Treatment refusal in schizophrenic patients : autonomy or irrationality?

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Conflict of interest!

- I am not a psychiatrist
- I am not a professional philosopher
- I am a medical doctor (an intensivist)
- I am the father of a schizophrenic patient
  - A young 20 yrs old man
    - « Dad : *I am* a Schizo! What's that life? »
- So : my defence of autonomy for such patients is not objectively but emotionally founded

Schizophrenia : a stigma

IT HAPPENED TO ME: I'M A PARANOID SCHIZOPHRENIC

My online friends, the few who know this story, say they are sad for me because I never experienced my early twenties in the way everyone else should. I've never been to a nightclub or held down a real job for long, I don't have friends, and I live with my mum and dad at an age where most of my old school friends have children and spouses of their own.

Still, I'm only 26. I have to hang onto that. I have to believe the best years are in front of me. (Posted on June 12, 2012 by Katy Hawkins on xojane.com)

Eliminating the Word "Schizophrenic"

« There's always been a double standard in mental health when it comes to schizophrenia. If you suffer from depression, are you a depressionist? Then why should a person who suffers from schizophrenia be a schizophrenic? » (Posted on September 17, 2012 by Chris Curry on healthyplace.com)

It's pronounced...

[skit-suh-FREE-nee-uh]

not

[KREY-zee]

Fight Stigma

Decision-making capacity impaired?

- Decision-making capacity involved several components
  - Understanding
    - ie, comprehending the nature of the consent-relevant information
  - Appreciation
    - ie, understanding how the information applies to one's own condition and situation
  - Reasoning
    - With the information provided
  - Evidencing a choice
    - About participation vs non participation

Jeste, *Schizophrenia Bulletin* 2006

Decision-making capacity impaired?

- Due to affective and cognitive complexity of these tasks :
  - Some clinicians may make assumptions about consistently impaired decision-making capacity in people with schizophrenia :
    - Unable to make autonomous (informed) decisions
    - Globally irrational
      - ie, unable to manifest coherent thought and action
      - Evidenced through incongruence and/or behaviours self-defeated or self-harming
    - By virtue of their ‘status’ diagnosis
      - The presence of delusions and hallucinaitons seen as sign of irrationality or as lack of mental capacity

Hewitt, *Theor Med Bioeth* 2010

Decision-making capacity impaired?

- Autonomy = rationality?
  - Logical consistency
    - Where one's desires, beliefs, actions, perceptions, intentions and decisions must fit together → coherent plan → action « reason-based » (cognitive coherence)
- Irrationality = lack of autonomy
  - Inconsistancy of behaviour *of the person*
    - Conflicting beliefs and desires
    - Fail to revise beliefs and desires / available evidence
  - Danger in cases of high-risk decisions
    - Ex : life-saving treatments
- Consequently : 2 « hard » principles invoked *by others:*
  - Beneficence
  - Non-maleficence

Hewitt, *Theor Med Bioeth* 2010

Local Ethics Consultation: 3 cases

- A 49 yrs old patient
  - AIDS and refusal of antiretroviral treatment
    - Question : « how to force the patient to take his treatment? »
- A 28 yrs old patient
  - End-stage renal insufficiency and refusal of dialysis
    - Question : « can we let this patient die? »
- A 40 yrs old patient
  - Testicular cancer and refusal of surgery
    - Question : « how to perform surgery against his will? »

Nantes Clinical Ethics Consultation

- Methodology
  - Request by :
    - medical and/or nursing staff
    - Patient
    - Family
  - Consultation with :
    - Medical doctor
    - Non medical consultant
  - Multidisciplinary staff :
    - Presentation of the case
    - Round table : hierarchy of principles
  - Restitution
  - Follow-up

J.F. case (1)

- Request by the psychiatric team and GP
  - « how to force the patient to take his anti-HIV treatment? »
  - « what to do in case of emergency? Let him die? »
- J.F., 49 yrs old single man
  - 25 yrs old : diagnosis with paranoid schizophrenia
    - Frequent relapses (frequent hospitalizations)
    - Grandiose delusions; lack of insight to her mental illness
  - Lives with his old parents (help them for their daily needs)
    - Father : « he is a like a god! » « always unpredictable » « original » « refused to pass his exams…against the « system » »
  - Few social relations
    - Drug abuse (alcohol, drugs); prostitution
- HIV
  - 2001: sero +
  - 2005: AIDS
    - Complications : lymphoma; cerebral toxoplasmosis; siphilis)
    - Continue to have unprotected sexual relations (hammam, etc.)
- Recent hospitalization (requested by his sister)
  - Refusal of anti-HIV and psychiatric treatment

J.F. case (2)

- Consultation (PB, MD; GD, philosopher; MJ, biologist)
  - Patient : 2 reasons for refusal:
    - « I feel good »; « I'm not ill »; « I'm being held hostage »; « god is protected me »
    - « I can't support diarrhea »; « I want to go back at home…take care of my cats »
      - Question : « do you want to die? »
      - Response : « I am 50 yrs old…I don't want to suffer »
  - Nursing staff : « the patient want to go back home »
  - Fellow : « partly autonomous. He would take his medication. The « Other » don't want »
  - Infectiologist : « This patient is out of reality. Can't judge »
  - Psychiatrist : « danger : conscient of the risks for him, not for others… »
  - Father : « he must be forced to take his treatment (when he no longer takes his treatment, he hears nothing), but I can't do it myself, I am 85 yrs old!
- Staff
  - degree of autonomy
    - Want to live
    - Reason for refusal : complications of the treatment
    - We can't force him to take his treatment
    - Negotiation+++
- Follow-up
  - Adaptation of the treatments
  - Acceptation of the treatments
  - Back home

L. case (1)

- Request by the psychiatric team
  - « Can we let the patient die without dialysis? »
- L., 28 yrs old man
  - Schizophrenia : frequent relapses and hospitalizations (against his will)
    - Drug abuse, drug trafficking, behavioural disorder, delusions of persecution, loss of reality, ambivalence
    - Treatment resistance
- Renal insufficiency (cause?)
  - 2011 : end-stage renal failure (dialysis 3/week)
  - Contra-indication to transplantation due to his mental illness
  - Anxiety during dialysis
- Recently
  - Refusal to dialysis despite high creatininemia-kaliemia

L. case (2)

- Consultation (GD, MD; DB, jurist)
  - Psychiatrist : « resistance to treatment (a new one is introduced) »; « maleficence to continue dialysis: suicidal risk »
  - Nursing staff: difficulty to stop the dialysis and let him die but can't force him : give him the possibility of choice
  - Patient : seems to understand the risk of death; want live; but prefers die if dialysis 3/week; want to be accompanied by his mother
- Staff
  - Degree of autonomy
    - Want to live
  - Beneficence/nonmaleficence > autonomy:
    - Necessary to continue dialysis against his will
    - negotiate 2 dialysis/week
    - If new refusal: respect the patient's desire (temporality)
- Follow-up
  - Back home
  - 2 dialysis/week
  - New refusal : not dialysed and died

Q. case (1)

- Request by the psychiatric team
  - « How to perform surgery against the will of the patient? »
- M. Q., 40 yrs old single man
  - Paranoid schirophrenia : schizophasia, affective dysregulation (distortion)
  - Independant in his daily life (curatorship)
  - Recently hospitalized for stopping treatment
- Testicular cancer
  - Fortuitous discovery
  - Surgical indication
  - Refusal of surgery
    - « aware of the seriousness of the disease »
    - Refused consultation of anaesthesia
- Kept at the hospital hoping he changes his mind

Q. case (2)

- Consultation (GD, MD; ML, lawyer)
  - Psychiatrist : hampered because it is « harmful not operate (good prognosis of testicular cancer) »; « M.Q. is happy in his life…is in his world »; « not suicidal »; « able to understand »
  - Nursing staff : « M.Q. is peaceful »; « no way to force him to have surgery »
  - Patient : agitated, verbally abusive, knows « how to heal »…but remains to us to keep the conversation
- Staff
  - autonomy? « complex »
    - Able to decide for his everyday life
    - Able to choose / testicular cancer?
  - Beneficence/nonmaleficence > autonomy
    - Dilemma : Harmful to force him but maleficence not to operate → « let time decide »
- Follow-up?

Discussion (1)

- These cases « confirm » that :
  - Clinicians may have a tendency to equate treatment refusal with incapacity to decide and treatment acceptance with capacity
    - « The more serious the decision, the greater the capacity required » (Hewitt)

- In a review of 12 published empirical studies (Jeste)
  - Impairement in capacity is not a distinguishing feature of schizophrenia
    - From 10% to 52% of the people with S and from 0% to 18% of nonpsychiatric comparison subjects (NPC) were classified as being impaired in capacity
    - S and NPC groups overlapped by 48% to 79% on the MacCAT measures
  - There exists considerable within-group heterogeneity in decisional capacity among patients with schizophrenia
- Other studies have shown that :
  - People with S reasoned more logically than healthy individuals (Owen)
  - Both normal and deluded subjects frequently made logical errors (Kemp)

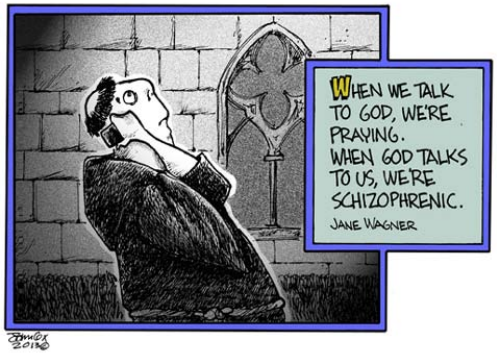
Hewitt, *Theor Med Bioeth* 2010
Jeste, *Schizophrenia Bulletin* 2006
Owen, *B J Psychiatry* 2007
Kemp, *B J Psychiatry* 1997

Discussion (2)

- These cases « suggest » that :
  - The patients are able to say what is *essential to them*
    - Whatever the capacity to make rational decisions at each time (ie means-ends reasoning and planning ability)
    - Think it is *correct* in wanting what they want (sense of self-worth?)
      - In terms of Jaworska : are *valuers*
        - Values (≠ desires) as « minimal requirements for the capacity for autonomy and for the authority concerning one's well-being »
  - The patients seem to have sense *of a whole life* (a past joined to a future ie *authenticity?*)
    - Despite lack of consistency and stability in their « daily » choices
    - Can grasp what's best for their life as a whole
      - In terms of Dworkin : have experiential interests (state of mind) *and* critical interests (doing the things we consider good and in avoiding the things we consider bad)

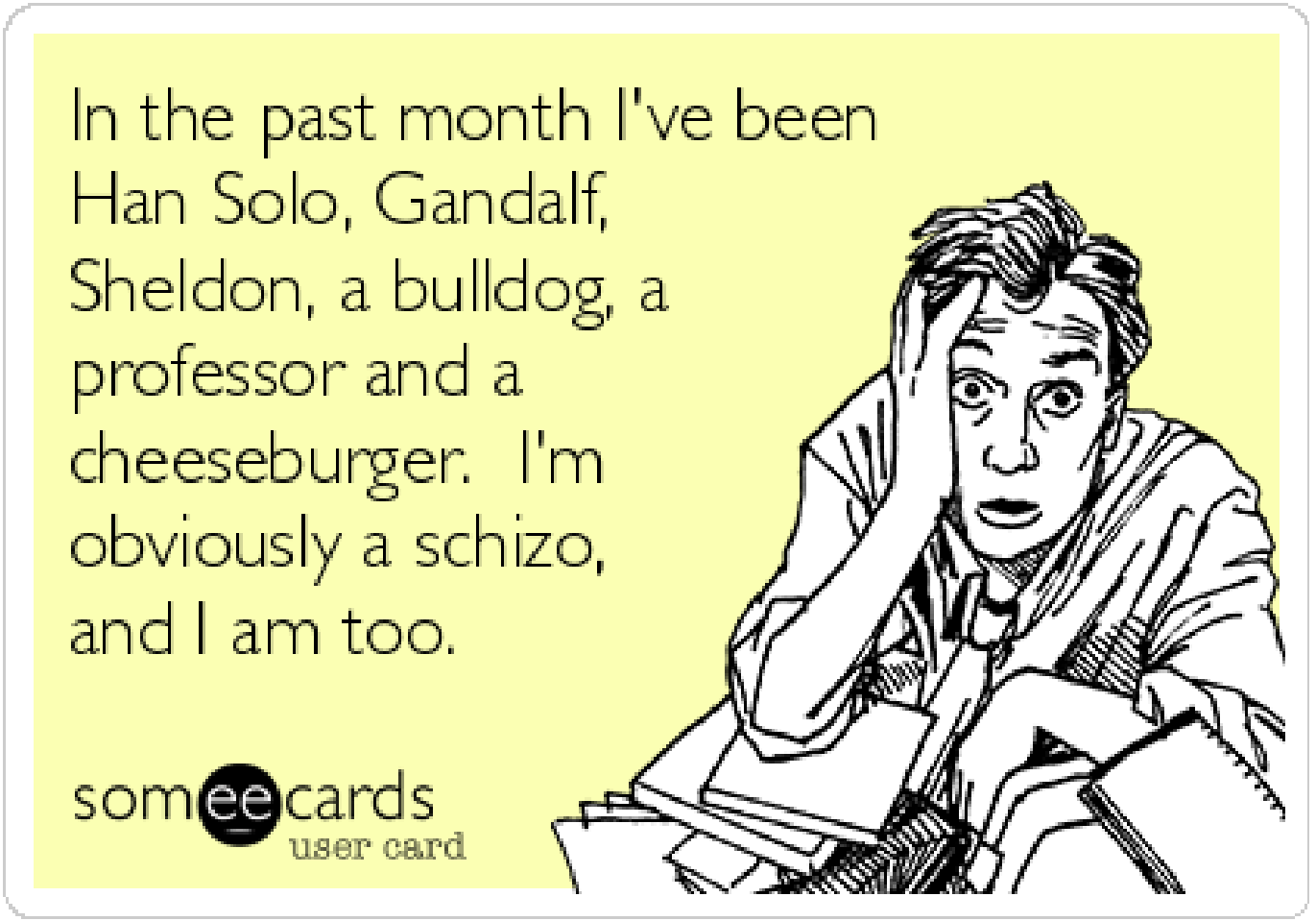
Agnieszka Jaworska, « Respecting the margins of agency: Alzheimer's patients and the capacity to value ». *Philosophy § Public Affairs* 1999
Ronald Dworkin, *Life's Dominion*, NY, Alfred Knopf 1993

Suggested conclusion



- This case study tried to show that :
  - decisional capacity to refuse life-saving treatments in schizophrenic patients is a context-specific construct in such patients frequently labelled as irrational by virtue of their mental disorder
    - leading to *paternalistic attitudes* among caregivers
  - autonomy remains a strong ethical principle
    - defined as *authenticity* (?) and *capacity to value*
    - Justifying the *right to refuse medical treatment*, whatever the personal consequences may be.

Thank You!


In the past month I've been Han Solo, Gandalf, Sheldon, a bulldog, a professor and a cheeseburger. I'm obviously a schizo, and I am too.
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