and "counter-transference") that they are experiencing is available from fellow staff, onsite program directors, and the consulting psychiatrists (these last two will be less obvious to clients). Note that the M.D.s are not in charge of the program.

5) Staff is trained to prevent unnecessary dependency and, insofar as possible, maintain autonomous decision making on the part of clients. They also encourage clients to stay in contact with their usual treatment and social networks. Clients frequently remark on how different the experience is from that of a hospitalization. This process may result in clients reporting they feel in control and a sense of security. They also experience a continued connectedness to their usual social environments.

6) Access and departure, both initially and subsequently, is made as easy as possible. Short of official readmission, there is an open social system through which clients can continue their connection to the program in nearly any way they choose; phone-in for support, information or advice, drop-in visits (usually at dinner time), or arranged time with someone with whom they had an especially important relationship. All former clients are invited back to an organized activity one evening a week.

Characteristics of Healing Social Environments

Both clinical descriptive and systematic staff and client perception data (from Moos, 1974, 1975) are available to compare and contrast Soteria, Crossing Place, and McAuliffe House with their respective acute general hospital wards and each other (Mosher, 1992; Mosher et al., 1986, 1995; Wendt et al., 1983).

Clinical characteristics of the hospital comparison wards included in the original Soteria study have been previously described (see Wendt et al., 1983) and are applicable to the hospital psychiatric ward studied in the Montgomery County research. The clinical Soteria-Crossing Place description and "Important Therapeutic Ingredients" explicated earlier are applicable across all three alternative settings. The Moos scale data comparing Soteria with Crossing Place and McAuliffe House are consistent between the three settings and different from the findings from the comparison wards in the general hospitals.

The Moos instrument, the Community-Oriented Program Environment Scales (COPEs), is a 100-item true/false measure that yields 10 psychometrically distinct variables that can be grouped into three supraordinate categories: relationship/psychotherapy, treatment, and administration. The patterns of similarities and differences between the two types of alternatives (Soteria vs. Crossing Place and McAuliffe House) have remained constant over many testings, as have the hospital differences and similarities to the two kinds of alternatives. The alternative programs share high scores on all three relationship variables (involvement, spontaneity, and support) and two of four treatment variables: personal problem orientation and staff tolerance of anger. Crossing Place and McAuliffe House, however, differ from Soteria in two of three administrative variables: the second generations are perceived as more organized and exerting more staff control (somewhat similar to the hospital scores) than the parent (Soteria). The differences are to be expected, given the differing nature of the clientele and the much shorter average length of stay (<30 days) in the Soteria offspring.

Other Alternatives to Hospitalization

In the 25 plus years since the Soteria Project's successful implementation, a variety of alternatives to psychiatric hospitalization have been developed in the U.S. Their results (including those of the Soteria Project) have been extensively reviewed by Braun et al., 1981; Mesler et al., 1982a, 1982b; Straw, 1982; Stroul, 1987. A subset were described in greater detail by Warner (1995).

Each of these reviews found consistently more positive results from descriptive and research data from a variety of alternative interventions as compared with control groups. Straw, for example, found that in 19 of 20 studies he reviewed, alternative treatments were as, or more, effective than hospital care and on the average 43% less expensive. The Soteria study was noted to be the most rigorous available in describing a comprehensive treatment approach to a subgroup of persons labeled as having schizophrenia. It was also noted that, for the most part, the effects of various models of hospitalization had not been subjected to equally serious scientific scrutiny.

Except in California, where there are a dozen, few "true" residential alternatives to acute hospitalization have been developed. Within the public sector, because of cost concerns, there is now a movement to develop "crisis houses." Their extent or success has not been completely described. However, they are not usually viewed or *used* as alternatives to acute psychiatric hospitalization-although this is subject to local variation. It is surprising that managed care, with its focus on reducing use of expensive hospitalization, has neither developed nor promoted the use of these cost-effective alternatives. It is truly notable that nearly all residential alternatives to acute psychiatric hospitalization are in the public mental health system. Private insurers and HMOs have been extremely reluctant to pay for care in such facilities (see Mosher, 1983).

The Fate of Soteria

As a clinical program Soteria closed in 1983. The replication facility, Emanon, had closed in 1980. Despite many publications (37 in all), without an active treatment facility, Soteria disappeared from the consciousness of American psychiatry. Its message was difficult for the field to acknowledge, assimilate, and use. It did not fit into the emerging scientific, descriptive, biomedical character of American psychiatry, and, in fact, called nearly every one of its tenets into question. In particular, it demedicalized, dehospitalized, deprofessionalized, and deneuroleptized what Szasz (1976) has called "psychiatry's sacred cow"-- As far as mainstream American psychiatry is concerned, it is, to this day, an experiment that appears to be the object of studied neglect. Neither of the two recent "comprehensive" literature reviews and treatment recommendations for schizophrenia references the project (Frances et al., 1996; Lehman and Steinwachs, 1998).

There are no new U.S. Soteria replications. It is possible that, if a replication were proposed as research, it might not receive I.R.B. approval for protection of human subjects as it would involve withholding a known effective treatment (neuroleptics) for a minimum of 2 weeks.

Surprisingly, Soteria has reemerged in Europe. Dr. Luc Ciompi, professor of social psychiatry in Bern, Switzerland, is primarily responsible for its renaissance. Operating since 1984, Soteria Bern has replicated the original Soteria study findings. That is, roughly two-thirds of newly diagnosed persons with schizophrenia recover with little or no drug treatment in 2 to 12 weeks (Ciompi, 1994, 1997a, 1997b; Ciompi et al., 1992). As original Soteria Project papers diffused to Europe and Ciompi began to publish his results, a number of similar projects were developed. At an October 1997 meeting held in Bern, a Soteria Association was formed, headed by Professor Weiland Machleidt of the Hannover University Medical Faculty. Soteria lives, and thrives, admittedly as variations on the original theme, in Europe.

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Appendix C

Letter from Ron Adler, CEO of Alaska Psychiatric Institute to Nelson Page, chair
of the Alaska Mental Health Trust Authority Finance Committee

STATE OF ALASKA
DEPT. OF HEALTH AND SOCIAL SERVICES
DIVISION OF BEHAVIORAL HEALTH

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Anchorage, Alaska 99501

RECEIVED

JUL 15 2004

Dear Mr. Page:

This correspondence concerns the Trust Budget Planning Process and focus areas for FY 06/07. I understand that a request for funding has been submitted to establish a 'Soteria-type' program in the state of Alaska. Such a program can provide an alternative to acute psychiatric hospitalization for those individuals interested in a different recovery pathway.

In my 25+ years of experience in this field, consumer and family members have taught me that recovery from serious and persistent mental illness is an individualized process. What works for some people does not always work for others. With absolutely no desire to be engaged in the medication vs. 'no' medication debate in Alaska, certain facts are evident: (1) there is sufficient debate, nationally, on this topic; (2) not all persons benefit from psychotropic drugs; (3) the newer atypical drugs yield the best results when combined with evidence-based psychosocial treatments; (4) some individuals can and will recover in alternative settings.

The fact that some individuals can and will recover in alternative settings was demonstrated during my employment at *THE CLUB*, a Fountain House psychosocial rehabilitation program operated by the University of Medicine and Dentistry of New Jersey. For several years, this internationally known program had 12 residential beds attached to the main clubhouse program. Since it was located in a very large CMHC, medical intervention was available if needed. Clubhouse members (consumers) had the opportunity to use a residential bed as an alternative to acute hospitalization under the following circumstances: (a) the member was 'active' in the program; (b) the treatment team supported the use of the alternative to hospitalization; (c) the member participated in the daily clubhouse activities to the best of his/her ability. Medication was not a requirement for club membership, therefore, not insisted upon for the residential bed. However, the member must be regularly engaged with the treating physician (phone calls, visits, etc.).

 **COPY**

My experience at Alaska Psychiatric Institute reinforces what I have been taught during my 'clubhouse' years. API admits over 1300 consumers each year to the hospital. It is estimated that approximately 10% of this population would benefit from an alternative environment for recovery. Such a program, located in the community, should have trained 'peer' counselors with no limitation on length of stay.

In summary, know that I support a planning, development and implementation strategy to establish such a program in Alaska. Moreover, please do not hesitate to use my experience in the planning process.

On a separate issue, Nelson, how about taking a tour of the new facility as it is 80 % complete. I'll follow up with a phone call in a couple of weeks.

Sincerely,



Ron Adler, CEO
Alaska Psychiatric Institute

cc: Jim Gottstein