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HOW REFLECTIONS ON CONCORDANCE IN MENTAL HEALTH CAN AFFECT RESEARCH AND CLINICAL PRACTICE IN ADHERENCE

Jennie Day draws on examples of concordance in mental health to illustrate some of the problems associated with carrying out research in the area of adherence

In this article I will attempt to draw together previous literature, research findings and clinical observations in the area of concordance. I will draw on examples from mental health, because this is the area I have concentrated on in my own research. Indeed mental health is an ideal area in which to lay bare some of the inconsistencies and problems in carrying out research and clinical practice in adherence. However, the problems and observations reported are relevant to other areas of health care and it is striking how similar the attitudes to taking medicines are in people with mental health problems and people with other health problems.[1]

Research in the area of medicine taking has been carried out for many years. However the quality of the research has not always been high and often research findings are not translated into clinical practice. In addition to the erroneous assumptions that plague previous research papers, research in the area of adherence is fraught with difficulties, as outlined below.

DEFINITIONS

Haynes *et al*[2] first defined compliance as: "The extent to which a person's behaviour in terms of taking medications, following diets, or executing lifestyle changes, coincides with medical or health advice."

The term "compliance" has been criticised for being paternalistic because it assumes that health professionals are correct in the advice they offer and that not taking medicines is irrational. To take such a one-sided view is clearly unhelpful. It is logical that health professionals should have such a paternalistic view to medicine-taking. Even before people start training as health professionals they are more likely than the general population to endorse the biomedical model of health. Horne *et al*[3] showed that pharmacy students are more likely to believe that medicines are beneficial and less likely to perceive medicines are harmful than students from other disciplines. Throughout training the benefits of medication are emphasised and adverse effects of treatment are often seem as a minor discomfort that should be borne quietly by patients.

Further definitions have been offered and the term "adherence" has been suggested but since this is defined as "to stick to exactly" it is difficult to see how it furthers thinking. The most positive move in this area was the setting up of the Concordance Working Party, which suggested the term "concordance" and set a definition which incorporated a two-sided approach to medication: respecting the consumer's view and acknowledging that the consumer's view should be respected even if he or she made choices that sometimes appeared unhealthy. This was a great step forward but, unfortunately, evidence from some research papers and teaching has shown that some people have substituted the word "concordance" for "compliance" in research papers and lecture notes without fully endorsing the true spirit of concordance.

MEASUREMENT

There is no gold-standard, valid and reliable measure of medicine-taking behaviour. Various scales have been produced such as the "Beliefs about medicines" questionnaire,[4] which is a valid and reliable 18-item scale.

In mental health some scales have been developed that are specific to mental health medication. For example, the "Drug attitude inventory" is a 30-item scale developed to measure attitudes to antipsychotic medication and has been shown reliably to predict adherence with medication.[5] Other scales developed in mental health include the "Rating of medication influences" scale in schizophrenia,[6] the "Attitudes to neuroleptic treatment" questionnaire[7] and the "Medication adherence rating" scale for psychoses.[8] The "Drug attitude inventory" remains popular with clinicians and researchers. Its strength lies in the fact that it was developed from the attitudes of consumers rather than researchers, in its good reliability and validity and in its ease of use.

Various quantitative methods for measuring adherence have been developed and include measuring biochemical levels of a drug, measurement of markers such as phenobarbital, pill counts, electronic screw cap devices, self-report and health professional report. All of these methods have considerable problems of reliability and validity, cost and ethical considerations. Even if these problems could be overcome, there is still the difficulty that many research studies attempt to classify people as either "adherent" or "non-adherent". However the decision to take medicines is a complex, dynamic and multifactorial process. For example, people may decide to take some of their medicines and not others, or they may take medicines at some times and not others. Poor congruence has been reported between different measures of adherence and this makes it difficult to compare findings from different studies and may explain the large variation in rates of adherence found in different studies.

Some of the most enlightening research in this area has been qualitative research. Although this does not produce quantitative measurement of adherence it does provide an insight into the reasons people choose to take or not to take medicines.[1,9,10] This research provides in-depth explanations of attitudes to treatment and the complex psychosocial factors that may influence people's views of treatment. On examining the transcript of such a qualitative interview it becomes clear that to try to simplify and measure adherence and attitudes to treatment, or to split people into two groups of "compliers" and "non-compliers", is flawed. Yet so many research studies take this approach and often psychosocial factors, including social isolation and relationships with health professionals, are omitted from the research design. Attitudes to treatment and decisions to take medicines are made in a complex and dynamic social world, and this should be reflected in research.

RECRUITMENT

Another problem in the research evidence we have is that the people who may have the most interesting views about taking medicines are unlikely to take part in research studies for two main reasons.

First, a proportion of people do not consult medical practitioners when they develop symptoms because they do not endorse the biomedical model. These people are not in touch with health services and therefore unlikely to be recruited in traditional research.

Secondly, those people who are in touch with health services but who have negative attitudes to medication are less likely to consent to take part in health service research carried out by health professionals.

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There are also contradictions in the attitudes of health professionals in that people who choose not to take medicines are criticised and labelled as belligerent, and yet people who show dependent behaviour on medical services and medication are criticised for their over-reliance.

ASSUMPTIONS

One of the greatest assumptions that overwhelms previous research in this area is that clinical rather than psychological or social factors have the greatest influence on adherence. Thus the literature is full of references to the disease state, the side effects of treatment, length of illness etc. However, when the adherence rates are compared across markedly different conditions and medications the rate of adherence in long term conditions is similar, at around 50 per cent. In the area of schizophrenia, drug companies, in particular, and many clinicians assume that adherence is improved with atypical antispychotics which have fewer extrapyramidal side effects than the older typical antipsychotics. Although some data support this assumption, more and more data are emerging that adherence rates are similar in both groups,[11] suggesting that side effects have a lesser influence on adherence than that previously assumed.

In our own research we found that the relationship between the consumer and the prescriber was the most important predictor of attitudes to treatment in a model of adherence with antipsychotics. Dolder *et al*[12] found that adherence rates to general medication (for conditions such as hypertension or hyperlipidaemia) were similar to those for antipsychotics at around 50 per cent in a group of older adults.

It has also been assumed that people with mental health conditions or older people are more likely to have problems in taking medicines and yet there is significant evidence to refute this, and adherence rates in these groups are similar to those of other groups at around 50 per cent.[13]

In addition, the tone of previous work is often paternalistic with an underlying theme that failing to take prescribed medicines is irrational and defiant and something that health professionals would not do. In our research in this area, it has been a striking and consistent finding that health professionals have a duplicitous approach to adherence, admonishing health service users who choose not to take medicines and yet giving plausible and justifiable reasons for their own decisions not to take medicines. This is shown in these quotes from a nurse in a recent study: "You do see massive improvements on medication, even though very often that insight isn't always there." "Everything has a price, everything has a side effect, so I'm quite wary now with anything I take."

The second of these quotes came from a nurse who criticised people for not adhering to antipsychotic medication: "I, as a parent, would be very frightened if someone was suggesting giving such severe drugs to a child of mine."[14]

INFORMATION

In clinical practice it has been observed that health professionals assume that patients do not want information unless they ask for it. Yet surveys of patients consistently show a lack of satisfaction with information provided. In the area of mental health this has been shown in a number of recent studies. For example, a study carried out by service users found that around 50 per cent of 254 service users believed they were not getting enough information on a range of issues.[15] This is an important finding because access to good information was associated with satisfaction with mental health services as a whole.

Another common assumption is that people do not take medicines because they do not understand how to take them or because they forget to.

Forgetfulness has been found to account for a small proportion of people who fail to take medicines and yet pharmacy practice research, in particular, is brimming with studies aimed at reducing forgetfulness and confusion. It follows from this that multicompartment compliance aids are unlikely to improve adherence. These costly provisions are widely used but there is a lack of evidence to show that they improve adherence.[16]

It has been consistently found that knowledge of medication does not improve adherence rates. Cognitive behavioural approaches, where medication is tailored to an individual's lifestyle, have been found to be more effective in increasing adherence than have education approaches.[17,18] This

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does not mean that people should not be given information. On the contrary, health professionals have a legal and ethical obligation to provide information about a person's condition or illness and the medicines they are asked to take.

There are few people who would unwittingly take a tablet from someone they do not know and swallow it without knowing what it would do and side effects it may cause. Yet today, in National Health Services hospitals throughout the United Kingdom, patients are administered medicines without an explanation and reproached if they refuse.

Kemp *et al*[19] used a motivational interviewing-based intervention "compliance therapy", which improved adherence, attitudes to treatment, insight and global functioning and prevented readmission in people with a diagnosis of schizophrenia.

Opportunities in mental health

Mental health is an ideal area in which to apply theory in order to improve concordance, and recent Government and user group initiatives have called for greater involvement of service users in decisions about their care. The National Service Framework for Mental Health, the expert patient initiative and the NHS plan strongly promote the importance of involving service users in the planning and delivery of health care within the NHS.

The new Mental Health Taskforce Board has emphasised the importance of service user involvement in the first line of their mission statement which says that mental health services should "treat individuals living with mental health problems with dignity and encourage their full involvement with care". This is directly in line with the principle of concordance, which propagates respect for the views of service users and negotiation about treatment options.

However, previous research has shown that mental health service providers have not traditionally endorsed these views and this suggests that training may be required that questions the value judgements of health professionals, service users and carers before real progress can be made. In a recent pilot study, we found that training inpatient mental health staff in user-focused pharmaceutical care with an emphasis on psychosocial approaches produced statistically significant improvements in knowledge and attitudes of staff. Methods for assessment of attitudes to treatment and evidence-based interventions to improve concordance are available and they should be implemented systematically.

There needs to be a sea-change in the views and values of service providers and health service staff so that the views of service users are truly respected, and there needs to be more research carried out to find effective ways of implementing this across the NHS.

Academic staff also need to embrace the whole concept of concordance and promote this to trainee health workers and apply it in their research. Researchers carrying out clinical trials need to consider adherence in their study design and all research in this area should consider psychosocial and relationships between service users, families and staff. We need to have a more formal and systematic approach as there are wide variations in clinical practice and in research.

Concordance is a great opportunity to bring about improvements in the way health care is delivered. Things are beginning to change, but it is time to leave behind the theoretical discussion and to take action.