Neuroleptic Awareness
Part 6

‘Schizophrenia’
Prognosis
Alternative Approaches
Informed Consent

Introduction

The purpose of this document is to provide an increased awareness about prognosis of ‘schizophrenia’ and informed consent in relation with neuroleptic ‘treatments’ made available in official literature.

An overview for prognosis and recovery in relation with alternative treatments is proffered which is not made transparent in mainstream literature.

The NICE Guideline on Core Interventions in the Treatment and Management of Schizophrenia in Adults in Primary and Secondary Care. Updated edition 2010
http://www.nice.org.uk/nicemedia/pdf/CG82FullGuideline.pdf

Prognosis, Course and Recovery

'Schizophrenia' patients:

- ***80% will relapse within 5 years of a treated first episode***
  NICE Guideline 2.1.3 Prognosis, course and recovery

- ***Studies over periods of 20 to 40 years suggest that there is a moderately good long-term global outcome in over half of people with schizophrenia.***
  NICE Guideline 2.1.3 Prognosis, course and recovery

The percentages are unclear in relation to prognosis because if 80% do poorly, how can over half do moderately well?

Prognosis, Course and Recovery

'Long-term global outcomes', include developed and *developing (less industrialised)* countries.
On closer examination in *developing* countries, patients ***"experienced significantly longer periods of unimpaired functioning in the community",*** compared with those in developed countries.
Source: *"What Did the WHO Studies Really Find?"(2008)*
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2632391/

The notable factor in comparing patients' recovery in *developing* and developed countries is ***"only 16% of them were on continuous antipsychotic medication (compared with to 61% in the developed countries)."***
Source: *"What Did the WHO Studies Really Find?" (2008)*
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2632391/

Prognosis Course and Recovery

Higher rates of chronic disability and dependency are found in developed high income countries, who are able to afford expensive neuroleptic drugs.

In developing countries i.e. India and Nigeria, who are least likely to afford costly neuroleptic medication, patients at 2-year and 5-year follow-up had markedly better overall outcomes.
Source: *"What Did the WHO Studies Really Find?" (2008)*
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2632391/

These findings indicate strongly that 'treatment' with neuroleptic medication is an obstacle to recovery in 'schizophrenia'.

Prognosis, Course and Recovery

Relapse rates *with* neuroleptic 'treatment' need to be compared to relapse rates *without* neuroleptic 'treatment':

Bockoven study 1947-1952 and 1967-1972.

- There was a greater rate of relapse in ***medicated*** patients - 66%.
- Only 44% of the first ***unmedicated*** cohort relapsed in a 5-year outcome period.

Source: "Rethinking Psychiatric Drugs A Guide for Informed Consent" Grace Jackson MD, 2005
Also in
Grace E. Jackson MD. Affidavit, Appendix B, Successful Alternatives to Antipsychotic Drug Therapy
http://psychrights.org/States/Alaska/CaseXX/3AN-08-493PS/JacksonOnNLtoxicity.pdf

Prognosis, Course and Recovery

The course of 'schizophrenia' has worsened over the passage of time with 'treatment' by ***medication.***

In the pre-neuroleptic ***unmedicated*** era, outcomes for patients were much better in developed or industrialised societies. In 1800 the Moral Treatment Movement, with humanitarian values, was the focus of care in European and American asylums; the rates of discharge reached 60 to 80%.

For today's ***medicated*** patients the treatment incurs a 30% recovery rate:
"around three quarters of people with the schizophrenia will suffer recurrent relapse…80% will relapse within 5 years of a treated first episode…"
NICE Guideline 2.1.3 Prognosis, course and recovery

However in Finland where the Open Dialogue Approach is used, ***medications are used significantly less,*** with an 82% rate of full remission of psychotic symptoms.
http://www.iarecovery.org/documents/open-dialogue-finland-outcomes.pdf

Selective Data

The DH and **NICE** are selective about the provision of Mental Health data, and regulate information available to the public.

Data selectivity stems from a 'need to know' basis. The main focus in **NICE** 'schizophrenia' guidelines is neuroleptic 'treatment'; by excluding sensitive material, e.g. global outcomes support findings that prognosis is better in developing countries, potential and valid challenges to **NICE** about medication treatment are prevented.

Sensitive Data

Challenges frequently result in promises of yet more research (with medication) and defensive excuses such as ‘the benefits far outweigh the risks’ despite evidence to the contrary depicting that ‘the risks far out weigh the benefits’ for 80% of patients and their carers.

Requests for mental health data can be refused by the application of exemptions to the Freedom of Information Act 2002.

Silence is another evasive tactic used in response to requests for information whether from professionals in the field or statutory and regulatory bodies and used in the assumption that eventually the challenges will go away.

Silence and evasive behaviour is the equivalent to ‘running away’ from relational difficulties and is classified as an autistic trait.

Effective Non-Neuroleptic Approaches

- **There are some 40 descriptions of Effective Non-Neuroleptic Treatments**: http://psychrights.org/Research/Digest/Effective/effective.htm

- **The Vermont Longitudinal Study revealed that all the patients with full recoveries had stopped medication completely.**
  Grace E. Jackson MD. Affidavit, Appendix B, Successful Alternatives to Antipsychotic Drug Therapy
  http://psychrights.org/States/Alaska/CaseXX/3AN-08-493PS/JacksonOnNLtoxicity.pdf

- **The Agnew State Hospital Experiment showed best outcomes in those who avoided neuroleptics during and after hospitalisation.**
  Grace E. Jackson MD. Affidavit, Appendix B, Successful Alternatives to Antipsychotic Drug Therapy
  http://psychrights.org/states/alaska/CaseXX/3AN-08-493PS/JacksonOnNLtoxicity.pdf

The Soteria Project 1973 – 1981

Over nine years 179 young psychotic people were treated: "Most significantly, Soteria involved the minimal use of neuroleptics or other drug therapies." A control group received standard care at a psychiatric hospital.

2 years outcomes for the Soteria group were significantly superior in terms of residual symptoms, need for re-hospitalization and ability to return to work.

76% remained drug-free during the early stages of treatment and 42% remained drug-free throughout the two-year period.

Source: Grace E. Jackson MD.Affidavit, Appendix B, Successful Alternatives to Antipsychotic Drug Therapy
http://psychrights.org/states/alaska/CaseXX/3AN-08-493PS/JacksonOnNLtoxicity.pdf

Soteria UK Movement: www.soterianetwork.org.uk

Psychological Resources

Neuroleptics may be contra indicated because of the negative impact upon psychological resources.

"…a number of clinicians have suggested that the period immediately following an acute schizophrenic break is critical and that how a patient is treated during this time is quite important… the acute schizophrenic needs to retain his sensitivity and awareness and must have full access to all his psychological resources. Phenothiazines (neuroleptics) by reducing neurological sensitivity, may interfere with these problem solving, re-integrative responses."
Source: Rappaport et al (1978)

"…compliance with neuroleptic drug treatment was neither necessary, nor sufficient, for recovery."

Source: PsychRights http://psychrights.org/index.htm : Dr. Grace E. Jackson Affidavit.

“Taken as a body of scientific evidence, it is clear that alternatives to acute hospitalization are as, or more effective than the traditional hospital care in the short term reduction rate of psychopathology and longer social adjustment”

Source: Mosher (1999) http://www.moshersoteria.com/soteriawp/wp-content/uploads/2009/12/soteria.pdf

Expenditure

"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."**

Source: Loren R. Mosher, M.D. (1999)
http://www.moshersoteria.com/soteriawp/wp-content/uploads/2009/12/soteria.pdf

Balancing the Cost

Currently the UK NHS trusts have financial difficulties in supplying acute services in Mental Health:

Sheffield Health and Social Care NHS Foundation Trust throughout 2009 had been running at well above the 85% inpatient ward occupancy rate nationally recommended by the Care Quality Commission, and Royal College of Psychiatrists.

During 2009 inpatient admission rates rose from 55 to 72 patients per month, and in the early part of 2010, this NHS Foundation Trust has been operating with an over-occupancy rate at 110%.

At Lower Cost

The over-occupancy rates reflect many of the difficulties resulting from neuroleptic ‘treatment’ incurring an 80% relapse rate, whether caused by discontinuation or Super Sensitivity Psychosis, necessitating rehospitalisation.

If the treatment was radically altered so that patients were cared for **HUMANISTICALLY**, similar to the Open Dialogue Approach and Soteria values, with better outcomes, then trusts would no longer experience financial difficulties and patients would not be sent ‘out of town’, because of over occupancy.

THIS WOULD LOWER COSTS

Therapeutic Alliance

NICE Guidelines Document:

"Establishment of trust is crucial and reliability and constancy on the part of professionals is an important component of this. The individual with schizophrenia may not share the professionals' view of what the main problem is."

NICE Guideline 2.5 Engagement, Consent and Therapeutic Alliance

Alternative interpretation:

When patients do not agree with the professionals' view of neuroleptic 'treatment', an attempt is made towards gaining patients trust with the purpose of correcting patients perceived 'lack of insight'.

Therapeutic Alliance

"Seeking out and assisting with what the individual regards as the main problem can provide a route towards 'common ground'. This common ground can establish trust and collaboration, allowing further collaborative care planning over time."

NICE Guideline 2.5 Engagement, Consent and Therapeutic Alliance

Alternative interpretation:

Through the 'common ground' developed in the 'therapeutic alliance' patients are manipulated and unwittingly coerced into the professional perspective that medication maintenance is the appropriate treatment.

Therapeutic Alliance

The ‘therapeutic alliance’ is disrespectful when used to coerce patients into taking neuroleptic medication. Manipulation and coercion is not conducive to the Person Centred therapeutic alliance relationship that nurtures trust which is essential for psychological growth resulting in recovery.

Informed Consent

*"Before each treatment decision is taken, healthcare professionals should ensure that they: provide service users and carers with full, patient-specific information in the **appropriate format** about schizophrenia and its management, to ensure **informed consent** before starting treatment."*
NICE Guideline 4.6.5.1 Consent, capacity and treatment decisions

'***Appropriate format'*** is designed with the objective of making medication seem like an acceptable risk by dumbing down neuroleptic adverse effects and by the use of language to the lowest common denominator which is potentially patronising.

Mental Health Agencies and Informed Consent

Surveys from MIND and Rethink show the inadequacies of medication side effects information given to patients by professionals:

Mind "Understanding Mental Illness" What are the different treatments?
"Users of mental health services…want to have more say in their own treatment. This means being properly informed about undesirable effects of drugs, for example."

Rethink "Only the Best" 2006
"Properly informed consent should be obtained whenever possible before treatment begins." In the Rethink survey there is an admission that ***"only half had been told about possible side effects."*** (NICE guideline 4.5.2 Service user experiences)

A more trusting relationship in the 'therapeutic alliance' would develop if professionals were transparent and upfront about neuroleptic side effects information from day one.

Mental Health Agencies and Informed Consent

Mental Capacity and Mental Health Legislation

Patient UK
Comprehensive health information as provided by GPs and nurses to patients during consultations

"An advance refusal is legally binding providing that the patient is an adult, the patient was competent and **properly informed** when reaching the decision, it is clearly applicable to the present circumstances and there is no reason to believe that the patient has changed his or her mind."

http://www.patient.co.uk/doctor/Consent-To-Treatment-%28Mental-Capacity-and-Mental-Health-Legislation%29.htm

Consent and First-Episode Psychosis

Consent To Treatment under the Mental Capacity and Mental Health Legislation, is applicable to patients who are currently in the mental health system. The first point of contact with the mental health system for many patients and carers is in a first-episode psychosis.
This raises various issues:

- Patients are often sectioned, having no right to refuse neuroleptic drugs and forced to comply with medications.
- Patients are severely stressed and it is doubtful they will be able to make an informed decision about medication and thereby give informed consent.
- Carers generally comply with ‘treatment’ out of anxiety and fear and a misguided trust of the ‘experts’.

Fully Informed Consent

- ‘Schizophrenia’ is not at all like diabetes, as many professionals, patients and carers are misled to believe, where you have to take Insulin for the rest of your life.

- According to Rob Whitaker the diabetes analogy is “an over-simplification and a fraudulent marketing metaphor.”

Source: Mosher et al (2006)
http://uk.video.search.yahoo.com/search/video?p=The+truth+about+fixing+chemical+imbalances

Fully Informed Consent

Professionals, patients and carers would benefit from the scientific neuroleptic knowledge found in:

“Rethinking Psychiatric Drugs:
A Guide for Informed Consent”
Grace E. Jackson, MD

This pertinent information does enable professionals to assist patients and carers in making a fully informed decision about ‘treatment’ to ensure **Fully Informed Consent.**

Fully Informed Consent and Pharmacogenetics

Neuro-Toxicity increases when you are unable to breakdown (metabolise) neuroleptics because of your inborn "make up" or Genotype.

If you have a **Poor Metaboliser Genotype** or an **Ultra Metaboliser Genotype** (for prodrugs) you are more likely to suffer adverse effects, both physically and psychologically, and have difficulty in withdrawing from neuroleptic medication.

A Genotyping Test to determine your genotype can help to minimise adverse effects up front and go a long way in preventing neuroleptic induced psychosis and suicide.

Being fully informed about the genotyping test facilitates properly informed consent and assists in treatment decisions.

Fully Informed Consent

Full consent to neuroleptic ‘treatment’ requires the following knowledge up front for both patients and carers.

- Comprehensive information about neuroleptic physical and psychological side effects.
- Pharmacogenetics and the genotyping test.
- Permanent brain damage due to increasing neuro-toxicity when neuroleptics are taken long term.
- Accurate global outcomes in association with long-term disability and prognosis.

Conclusion

NICE is selective in the provision of data about prognosis course and recovery in medicated patients. Pertinent data about better outcomes in developing countries is excluded and research supporting successful non-medicated approaches with far superior outcomes is not addressed.

The omission of relevant information ensures mental health care professionals, patients and carers are misled as to the accurate global prognosis; it also ensures local polices inherit and perpetuate non-successful medication ‘treatment’ for patients in the system and for many unsuspecting patients in the future.

Pharmaceutical industries inevitably foster neuroleptic ‘treatment’ and the withholding of undesirable side effect information prevents professionals, patients and carers from having properly informed consent in decision making about treatment. Those who are more discerning in their sources of information, particularly the professionals acting in good faith, are left with uncomfortable truths.

Conclusion cont…

In regards to mental health expenditure, it seems 'experts' cannot see the wood for the trees. Costs would be cut, provided the focus on disabling neuroleptic treatments was replaced by humanitarian care and values.

Professionals are expected by **NICE** to do their duty in providing ***"…good clear and honest information regarding schizophrenia and about the treatments…"***.

There is a lack of transparency in the Guideline about better outcomes resultant from treatment without neuroleptics, about the withholding of sensitive data, and about communication in the guidelines which is wholly ambiguous. Professionals who follow the guidelines are unable to impart information to patients and carers which is honest and reliable.

Only when national guidelines are underpinned by professional people - who have undertaken personal self-development and have strong personal boundaries - will official documents provide reliable data for professionals to respectfully fulfil their duty and supply 'good clear and honest information' about schizophrenia and treatments to patients and carers.

Otherwise it is like the blind leading the blind.

Useful websites for further information:

Law Project for Psychiatric Rights:
http://psychrights.org/index.htm

AHRP Alliance for Human Research Protection
www.ahrp.org

MindFreedom International: Mental Health Rights and Alternative Mental Health
http://www.mindfreedom.org/

The Center for the Study of Empathic Therapy, Education and Living.
http://www.empathictherapy.org/

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April 2012