

OUR RESEARCH
THEMES:

Patient Experiences and
Involvement

Patient Reported
Outcomes

Translating Knowledge
into Practice

This newsletter presents
selected highlights of our
Research. For details of
the full programme please
see our website.

INSIDE THIS
ISSUE:

PPI 2

Trauma Nurses 2

PhD Students 3

Relaxation 3

Publications 4

Website address:

<http://www2.warwick.ac.uk/fac/soc/shss/rcn>

Collaborating with RCN Forums

Chronic Fatigue Syndrome/Myalgic Encephalitis (CFS/ME), Patient Reported Outcomes and Patient Involvement.

A recent, exciting collaboration is between Dr Kirstie Haywood (Patient Reported Outcomes), Dr Sophie Staniszewska (Patient Involvement), Dianne Burns, Steering Committee Member of the RCN Education Forum and Amanda McGough, Nurse Specialist in CFS/ME. Both Dianne and Amanda are members of a new Specialist Interest Group (SIG) for CFS/ME.

Kirstie and Sophie have a track record of research exploring the patient perspective in CFS/ME (Partnership for Research in ME/CFS: PRIME – www.prime.org.uk/), and are members of the National ME Observatory Steering Group. Concerns were raised about the knowledge and education of nurses in relation to the needs of patients with CFS/ME, prompting Kirstie to contact Dianne, who, as a representative of the RCN Education Forum, was subsequently invited to the House of Lords to meet with the Countess of Mar and the Forward ME Group to discuss these issues. Amanda

contacted Kirstie, through the PRIME website, to discuss appropriate patient-based assessment in CFS/ME.

It is clear that raising awareness of the needs of patients and their families with regards to their experience of CFS/ME and associated healthcare; identifying and understanding core quality of life (QoL) issues that support appropriate measurement of the impact and outcome of the condition; and improving the knowledge and education of nurses providing care for people with CFS/ME are major challenges for research in this field, and for the SIG. Moreover, NICE have recently highlighted the need for research to identify the best way of measuring outcome in CFS/ME, with particular focus on understanding QoL from the perspective of the patient, as a priority.

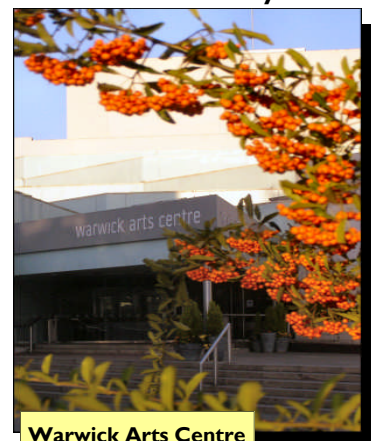
Kirstie has led a bid with Sophie, Amanda and Dianne (Advisory Group), recently submitted to the Medical Research Council (MRC) for further funding, to support exploration of QoL in CFS/ME, and the development and initial evaluation of a new patient-reported outcome measure. The proposal describes an important collaboration between patients, carers, health professionals and researchers.

References:

Haywood K, Staniszewska S, Chapman S. (2009) Health status and quality of life in people with ME/CFS: a structured review of patient-reported outcome measures. *Qual Life Res. Under review.*

Staniszewska S (2009). The PRIME Project: Developing a Patient Evidence-Base. *Health Expectations. In press.*

Contact: Kirstie Haywood



Warwick Arts Centre

The work of the RCN RI aims to:

- ▶ Produce high quality research that improves patient care and impacts on policy
- ▶ Increase research capacity within nursing by providing high quality research training
- ▶ Contribute towards the RCN delivering on its strategic objectives

Contact: Kate Seers

“Because in a busy ward environment, you know, where you've got 28-30 patients being cared for, a limited number of staff available to them, actually the patient and public involvement bit could be seen as the icing on the cake really”

Focus Group 2

RCN: Nurses and Public and Patient Involvement in England

Nurses and Patient and Public Involvement: A Consultation in Four Strategic Health Authorities in England. Markella Boudioni and Susan MacLaren. Report commissioned by the RCN.

15 Senior Nurses from four Strategic Health Authorities took part in three focus groups. Themes from the focus groups covered definitions, experience of Patients and Public Involvement (PPI), barriers facilitators, effective PPI and ideal scenarios.

The findings suggest that nurses have a range of ways of involving patients in their service at different organisational levels and were

supportive of the process of involvement. Many barriers to patient and public involvement were identified including lack of resources and time, and varying beliefs and values that affect how nurses respond to patient and public feedback.

The role of the nurse was considered to be a real strength in PPI due to the caring nature of nursing work; providing opportunities to listen to patient stories and experience of care.

There was a sense that many existing frameworks support PPI such as the Essence of Care Standards and Knowledge and Skills Framework, further frameworks were not required.

The way forward was identified as: increasing time and resources for PPI; changing cultural beliefs around PPI though education and opportunities for nurses to be involved in the process; dealing with limitations in the commissioning process.

Overall it was felt that strong nursing leadership was required to move the PPI agenda forward.

Contact:
Sophie Staniszewska

Trauma Nurses: Inputting into policy

Debbie Langstaff (Matron) and Julie Wright (Practice Development Nurse) at the Oxford Trauma Unit, who collaborate with Liz Tutton, have been actively ensuring a nursing voice is heard in key debates around practice.

Debbie Langstaff spoke at a meeting to discuss same-gender hospital accommodation at the Royal Society of Medicine.

The day started with an overview of government policy but developed to explore the real issues that affect patients in a range of different practice areas that make a blanket policy unworkable. Debbie contributed to this debate by identifying the cultural and quality consequences raised by same gender wards on a

trauma unit citing examples of: intergenerational and inter-gender support; benefits of nursing families together in bays and importance of maintaining a high level of expertise in all aspects of treatment and care across the unit. Lady Barker took a report based on the presentations and discussion back to the Department of Health.

Julie Wright added a nursing voice to the Westminster Food and Nutrition Forum keynote Seminar-Improving Nutrition: elderly and vulnerable groups. The day focused on themes around malnutrition, the importance of nutrition, the role of the care quality commission, service improvement and implementing change. Julie closed the session by

identifying the real daily practical difficulties of providing adequate nutrition in a busy acute setting using audit and patient feedback data accumulated over five years.

Highlighted was the importance of strong leadership and a critical mass of experience staff who role model appropriate behaviours and develop less experienced staff. It was noted that nutrition was not a simple fix such as red trays or no visitors at meal times. Any change should be tailored to the speciality, built into existing models of practice development, dynamic, flexible and regularly evaluated.

Contact: Liz Tutton



Daybreak at University of Warwick

“You can have as much strategy and policy as you like but however willing the the spoon holders are, the increasing frail and dependant patient population is often overwhelming”.

Debbie Langstaff (Matron)

PhD Student: Dr Lorna Henderson

We are delighted to announce that Lorna Henderson has received her doctorate from the University of Warwick. Lorna's work has explored the role of disclosure in the management of long term conditions. Disclosure of illness is an important area that is often overlooked in day to day practice despite the impact it has on peoples' daily lives.

Lorna's study used constructivist grounded theory to explore the role of disclosure with 35 people living with epilepsy or type 1 diabetes. Using in depth qualitative interviews she explored what it is like to live with the condition and the role that disclosure of their illness played in their lives.

The study has identified the importance of disclosure in order to access self care and social support, for redressing myths about the

condition in advance to avoid stigma and as a form of non disclosure to conceal the condition and protect the individual's identity.

The participants identified they would only disclose their illness for a specific reason and did their best to lead as normal a life as possible; if necessary covering up their illness. Often disclosure would occur as a natural part of daily life, such as, do you drive? Or, why have you got a fridge in your room? Disclosure in social settings, outside family and friends, was considered to be risky. Often only occurring if social support or medical attention was required.

Participants learnt about disclosure through trial and error and this is an area that specialist nurses could provide an important educative and supportive role.

The RCN Research Institute, within the School of Health and Social Studies, at the University of Warwick, provides a vibrant student research community. If you are interested in undertaking a PhD, part time or full time, please contact:

Prof Kate Seers.

"In some ways I probably have more regrets about not telling people, because instead of telling them and letting them deal with the problem if they found it an issue...I've changed my behaviour by not taking insulin and not eating when I should have done".

Effectiveness of relaxation for postoperative pain and anxiety: randomized controlled trial

Seers, K. Crichton, N. Tutton, L. Smith, L. Saunders, T. (2008) Effectiveness of relaxation for postoperative pain and anxiety: randomised controlled trial. *Journal of Advanced Nursing*, 62(6),681-688.

This paper examines the utility of relaxation as a tool for reducing post operative pain and anxiety in patients who had hip or knee replacements. The study was a randomized controlled trial comparing total body relaxation, jaw relaxation, attention control and usual care.

Total body relaxation was an intervention in which the researcher talked the patient through tensing and relaxing

major groups of muscles in the body. Jaw relaxation involved learning to breath deeply, relax the jaw, resting the tongue and softening the lips. The study had two control groups the first was talking about the pain experience and how participants managed their pain. This was used to control for the researcher's presence. The second was usual care where the participants rested quietly on their bed and no researcher was present. All interventions lasted 15-20 minutes.

Participants rated their pain, anxiety and relaxation before they had the surgery at pre admission clinic, and then

before and after the intervention, and 1, 2, 3, and 4 hours later.

There were statistically significant reductions in pain at rest from pre to post relaxation for both relaxation groups and the attention control group.

The findings suggest that the differences between the groups were small but relaxation can provide a short- lasting additional amount of pain relief.

Contact: Kate Seers

"..the main source of the pain that had been adversely affecting their lives for months or years had been removed, and so the pain from surgery was seen as much less of a problem as it was less intense" (p687).

Recent Publication

Editorial by Andrew Keat

Sex and the Spondylitic
Rheumatology 2009 doi: 10.1093/
rheumatology/Kepl43

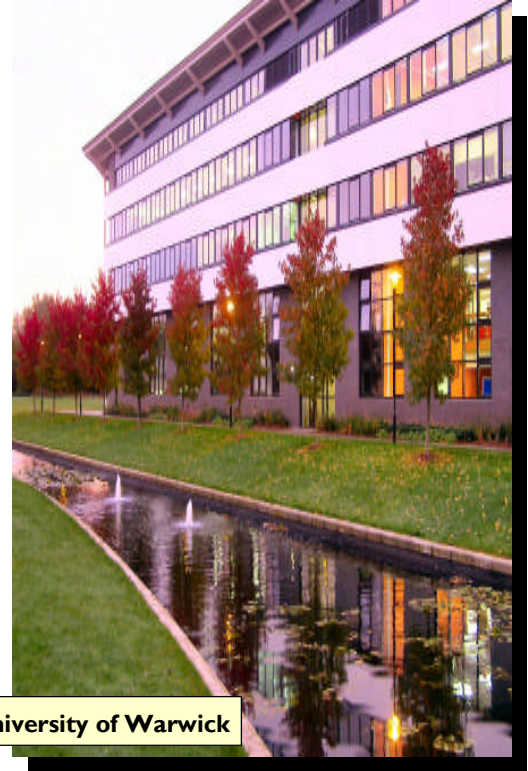
This editorial reviews the paper:
Healey EL, **Haywood KL**, Jordan KP,
Garratt AM, Packham JC
(2009) Ankylosing Spondylitis and its
impact on sexual relationships.
Rheumatology (Oxford). 2009 Jun 17.
doi: 10.1093/rheumatology/Kepl43

The review supports the paper's focus
on considering peoples' sex lives as a
measure of 'wellbeing' and 'quality of
life'. It is suggested that this is an area
where further research is required to
examine how people living with
ankylosing spondylitis (AS) differ from
the normal population, the nature of
the problems within the context of
their relationships and how
dysfunction relates to specific disease

related symptoms. Attaining a normal life
is a key message and it is clear that the
affects of AS on peoples' lives is
considerable despite the view that it is a
relatively mild condition.

The editorial adds to the debate about
the use and value of different treatments,
the cost versus the potential benefits
and difficulties of identifying outcomes.
In making decisions about treatment the
importance of including patient reported
outcomes is highlighted.

Sex is obviously a significant issue and
should be included as an indicator of
quality of life and psychological health.
Currently it is not often measured in
existing scales and would be a useful
addition.



Autumn at the University of Warwick

RCN Research Institute

School of Health and Social Studies
University of Warwick
COVENTRY
CV4 7AL

Website Address:

www2.warwick.ac.uk/fac/soc/shss/rcn

RCNRI Research Team Administrator: **Paul Kent**

Phone: **024 761 50618**

Fax: **024 761 50643**

email: p.d.kent@warwick.ac.uk

RCNRI Staff Email Contacts:

j.brett@warwick.ac.uk

k.l.haywood@warwick.ac.uk

d.r.kennedy@warwick.ac.uk

carole.mockford@warwick.ac.uk

natasha.posner@warwick.ac.uk

kate.seers@warwick.ac.uk

sophie.staniszevska@warwick.ac.uk

liz.tutton@warwick.ac.uk



THE UNIVERSITY OF
WARWICK

All photos by Paul Kent