

## International Journal of Applied Health Studies

Volume 1 Issue 2

A light gray world map is centered on the page, showing the outlines of continents and major islands. The text 'Empowered to Comply' is overlaid on the map, centered over the African continent.

### Empowered to Comply

**Dr Lovemore Nyatanga**

Faculty of Education, Health & Science, University of Derby

&

**Chris Lyle**

Senior Lecturer, University of Wolverhampton

ISSN 1742-5263

## *Introduction*

In 2000 the National Health Service (NHS) Plan cited patient empowerment as one of its key modernisation agenda items. For instance, chapter ten of the NHS Plan clearly states patients are the most important people within the health service (Department of Health 2000). Within the context of the NHS Plan, communication and information exchange are considered critical mechanisms for patient empowerment. One document produced specifically to support the ideals of patient empowerment is "Shifting the Balance of Power" (Department of Health 2002). This document explains that under section eleven of the "Health and Social Care Act" the empowerment of patient, staff and the public will require major cultural and attitudinal change. In order to effect this cultural and attitudinal change, a duty has been placed upon the NHS Trusts, Primary Care Trusts (PCT) and Strategic Health Authorities (StHAs) to set up appropriate mechanisms for consulting and involving patients and the public in all matters involving the planning and delivery of services. Patients are expected to be represented on such forums as National Trusts Boards, Modernisation Boards. There will also be Expert Patient Programmes (EPP) as well as Patient Advisory and liaison Service (PALS). These seem far reaching changes capable of truly empowering patients and any service user. For non-patients or general service users, attention to the rights and responsibilities of citizens to participate and promote their own health has been sustained within the 2004 NHS Improvement Plan. Within this context people are put at the forefront of service provision in particular public service (Department of Health 2004). An extract from the NHS Improvement Plan reads thus, "..So that there is more choice, more personalised care, real empowerment of people to improve their health – a fundamental change in our relationships with patients and the public. In other words, we need to move from a service that does things to and for patients to one that is patient led where the service works with patients to support them with their health needs", (DoH 2004).

Hot on the heels of the NHS Improvement Plan has been the related Government vision of:

- Creating a patient led NHS,
- Offering a detailed explanation of how the delivery of the NHS Improvement plan
- Changing attitudes towards empowerment.

The document is crystal clear about what patient-led services actually look like from a patients point of view and does indeed conjure up a rather Utopian NHS provision. It is rather utopian in the sense that the empowerment theme will run through care delivery practice. Patients will be respected, listened to, valued and will be seen as the best judge of what is needed for them as individuals, (DoH 2004).

The fact that empowerment is a fundamental part of the new health policy has been made crystal clear. Some policy analysts, however, would argue that The NHS reforms are overly focused on the wealth of the NHS rather than empowerment and the health of the population. The policy analysts may be sceptical because it is not clear how this new empowerment philosophy will necessarily change existing attitudes. The conventional attitude has tended to demand conformity from patients. Patients that question the conformity convention tend to be labelled as unpopular, (Johnson and Webb 1995). This makes it difficult if not paradoxical to see how the Patient-led NHS view of empowerment can be realised. The view suggests that care will be delivered not only with full agreement with the patient, but also with due

consideration of their own knowledge and experience of their condition. For this seeming rhetoric to become reality then the conventional attitudes have to change and communication needs to be truly reciprocal (without denying professional expertise) in order to achieve true empowerment and utopian NHS provision. But there are certain other discrepancies within the empowerment approach. For example, the issue of compliance is being promoted alongside empowerment. Empowerment and compliance are arguably diametrically opposed to each other. Empowerment as advocated through health policy has a sense of autonomy and ownership. On the other hand compliance is about obeying or adhering to a set of given rules or treatment regimes often decided by experts. Yet as rapidly as empowerment has gained common parlance within health care, patient compliance has become an increasingly familiar term that is casually thrown into health discourse as the former. The act of compliance is normally associated with the taking of medication or complying with a prescribed course of treatment. Most people who are familiar with the NHS will also be familiar with the concept of following to the letter prescriptions of such treatment as antibiotics. It is a common phenomenon for people to wish to discontinue taking their medication and yet discontinuing without medical say so is the essential definition of non-compliance (Marinker 2000, Puri 2000). By implication, non-complying patients are deemed to waste NHS resources so ways of maximising compliance must be sought for these patients. Compliance and empowerment will be discussed again later, but attention will now turn to the seeming paradox of patient empowerment.

### *The paradox of empowerment*

This paper argues that the whole concept of patient empowerment is an example of the falsely obvious. The NHS is promoting patient empowerment while simultaneously supporting compliance programmes that compromise it. This suggests a situation where ideology is often confused with reality and rhetoric dominates over practice. For instance, "Creating a Patient-led NHS" is the new revolutionary policy document that seeks to empower patients. Yet the concept of empowerment itself remains enigmatic mainly because it is left to the reader to determine its real meaning. There is no real attempt to unravel the true meaning of patient empowerment particularly in an interactional or care delivery setting. In fairness, there is a somewhat guarded reference within the NHS Improvement Plan (2004) about empowering patients which states:

"ensuring that all patients are empowered to make decisions about their care and treatment means that individuals must have the necessary skills to access, understand and use information" (DoH 2004). Instead of clarifying patient empowerment, the statement actually adds further difficulties because knowledge and skills immediately become the pre-requisite for such empowerment. This in turn might mean that professionals themselves (e.g. doctors and nurses) would need to be empowered in order to educate patients that wish to pursue the empowerment option. What if the necessary knowledge and skills were beyond the patient's grasp because of physical or mental illness. Such empowerment would also appear to contradict the concept of "Patient-led NHS", as the average patient does not have the necessary knowledge and skills. The cynic might be forgiven for suggesting that all potential patients (i.e. practically the whole nation) need to have attended an empowerment course prior to receiving medical intervention. However this minor and somewhat fleeting realization that empowerment is a complex issue has not deterred health policy makers from the continuing crusade for patient empowerment. Within the document, "Shifting the balance of power" the dialogue about empowering

patients, staff and the public can only be construed as a positive vision of how NHS services should be developed and delivered. The paradox of translating complex ideas such as empowerment into a workable reality is only preceded by the danger that empowerment may simply become a decorative display of professional creativity where compliance may be traded as empowerment. It has been argued that the current policy preoccupation with public participation and empowering patients is more to do with New Labour's purposeful shift away from the market driven mechanisms proposed by previous governments, which in turn has its roots in societal change which advocates inclusion and participation, (Duggan 2002). In other words, when transferred to Health Professionals, a degree of creative misunderstanding of the meaning of patient empowerment and compliance is feasible (Trostle 1988). Thus by leaving the concept of empowerment relatively vague and open to interpretation it allows the word itself to take on a meaning, albeit ambiguous, that resembles the syndrome of the "emperor's new clothes" or old wine in new bottles or professional control by any other name. This seems a very good characterisation of the current paradox of patient empowerment.

### ***The paradox of the sick role and patient empowerment***

Within the context of the existence of Patient empowerment as advocated through key policy documents this section will now turn to an examination of the paradoxical assumptions that underpin the sick role and patient empowerment. Indeed from an ideological perspective patient empowerment is to be strived for and should be pursued, but attention needs to be drawn to the paradoxes that surround patient empowerment. The very first paradox is to do with the label "patient". Generally, a patient is a person under medical treatment. Being under medical treatment implies being guided and helped in ways that aid recovery. While there is nothing wrong with this conception, the problem emerges if one tries to envisage how the "patient" can be empowered while under the control and guidance of medical treatment. In case this conclusion is seen as premature, further analysis will be offered. According to Parsons (1950) the label "patient" denotes sickness or illness often associated with specific role, traditionally known as the sick role. Parsons (1950), a well known structural functionalist of his time, analysed the sick role and suggested at least four defining characteristics:

- The patient is exempted from daily responsibilities on the basis that he or she is genuinely sick
- The patient is exempted from the responsibility of totally helping himself to get better as he does not have the means and know how
- The patient is expected to accept that illness is a temporary state of deviance that must be corrected
- The patient is expected to comply with treatment regimes

The assumptions and attitudes portrayed in the sick role are critical for our understanding of how the past influences the present as well as the future. For instance, in the past the sick role placed the patient in a blatantly powerless and subservient role. The prevailing attitude to the experience of being ill was that of some imbalance between the ill person and the environment or some expression of deviant behaviour but in a way amenable to help or correction. These attitudes and assumptions were more frightening for those with mental illness. The mentally ill were often seen as lunatics, people who were mentally deranged, people with moral weaknesses etc (Foucault 2001). This perception and related attitude to mental illness led to the creation of asylums used essentially as correction houses for the

insane. Asylums became like religious centres without any religion other than their fanaticism about morality and insanity. It would appear logical that the sick role was even more obvious in an asylum than in the then royal infirmary. For example, in the asylum, rationality and power were seldom associated with mental patients. Patients certainly did not require any power over their condition. People suffering from schizophrenia, for example, simply became schizophrenics whose behaviour was often seen as unpredictable because of the erroneous assumption that they had a split personality. To a lesser extent, this conception still exists, (Szasz 1988), and there still remains the tendency for mental health professionals to engage with the disorder and not the person (Barker 2001). For people who subscribe to this conception, patient empowerment must be the ultimate paradox because they probably cannot see a good reason for it. Indeed the very idea that someone who is mentally disordered or insane should be empowered seems an irrational and dangerous standpoint. On the other hand, they may see compliance and adherence as synonymous with empowerment. But even in the less extreme cases of the worried well, as in some minor physical or mental illnesses, patient empowerment is still a paradox because the patient is still expected to be obedient and compliant. As stated by an ex- service user

“ In my experience the primary defence used to prevent power sharing and authentic communication stems from professionally constructed judgements about the validity and meaning of the users experience of mental distress and their perceived competence. Many professionals really believe they know what is best for their patients” (Campbell 1999).

Subconsciously the meaning of being a patient is the symbolic regression to a psychological state of helplessness and dependence that allows professional people to assume power and control. This must mean that any empowerment would be conditional to compliance with the wishes and prescriptions of the doctors, nurses and other professional groups. Consistently professionals maintain a defensive need to separate and sustain a secure base of identity, status and power. These sentiments are shared by Nyatanga and Dann (2002) who claim, for example, that nursing cannot empower patients because of the power dynamics embedded within the hierarchical structures in health.

### *Empowered to comply*

Many professional groups have become increasingly aware of the need to involve patients in most aspects of care. It is argued that the ideologies of consumerism and patient empowerment have been instrumental in this awareness and are congruent with the current government agenda (Simmons and Birchall 2005). As such, patient empowerment has to be included in many professional decision making forums even though that inclusion may be rhetorical (Cook 2002). The reasons why patient empowerment may remain rhetorical are many. These include the traditional meaning of being a patient (helpless and dependent on care), the superior knowledge of professional people whose role it is to tell the patient what is best and the ultimate attribution error that patients are not capable of understanding medical matters let alone managing them. In these circumstances, the compromise is to create pseudo-empowerment programmes where compliance becomes the essential prerequisite. For example, there are several “concordance programmes” that claim to work on partnership between the patient and the professionals. Such partnership presumably reflects mutual understanding and reciprocity of influence. This, indeed, is a good example of one way achieving pseudo patient empowerment. Indeed when



one looks at the language used within these concordance programmes and the assumptions being made it quickly becomes clear that patients are actually only being empowered to comply. In "Primary Care Pharmacy" Marinker (2000), has clarified the concept of concordance by saying that compliance is simply another way of saying that patients should follow doctors' orders while concordance is about the patients being empowered to manage their own life and to be satisfied with a consultation. Within the same article, Professor Marinker does suggest that concordance still leads to compliance but perhaps in a more acceptable way. Perhaps more to the point is the rationale for concordance programmes. The "All-Party Pharmacy Group" deliberated and sent its report to health ministers entitled "Concordance and wasted medicines". The opening gambit to the report said that the patients' failure to comply with prescribed medication is a well-known problem that is costing about £230 million in wasted medicines. The All-Party Pharmacy Group (APPG 2000) concluded that concordance was (a jolly refreshing idea) !!!!, an effective strategy that could be used to empower patients to take responsibility for their medicines. These accounts of concordance or adherence are numerous and all seem to suggest patients are empowered to comply. Elsewhere, the Cancer Treatment Centres of America (CTCA 2002) have developed what they call "Patient Empowerment Medicine". Here the philosophy is to put the patient first. CTCA prides itself on valuing what the patient wants and will work diligently towards that objective. There is, however, the same traditional attitude that assumes the patient will need to be educated and guided by the professional in order to realise the potential of "patient Empowered Medicine". Again this resembles the syndrome of "empowered to comply" with cancer treatment.

It is perhaps within the area of mental health that the paradox of empowerment and compliance becomes even more complex. People with serious mental illnesses such as schizophrenia have historically been viewed as incompetent or dangerous requiring professional support and control. Policy commentators Coppock and Hopton (2000), and Pringle and Thompson (1999), draw attention to the tensions of implementing patient centred community services within a legal framework, which was designed around psychiatric services centred on hospitals. Hospitals that are reliant on medication and restraint and under the de facto control of the medical hierarchies. The 1983 Mental Health Act, despite pressure for changes by campaigners for a more humane approach to people in mental distress, makes the criteria for forcible admission into a psychiatric hospital quite clear. The patient must be considered to be a danger to themselves or to others. The Act continues to state that this decision is to be made by the relevant medical practitioners who under section 12 hold considerable power over that individual and other professionals in making this level of decision. The draft Mental Health Bill, (Winterton 2006), which has been at the centre of controversy over these very issues since 2004 has recently been effectively abandoned. The draft Mental Health Bill seemed to, through and through, re-enforce one of the NHS biggest paradox of empowerment. Its main theme seemed to be patient compliance for the protection of the public and very little to do with the individual patient. "It wanted to introduce supervised treatment in the community to ensure that patients who have been discharged from a compulsory treatment in hospital continue to comply with treatment. This will benefit patients and improve public safety" (Winterton 2006).

Yet the modern agenda for Mental Health services holds the concept of patient empowerment close to its heart and the user movement and more recently the recovery movement emphasise the need for service users to be empowered within mental health care, (e.g. Kelly and Gamble 2005, Borg and Kristiansen 2004). There is thus considerable tension between these two points of view that painfully stares at all of us. Empowerment and perceived dangerousness do not sit comfortably

together. Recent developments in mental health, which claim to be promoting modern community services further demonstrate the tension. Assertive Outreach Teams were set up to identify “difficult to engage patients” who were likely to disappear from mental health services (Department of Health 1998). Encouraging these patients to comply with treatment regimes is a fundamental part of this development. It would seem that the empowerment of these patients is contrived purely on the grounds of compliance to professional decision-making, if there is any empowerment in place at all. A further example is that of Integrated Care Pathways. Adopted from general medicine, Care pathways in Mental Health aim to create a cohesive care structure through services which allow the patient to be at the heart of the decision making process and be fully involved in all aspects of care (Dykes 1997). This in principle would appear to be fully supportive of the desire to empower the mental health patient. However on closer analysis it transpires that for the Care Pathway to work effectively the patient needs to comply with a number of things. Firstly the pathway is diagnosis focused so the patient has to accept and comply with a given diagnosis. Secondly in order for the pathway to proceed there must be compliance to prescribed medication for that condition. Thirdly the Care Pathway document is multi-disciplinary. It is unlikely that the patient voice would be heard above such a range of professionals let alone be instrumental in the decisions made. The reality of pathways through psychiatric care is that the patient far from being empowered is more likely to be at the mercy of health professionals and the often inadequate resources that they have access to.

## *Conclusion*

Nyatanga and Dann (2002) have argued that there are real problems and tensions between the ideals and realities of patient empowerment. The reality of patient empowerment will require much more than mission statements and information giving. It will require, as stated in "shifting the balance of power", a change of organisational culture and ways of working that reflect genuine partnership and not pseudo-empowerment.

There appears to be a serious struggle and tension between patient empowerment and the various professional attitudes that see the patient as helpless and dependent. Part of the struggle is embedded in the very label of "patient" which conjures up images of:

- The sick role and deviance
- Helpless and dependent
- Powerless and unstable
- Irrational and indecisive
- Expensive and troublesome
- In need of education and guidance
- Can be manipulated by professional reinforcements e.g. empowered compliance or some forms of token economy

Empowerment is a concept with powerful connotations. It suggests a state of autonomy and ownership. It is a process of becoming fully functional or the process by which people may turn ideals to reality. To reduce it to rhetoric and window dressing is to trivialise its role and importance in health care. To fail to recognise the numerous paradoxes and contradictions and to fail to recognise existing professional attitudes would be a serious failure by all concerned. We need to think carefully about initiatives and programmes that claim to empower patients when in reality they are only empowering them to comply.



## References

All-Party Pharmacy Group (2000) Concordance and wasted medicines: a report to health ministers. House of Commons: London

Barker,P (2001) The Tidal Model. Developing an empowering, person centred approach to recovery within psychiatric and mental health nursing. *Journal of Psychiatric and Mental Health Nursing*. 8,233-240

Borg,M and Kristiansen, K. (2004) Recovery oriented professionals: Helping Relationships in mental health services. *Journal of Mental Health*. 13 (5): 493-505

Campbell, P. (1999) *The Service User? Survivor movement*, in Newnes,C, Holmes,G and Dunn, C. *This is Madness: A critical look at psychiatry and the future of mental health services*. Ross on Wye: PCCS Books

Cook, D. (2002) Consultation for a change? Engaging service users and communities in the policy process. *Social policy and Administration*, Vol 36 No.5: pp 516-31

Coppock, V. and Hopton, J. (2000) *Critical Perspectives On Mental Health*. London: Routledge.

CTCA (2002) Patient Empowerment Medicine. Accessed from the Internet on 26 March 2006 at : <http://www.cancercenters.com/aboutUs/philosophy.cfm>

Department of Health (2004) NHS Improvement Plan: Putting people at the heart of public services, (D.oH June 2004)

Department of Health (2002) Shifting the balance of power within the National Health Service (NHS). DH Communications: February 2002.

Department of Health (2001) Valuing People. A new strategy for Learning Disability for the 21<sup>st</sup> century. DoH. London.

Department of Health (2000) The NHS Plan: a plan for investment; a plan for reform. CM 4818-I July 2000.

Department of Health (1998) *Modernising Mental Health Services: Safe, sound and supportive*. London.

Duggan, M (2002) *Modernising the social model in mental health: A discussion paper*. Social Perspective Network for modern mental health.

Dykes P .C. (1997) *An Introduction To Critical Pathways*. In Planning, implementing and evaluating critical pathways. (eds DykesP.C and Wheeler K). Pringer Publishing company, New York.

Foucault, M. (2001). *Madness and civilisation (classic edition)* Routledge: London

Johnson, M. and Webb, C. (1995) Rediscovering unpopular patients: the concept of moral judgement. *Journal of Advanced Nursing* 21: 466-475.

Kelly, M. and Gamble, C. (2005) Exploring the concept of recovery in schizophrenia. *Journal of Psychiatric and Mental Health Nursing*, 12, 245-251

Marinker, M. (2000) Achieving concordance. *Primary Care Pharmacy*, 1, (4) 93-95.

Nyatanga, L. and Dann, K. (2002) Empowerment in nursing: the role of philosophical and psychological factors. *Nursing Philosophy*, 3, 234-239

Parsons, T. (1950) *The social system*. The Free Press: New York.

Pringle N and Thompson P (1999) *Social Work, Psychiatry and the Law*. 2<sup>nd</sup> Edition. Aldershot, Ashgate.

Puri, R. (2000) Non-compliance: the pursuit for concordance. *Trinity Student Medical Journal*, 1, May 2000.

Simmons, R. and Birchall, J. (2005) A joined up approach to user participation in public services: strengthening the "participation chain". *Social Policy and Administration*, Vol 39 No.3 pp 260-283

Szasz, T. (1988) *Schizophrenia – The Sacred Symbol of Psychiatry*. Syracuse University Press. USA

Trostle, J. (1988) Medical compliance as an ideology: *Social Sciences and Medicine*, 27 (12) 1299-1308

Winterton, R. (2006) Ministerial statement on the Mental Health Bill. Department of Health, 23 March 2006.