Institution: King's College London

Unit of Assessment: 3B - Pharmacy and Nutritional Sciences

Title of case study: Optimising recovery and adherence to treatment in patients with major physical health problems

1. Summary of the impact (indicative maximum 100 words)

Poor treatment adherence and self-management are universally recognised as major problems across all illnesses. Research at Kings College London (KCL) has resulted in new ways of assessing, investigating and improving these problems. These are now achieving widespread impact through the highly successful commercial organisation Atlantic Healthcare, which provides medication adherence and patient support programmes on a global scale. These programmes, which are now reaching patients with over 50 major medical conditions in a large number of countries, are very solidly based on the findings from KCL research.

2. Underpinning research (indicative maximum 500 words)

There is growing evidence that variability in the psychosocial effects of major physical illness, and recovery from such, is in part due to patient's perception of, and behavioural and/or emotional responses to, their illness. Prof John Weinman (1990-present, Professor of Psychology as Applied to Medicines) and colleagues at King's College London (KCL) have developed and validated methods for assessing patients' perceptions of illness and treatment. Much of this research has been in collaboration with Prof Keith Petrie at Auckland Medical School, New Zealand.

Adjustment to Illness

In the mid 1990's, KCL researchers developed the psychometrically robust Illness Perception Questionnaire (IPQ), one of the first to provide valid and reliable measures of the ways in which patients make sense of their illness. Development involved initial qualitative studies to elicit key statements from patients, followed by a series of studies and statistical analyses to establish the reliability and validity of the scales. The five scales of the IPQ assess identity (symptoms the patient associates with the illness); cause (personal ideas about aetiology); time-line (perceived illness duration); consequences (expected effects and outcome) and cure control (how one controls/recovers from the illness). The IPQ has a number of core items and allows the user to add items for particular patient groups or health threats (1).

This questionnaire has been used in many KCL studies that have shown the significant contribution that patient's perception of their illness can make to their recovery from and/or adaptation to a major health problem. For example, in a study to measure causal beliefs in 141 individuals with psoriasis, 61% had a strong belief in stress and/or psychological attributes as causal factors, a belief significantly associated with higher levels of anxiety, depression and perceived stress (2)**.** Other studies have provided extensive evidence of the role of illness perceptions in predicting behaviour change, illness adjustment and quality of life. For instance, in a study involving 125 patients with rheumatoid arthritis, higher disability scores were significantly associated with beliefs about identity and consequences. Stronger control beliefs were associated with lower disability and better physical quality of life (3).

KCL researchers have also looked at patient's beliefs in mental illness. Using the IPQ with 92 patients with a recent relapse of psychosis, it was found that those who failed to attend cognitive behaviour therapy sessions believed their problems would not last as long as those who did attend. Those who attended sessions but didn't proceed to full therapy had a lower sense of control over their problems and a more biological view of their causes. Patients who took up full therapy were more likely to attribute the cause of their problems to their personality and state of mind (4).

Adherence to treatment

KCL researchers have also developed psychometrically sound measures for assessing patients' beliefs about their medication. The two section Beliefs about Medicines Questionnaire (BMQ) is composed of the BMQ-Specific, with two 5-item factors assessing beliefs about the necessity of prescribed medication and concerns about prescribed medication, and the BMQ-General, with two 4-item factors assessing beliefs that medicines are harmful, addictive, poisons which should not be taken continuously and that medicines are overused by doctors. The two sections of the BMQ can

be used in combination or separately (5). Researchers at KCL have carried out a number of studies with a BMQ adapted for assessing patients' beliefs about cardiac rehabilitation. An initial study of 152 cardiac patients, of whom 41% had attended such sessions, showed non-attenders were less likely to believe their condition was controllable and that their lifestyle may have contributed to their illness (6). The development of a 26-item 'Beliefs about Cardiac Rehabilitation' questionnaire was carried out with 130 patients with acute myocardial infarction. Four subscales pertaining to patients' beliefs about cardiac rehabilitation were produced. Patients who attended rehabilitation were significantly more likely to believe it was necessary and to understand its role compared with non-attenders. Patients who thought cardiac rehabilitation was suitable for a younger, more active person were significantly less likely to attend (7).

Further studies have used both the IPQ and the BMQ to evaluate adherence to preventer medication for asthma. Findings showed that non-adherent behaviours were associated with doubts about the necessity of medication and concerns about its potential adverse effects and with more negative perceived consequences of illness. Illness perceptions influenced adherence both directly and indirectly via treatment beliefs, which, in turn, were the strongest predictors (8).

3. References to the research (indicative maximum of six references)

1. Weinman J, Petrie K, Moss Morris R, Horne R. The Illness Perception Questionnaire: A new method for assessing the cognitive representation of illness. Psychology Health 1996;11:431-45. Doi: 10.1080/08870449608400270 (610 Scopus citations).
2. O'Leary CJ, Creamer D, Higgins E, Weinman J. Perceived stress, stress attributions and psychological distress in psoriasis. J Psychosom Res 2004;57(5):465-71. Doi: 10.1016/j.jpsychores.2004.03.012 (38 Scopus citations)
3. Graves H, Scott DL, Lempp H, Weinman J. Illness beliefs predict disability in rheumatoid arthritis. J Psychosom Res 2009;67(5):417-23. Doi: 10.1016/j.jpsychores.2009.01.006 (15 Scopus citations)
4. Freeman D, Dunn G, Garety P, Weinman J, Kuipers E, Fowler D, Jolley S, Bebbington P. Patients' beliefs about the causes, persistence and control of psychotic experiences predict take-up of effective cognitive behaviour therapy for psychosis. Psychol Med 2013;43(2):269-77. Doi: 10.1017/S0033291712001225 (0 Scopus citations: recent publication)
5. Horne R, Weinman J, Hankins, M. The beliefs about medicines questionnaire: the development and evaluation of a new method for assessing the cognitive representation of medication. Psychology Health 1999;14(1)1-24. Doi: 10.1080/08870449908407311 (434 Scopus citations)
6. Cooper A, Lloyd G, Weinman J, Jackson G. Why patients do not attend cardiac rehabilitation: role of intentions and illness beliefs. Heart 1999;82(2):234-36. http://heart.bmj.com/content/82/2/234.long (142 Scopus citations)
7. Cooper AF, Weinman J, Hankins M, Jackson G, Horne R. Assessing patients' beliefs about cardiac rehabilitation as a basis for predicting attendance after acute myocardial infarction. Heart 2007;93(1):53-8. Doi: 10.1136/hrt.2005.081299 (30 Scopus citations)
8. Horne RA, Weinman JB. Self-regulation and self-management in asthma: Exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication. Psychol Health 2002;17(1):17-32. Doi: 10.1080/08870440290001502 (242 Scopus citations)

Grants PI/Co PI: John Weinman

- 1998-2000. The role of patients beliefs about illness and treatment in adherence medication for heart failure. South Thames NHS Research & Development, £52,416
- 2000-2001. Pilot study of patients' illness and treatment beliefs and their relation to treatment compliance in asthma. National NHS R & D and National Asthma Campaign, £26,548
- 2002-2004. Study of patients' illness and treatment beliefs and their relation to treatment compliance in asthma. National NHS R & D and National Asthma Campaign, £188,631

4. Details of the impact

The two specific areas of underpinning research by King's College London (KCL) outlined above have enabled clinicians and researchers to gain a greater understanding of patients' illness and treatment perceptions and their effects on a wide range of illness-related behaviours and health outcomes. This, in turn, has resulted in the development of psychological interventions, which have been found to be effective not only in modifying dysfunctional illness beliefs and improving

recovery, quality of life and mood, but also in improving treatment adherence by changing negative illness and treatment beliefs.

Commercial Application

The success of the work described above has been recognised by Atlantis Healthcare, a leading worldwide commercial provider of patient adherence and support programmes with offices in Europe, Australasia and the United States (1). Atlantis Healthcare works closely with a number of leading pharmaceutical companies and with public health organisations to provide effective interventions for patients to manage their illness and treatment. They employ a large team of health psychologists worldwide and involve Prof Weinman in a consultancy role and as Head of the European Health Psychology team (2, 3). Much of Atlantis Healthcare's approach is based on the underpinning research and the assessments and interventions described above. Their interventions are tailored to elicit and, if necessary, modify patients' illness and treatment beliefs, both of which are routinely assessed using the measures developed at KCL.

Atlantis Healthcare has delivered over 80 programmes across 51 disease states including: Alzheimer's disease, asthma, breast cancer, diabetes, erectile dysfunction, glaucoma, gout, growth hormone deficiency, haemophilia, hearing loss, hepatitis C, incontinence, lung cancer, osteoporosis, pain, rheumatoid arthritis and wet AMD, among others, as well as programmes to support health screenings and blood donor management. The evidence base on their website lists a large number of published studies by KCL and collaborators (including Weinman 1996, Cooper 1999, Horne 1999, and Freeman 2012), which have shown not only that patients' illness beliefs, as measured by the IPQ, consistently predict an important range of clinical and psychosocial outcomes of illness but also that interventions based on these findings have successfully improved many of these outcomes (3).

In a letter of professional support, the Managing Director of Atlantic Healthcare UK, says that:

> "*as an acknowledged global market leader in the provision of patient adherence support programmes, our distinctiveness and acclaimed success is highly dependent on the fact that our approach is very much based on the rigorous and proven approaches, which have been pioneered by Professor Weinman and his colleagues at Kings College London over the past 15 years*."

He discusses how they are currently running 12 programmes for patients with a wide range of long term health problems, saying that:

> "*the core clinical basis of these programmes and communications approach are based on Prof Weinman's highly influential research on assessing and modifying patients' beliefs about illness and treatment.*"

Atlantis Healthcare's Managing Director also details how their 'One Heart' programme, funded by Astra Zeneca and running in three countries, is based on:

> "*the findings from (KCL) research on evaluating and improving illness beliefs in patients following myocardial infarction*."

Here he cites Cooper 1999 and 2007 along with a number of collaborative studies with Auckland Medical School (4).

In Addition, the Managing Director says that KCL's:

> "*research on the role of illness perception in the outcome of major inflammatory diseases, such as rheumatoid arthritis* (citing Graves 2009) *and psoriasis* (citing O'Leary 2004)*, has enabled us to develop global patient adherence support programmes in collaboration with AbbVie and Leo Laboratories, which are being offered to patients in many countries around the world*" (4).

Atlantis Healthcare's Rheumatology Care Patient Workbook for AbbVie, which included KCL work, won a 2013 Communique Award for Writing Excellence with judges commenting that "*We selected this as a winner because it successfully combined the behavioural factors, which underpinned the programme, with clear and engaging writing that would be very appealing to patients with rheumatoid arthritis. It is genuinely savvy, making very good use of psychology and behaviour change theory*" (5).

Similarly, in another letter of support the CEO of Atlantis Healthcare says that:

"*we quickly recognised that the research by Professor Weinman and his colleagues at King's College London could provide the basis for the development of our own global programmes.*"

She cites Weinman 1996 and Horne 1999 as being particularly influential and goes on to say that:

"*of particular value for our programmes is that Professor Weinman's approaches allow us to assess each patient's beliefs and motivation in an individualised way, and then to offer tailored interventions based on this understanding."*

The CEO of Atlantis Healthcare also corroborated that:

"the really impressive results obtained by Professor Weinman and colleagues in developing successful interventions for patients across a wide range of serious health problems, including end stage renal disease and cardiac disease (citing Cooper 2007) *have provided us with the evidence base and the confidence to build our own programmes, which we now offer to close to a million patients in 15 countries. In this way, his research is achieving considerable impact in the lives of many patients around the world*" (6).

Illness Perception Questionnaire Website

The questionnaires developed by KCL and colleagues have been translated into over 20 languages and modified for a number of different diseases. For instance, the Illness Perception Questionnaire (IPQ) has been translated into French, Italian, Norwegian, Romanian, Samoan, Tongan and Sri Lankan and adapted for specific use in those with diabetes, chronic fatigue syndrome, hypertension and HIV. Working with colleagues at the Auckland Medical School, New Zealand, there is now a revised IPQ (IPQ-R) and a brief version. All these versions are available on an open access website, which has attracted over 100,000 hits from researchers from all around the world. The website includes the key papers, describing the development and application of the different versions of the IPQ, including Weinman 1996 (7).

Findings from KCL studies have provided the basis for effective new interventions for patients and carers. For example, following from Horne and Weinman's 2002 study identifying the key beliefs underlying patients' levels of adherence to preventer medication in patients with asthma, an innovative text messaging intervention was developed with colleagues at the Auckland Medical School to change patients' illness and treatment beliefs. The intervention has been evaluated in a recently published randomised controlled trial involving 216 patients aged between 16 and 45. Two texts were sent daily for 6 weeks, one text daily for another 6 weeks, then three texts per week for a further 6 weeks. The type of texts sent was determined by the participant's baseline scores on a modified version of the IPQ and the level of medication belief ratings. Results showed that text messaging was not only successful in bringing about changes in patients' beliefs but that this resulted in a significant uplift in reported treatment adherence, maintained 6 months after the intervention had stopped (8).

5. Sources to corroborate the impact (indicative maximum of 10 references)

1. Atlantis Healthcare: www.atlantishealthcare.com/
2. Professor John Weinman: http://www.atlantishealthcare.com/Clinical-Team/
3. Evidence base: http://www.atlantishealthcare.com/about-us/our-evidence-base
4. Letter of professional support from the Managing Director for Atlantic Healthcare UK
5. Lions Den Award for Writing Excellence – Patients. Awarded July 4th 2013: http://www.pmlive.com/awards/communique/communique_awards_2013_results/excellence_in_communications/The_LionsDen_Award_for_Writing_Excellence_Patients
6. Letter of professional support from the Global CEO of Atlantic Healthcare
7. Illness Perception Questionnaire: www.uib.no/ipq/
8. Petrie KJ, Perry K, Broadbent E, Weinman J. A text message programme designed to modify patients' illness and treatment beliefs improves self-reported adherence to asthma preventer medication. Br J Health Psychol 2012;17(1):74-84. Doi: 10.1111/j.2044-8287.2011.02033.x