

Service User or Patient? – just a question of semantics?

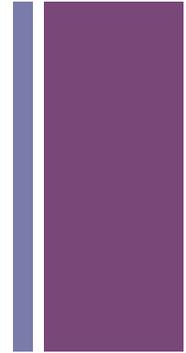
NAPICU 11-13 September 2013 – Debate

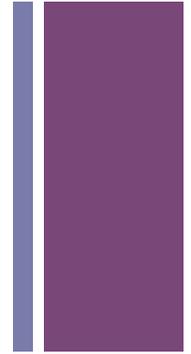
Dr Stephen Pereira

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+ Retention of the term 'patient'

1. 'Patient' origins and connotations : medical model
2. Service user meaning and connotations
3. Defining roles of patients
4. Defining roles of caregivers
5. Risk assessment, Mental Capacity & safeguarding
6. Mental Health Stigmatism
7. Critique of 'service user'
8. In Summary

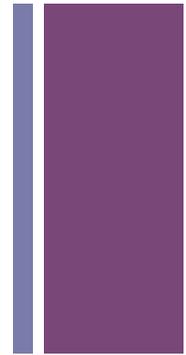




Patient Definition and Connotations

+ 'Patient' Definition

- Latin definition is that of 'one who suffers'
- Can be easily identified as one who is being attended to by a health professional
- Captures unique doctor-patient relationship
- The relationship evolved over centuries and is based on mutual respect, openness, shared values, trust and knowledge

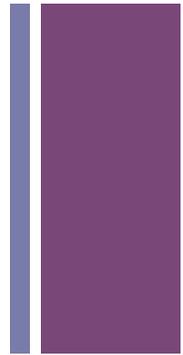


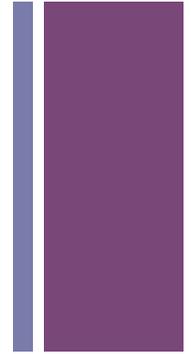
+ Connotations of 'Patient'

- Someone who is less capable
- Someone who needs help and is unable to help themselves
- The word 'patient' implies ill or suffering with a type of mental illness

Treatment Implications

- The caregiver in this instance is supportive, accepting, empathic to suffering

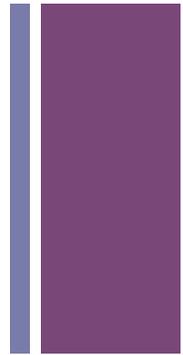




Service User Definition and Connotations

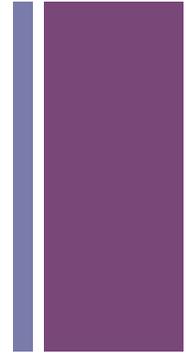
+ Definition: 'Service User'

- A user of a service, in this case a user of services provided by health care organisations
- A global term which can encompass any service
- It is a neutral, objective and detached phrase





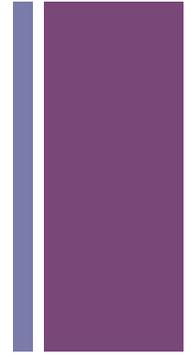
Connotations of 'Service User'



- Often the term is shortened to 'user' which has connotations with drug use and abuse
- Can be misleading as it is not specific to health care
- Service user insinuates that participants are voluntary. Often those lacking insight are not seeking treatment on a voluntary basis

Treatment Implications

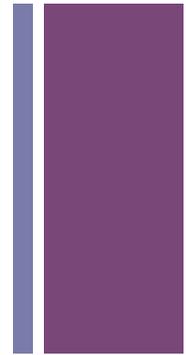
- The caregiver in this instance is also detached if 'equal dynamic/position of power' is aspired to



Defining Roles of Patient

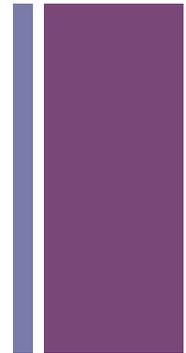
+ Patient Role

- To be in receipt of good rapport with physician and have a relationship built on mutual respect, knowledge and trust
- It is of use for the patient to understand that their problems are medical and the term 'patient' is instantly recognisable (Beresford et al (2010))



+ Patient Role

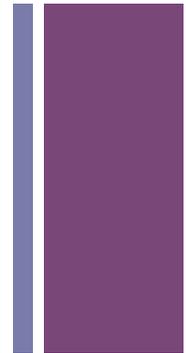
- It is more scientific: a rational explanation of problems met with a range of experts who can deal with them also known as the 'medical model'
- It is more directive to access rights and entitlements such as time off work and medical certification



+ 'Patient' View Point

Patient vs Service User

- “I believe the word ‘user’ is inappropriate and would make people feel bad about being here”
- “I see mental health problems in the same way as physical problems, and therefore being called a patient is appropriate for both. I see a counsellor, for which I pay – for this I think either patient or client is appropriate”
- “Mental health issues should be treated in a similar way to other health issues, therefore a medical model is most appropriate in a medical context”



+ 'Patient' View Point

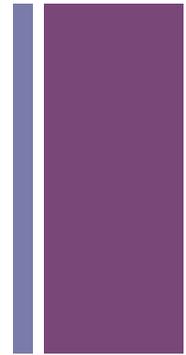
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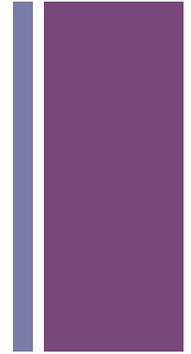
- 'Patient is the only title that seems relevant'
- 'I would like to be referred to as a patient, but I feel I am trying hard to be a survivor'
- 'I am not a USER of any kind. I didn't like any of the labels, patient is too formal, but the nearest'
- I believe the word user is inappropriate and would make people feel bad about being here
- I do not like client – it's reminiscent of prostitutes'

(Simmons et al, 2010)

+ 'Patient' View Point Statistics

- Out of 133 community care patients surveyed 75% preferred the term 'patient' to be used by their GP and 67% preferred the term 'patient' to be used by their psychiatrist (**Psychiatric Bulletin 2003**)
- Out of 336 participants from local catchment area secondary care community 'patient' was the preferred term when consulted by psychiatrists and nurses and 'service user' was disliked more than liked (**The Psychiatrist, Simmons et al. 2010**)

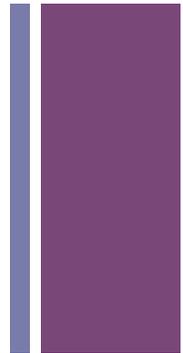




Defining Roles of Caregivers

+ Caregiver Role

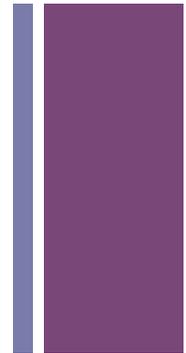
- According to the GMC “the primary duty of all doctors is for the care and safety of patients”
- A Consensus statement on the Role of the Doctor 2008:
 - *“Doctors alone amongst healthcare professionals must be capable of regularly taking ultimate responsibility for difficult decisions in situations of clinical complexity and uncertainty, drawing on their scientific knowledge and well developed clinical judgement.”*
- Caregivers should be aware of disparities within the patient’s suffering and establish a good rapport with those in receipt of care

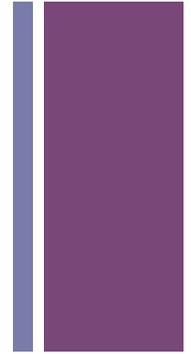


+ Caregiver View Point

Patient vs Service User

- The expected role of a doctor, psychiatrist, occupational therapist and psychologist is to primarily provide care and treatment for patients
- Using the term 'service user' could mean losing the patient-health professional bond wherein some level of trust is given to the health professional to understand the best treatment to give
- To use 'service user' does not fully encompass those with conditions such as Anosognosia (lack of awareness of a disability) who rely on the judgment of a caregiver to give them the best treatment, thus 'patient' is more appropriate





Risk assessment, Mental Capacity & Safeguarding issues

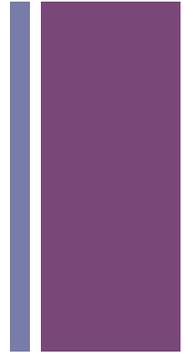
+ Risk assessment, Mental Capacity & Safeguarding issues

- High-risk end of mental health / social work
- Compulsory mental health admissions and tx
- Deprivation of liberty
- Safeguarding
- Dr / Social Worker / Clinician is expected to act on their own professional assessment of the situation, informed by agency policy, legal mandates and research, irrespective of individuals views/ opinions.

(Cowden & Singh, 2007)

+ Mental Disorders Associated with Poor Insight

- Schizophrenia
- Obsessive Compulsive Disorder
- Bipolar Disorder
- Mania
- Anorexia Nervosa



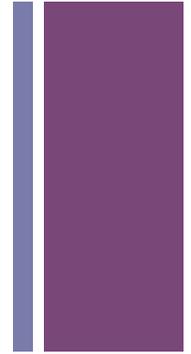
+ High Risk End of Mental Health

- Anosognosia can lead to an increase in violent behaviours and nonadherence
- In the United States (multisite study), 1,906 individuals with schizophrenia and related disorders were prospectively followed and assessed for three years. Medication nonadherence was significantly associated with being violent, arrested, and victimized (all significant at a level of $p < 0.001$).

Ascher-Svanum H, Faries DE, Zhu B, et al. Medication adherence and long-term functional outcomes in the treatment of schizophrenia in usual care. Journal of Clinical Psychiatry 67:453-460, 2006

+ High Risk End of Mental Health

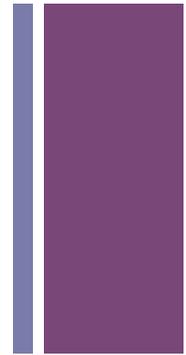
- In the United States (Ohio), 115 individuals with schizophrenia who had committed violent acts for which legal charges were incurred were compared to 111 individuals with schizophrenia who had no history of violent acts. The violent individuals had "marked deficits in insight" and were much more symptomatic. Compared to the nonviolent individuals, those who had been violent scored significantly lower ($p < 0.001$) on awareness of mental disorder, awareness of achieved effect of medications, and awareness of social consequences of mental disorders.
Buckley PF, Hrouda DR, Friedman L, et al. Insight and its relationship to violent behavior in patients with schizophrenia. American Journal of Psychiatry 161:1712-1714, 2004.

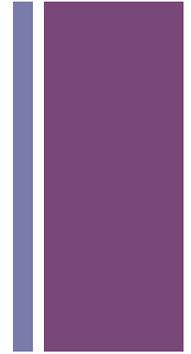


Mental Health Stigmatism

+ Stigmatism of Mental Illness

- The distinction between mental and physical illness is ill-founded
 - In reality, neither minds nor bodies develop illnesses. Only people (or, in a wider context, organisms) do so, and when they do both mind and body, psyche and soma, are usually involved (**Kendell 2001**)
- Mental disorders are illnesses and so it is inappropriate to call those suffering from them 'service users' as a differential term from others with physical illnesses like cancer who are known as 'patients'
- Using 'service user' for mental health patients serves to perpetuate the stigma of mental illness

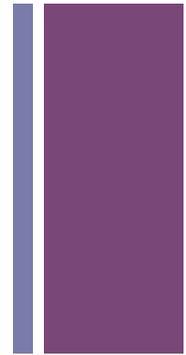




Critique of term 'service user'

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- Are service users a homogenous population ?
- ignores differences - between those who access different services, but also those who access the same service.
- Prostle & Beresford (2007) point out in relation to service user movements, that the issue is not one of representativeness, but inclusion.
- Term denies diversity and complexity and in its place promotes a simplifying of the human condition.

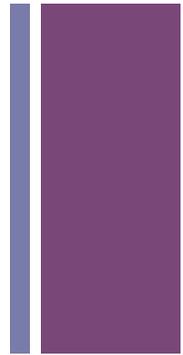


+ Critique of term 'service user'

- Service users / Clients / Customer / Consumer/ Ambulatory Health seeker
- Lacks compassion and a relationship of trust
- Patient – often vulnerable, certainly worries, sometimes uncomfortable and usually frightened
- Distinctiveness of patient reminds us of the vulnerabilities of the ill person and the responsibilities of the Dr / Clinician

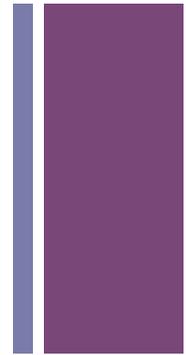
+ Critique of term 'service user'

- Mental illness is not a casual usage of a service, it requires careful treatment plans and often medication
- When someone is using a service they are generally doing so on an insightful basis
- Children and those with learning disabilities seeking medical assistance generally lack basic insight into their difficulties – 'service user' does not encompass these



+ Involvement at cost of being Effective?

- Does further research into which terms patients prefer risk diversions of scarce NHS resources away from patient care ? (Tallis, 1999)
- Has the act of involving 'service-users' become more important than providing effective services ? (McLaughlin, 2009)
- Will another term be favoured in the next 10 years as NHS services are re-commissioned by Primary Care Commissioning groups and rise of Any Qualified Providers ?



+ Summary

1. I have argued for the use of 'patient' as it makes sense to the patient and the personal and professional carers
2. Reduces stigmatisation of patients and mental illness
3. Encapsulates the biological and medical model of mental illness and the treatments to alleviate suffering.
4. Provides psychological comfort to those seeking sense of their symptoms and also avenues to treatment
5. Caring vs detached professionals
6. Essential for access to certain benefits
7. May be relevant in any criminal proceedings and treatment / convictions
8. Required by law regarding deprivation of liberty and/or safeguarding.
9. Lack of consensus regarding alternatives
10. Diverted attention / resources from quality & effectiveness