‘Psycho-Social Update’ (PSU) is a newsletter from the International Program of Psycho-Social Health Research (IPP-SHR), Central Queensland University, circulated four times a year to an international audience of service providers, policy makers and academics with an interest in the human experience of serious physical and mental illness.

The newsletter celebrates the fact that psycho-social research is now a well established discipline that is ‘making a difference’ in the real world of health care.

Further information of all articles and programs summarised in the newsletter are available on the IPP-SHR web site at:

www.ipp-shr.cqu.edu.au

Off the Press @ IPP-SHR

Including the Fathers’ Perspective in Holistive Care: Fathers Experience with Childhood Cancer

Whilst an understanding of family dynamics and experiences is considered to be an essential antecedent in the provision of holistic health care, scant research has been done to explore fathers’ experiences of having a child undergo treatment for childhood cancer.

In response to this paucity of work, an IPP-SHR study has documented fathers’ perspectives on coping with the multiple challenges associated with having a child diagnosed and treated for a common form of childhood cancer, acute lymphoblastic leukaemia.

The findings indicate that many fathers do play a significant role in their child’s treatment experience, either through direct care of the child-patient and well siblings, or indirectly through the provision of support to the mother. Whilst the intensity of fathers’ roles was found to vary between families, the study indicated that a majority of fathers are strongly involved and committed, with many sharing the responsibility of staying with the ill child in hospital.

Significant obstacles were found to block fathers’ abilities to be present at the hospital with their patient-child, most notably fathers’ breadwinner status and consequent work commitments. Tensions were also documented to exist between fathers’ longing to be in the hospital with their ill child and their need to support other siblings at home.

These findings have important implications for the development of holistic care strategies that are sensitive to fathers’ needs and responsive to the roles that they play in the treatment of seriously ill children.

Dear Reader,

At the heart of the motivation, for the production of this newsletter, is the desire to affirm the work of those involved in initiating and keeping psycho-social issues on the health care agenda. Your work responding to the human experience of health care, in its varied settings, is very important. It is the hope and expectation that this newsletter will provide a medium by which you can connect with each other. Thus, it is greatly satisfying to hear stories from our readers of the relevance of our articles and the similarities between the reports we publish and your own experience. For this reason we have decided to offer a formal opportunity for you to provide feedback on items published. Starting with this edition we now have a column called ‘Chat Back’ where we will be able to publish your thoughts, insights and shared experiences on the stories we run. I extend a warm invitation to all our readers to contribute. Our contact details are on the back page.

Again, with this edition we are able to offer you a taste of richness and diversity of psycho-social research and initiatives from around the globe: from Spain we hear inspiring insights and expectation that this newsletter will provide a medium by which you can connect with each other. Thus, it is greatly satisfying to hear stories from our readers of the relevance of our articles and the similarities between the reports we publish and your own experience. For this reason we have decided to offer a formal opportunity for you to provide feedback on items published. Starting with this edition we now have a column called ‘Chat Back’ where we will be able to publish your thoughts, insights and shared experiences on the stories we run. I extend a warm invitation to all our readers to contribute. Our contact details are on the back page.

The research indicated that health professionals were able to clearly articulate notions of ethics and that a common definition of ethics as “patient-centred care” was shared by participants from diverse health care disciplines. All professional groups indicated that acting in a way that furthered the interests of patients and their families was the primary principle guiding their ethical sense of the “good” or the “ought”.

Whilst these findings indicated that diverse professions share a common concept of ethics, participants indicated that inter-professional conflict and tensions did sometimes arise in relation to defining what was best for the patient.

Effective strategies for dealing with ethical conflict within a multidisciplinary setting were outlined by the study’s participants. Interdisciplinary respect, mutuality and communication were noted to be a necessary precursor for proactively addressing issues before problems arose. A flat, democratic multidisciplinary team structure was also seen as vital in preventing ethical tensions and enabling them to be constructively dealt with when they do arise.

The findings of this study support a dialectic approach to ethical decision making that places greater emphasis on open deliberation and the articulation, negotiation, exploration, and generation of new ethical perspectives in the here and now of clinical practice.


Care Plus is an innovative palliative care service that works with cancer patients and their families in the Indian state of Kerala. This non-government organisation operates out of the Palliative Care Division of the Regional Cancer Centre, located in Kerala’s capital city, Trivandrum.

Care Plus is committed to providing cancer patients and their families with holistic care through a range of free, individually tailored services. These include: at-home care provision; consumer health information and training; pre-death planning; support for immediate and extended family; bereavement support and follow-up, and programs designed to promote patient and carer independence. Care Plus also operates four clinics throughout the region, enabling patients unable to travel to major treatment centres to access specialist care.

In keeping with the organisation’s holistic outlook, Care Plus delivers long term educational and employment support to patients’ families, both before and after bereavement. Care Plus sees this as an essential aspect of care provision, and its services have assisted many bereaved families to become economically self sufficient, often through the development of small business opportunities.
A community program assists disadvantaged mothers at high psychological risk

A Spanish study evaluated a community centre-based program for mothers at high psychological risk. The “Apoyo Personal y Familiar” (APF) program is for poorly-educated mothers from multi-problem families who show inadequate behaviour with their children. Mothers were referred by the municipal social services of Tenerife, Spain for assessment. The APF program is a community-based multi-site program delivered through weekly group meetings in municipal resource centres. 185 mothers participated in the APF program over eight months, of which 155 mothers were included in the study. Comparisons were made on the mothers’ self-rated maternal beliefs, personal agency and child-rearing practices. It was found that the program was very effective in changing the mothers’ perceived competences, and modestly effective in changing their beliefs about child development and education, and child-rearing practices. Changes in personal agency are very important for at-risk parents who feel helpless and with no control over their lives. It was also found that the program was especially effective for older mothers, with fewer children, living in a two-parent family, in urban areas and with either low or medium educational levels.

African first-time mothers, breastfeeding and childbirth education classes

A study in South Africa investigates the experiences of first-time mothers who attend childbirth classes. The objectives of the research were to explore and describe how childbirth education contributed to the birthing and breastfeeding experiences of these mothers, and to write guidelines for the childbirth educators to aid them in improving the childbirth education resources. The research found that childbirth education and support reduces fear and helps women to cope better with labour. Lack of all the information leads to unrealistic expectations and may result in negative birthing experiences. Emotional support from the midwife in the hospital is important to the labouring women; therefore, it is important for the childbirth educator to work together with the midwives in the hospital in order to avoid disappointment and unmet expectations. Guidelines were written for childbirth educators, labour ward and maternity staff and midwifery practice.

“... lack of information (about birthing) leads to unrealistic expectations and may result in a negative birthing experience ...”

“You feel so hopeless” A study of GP management of acute back pain in the UK

The management of non-specific back pain in general practice has been problematical, resulting in inappropriate referrals and a lack of self-confidence in the ability to provide evidence-based care. A qualitative study in the Dorset and Somerset regions of the UK examined the attitudes of General Practitioners when dealing with patients complaining of back pain. From the transcripts of telephone interviews emerged five main themes. These were generally negative and dominated by concerns about doctor-patient interaction. They included feelings of frustration, mismatches of perceptions in the doctor-patient relationship, problems in relation to time, challenges and discord between stakeholders in the process (for example, over sickness certification) and a lack of resources for education, awareness and local services to refer to. Psychosocial aspects of the actual care process were rarely raised. Participants favoured education that is multidisciplinary, in small group format and involves the participation of patients. The study illustrates the difficulties that GPs may have in applying the relevant evidence for the successful management of back pain. A desire to avoid conflict, in the relationship with patients, explained much of the problem of implementing evidence in general practice. This indicates a need for insightful educational strategies that involve active GP participation.

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Client-operated self-help services, Journal of Psychosocial Nursing and Mental Health Services (J PSYCHOSOC NURS MENT HEALTH SERV), 2006 Dec; 44(12): 26-35 (23 ref)
I am a Danish psychologist, who has been working with pain patients since 1990. In 2005, I visited Australia at The 11th World Congress on Pain in Sydney. In 14 days I travelled around in Australia and got deeply in love with the beautiful country. When visiting Uluru I became totally fascinated of the story of the Aboriginals and their culture. Since then I have been thinking about the many connections between being a minority in Australia and being a chronic pain patient in Denmark. The chronic non-malignant pain patients without sufficient medical diagnosis often think that they are isolated from the rest of the community and their only connection to the “real world” is through the “Embassy” (The Community Health Service). When they try to go back to a normal life with work, they often fail and become even more limited of their pain and they often get other problems, very often abuse problems. Often these patients haven’t got a sufficient medical diagnosis, because their pain experience is coloured of their “pain in life” more than it is a somatic problem. As a pain practitioner you might experience that “the soul” is suffering in the body, and if you try to solve the pain problem only looking at the body, the soul will go on suffering.

In April I am planning to join the 27th Annual Scientific Meeting of the Australian Pain Society with the theme “The torture of Pain”. My hope is that it could be possible to meet people to learn from the Aboriginals. I would like to learn about “Illness experience/illness behaviour” - “pain experience/pain behaviour” of the aboriginals. I believe that this knowledge could inspire me in my work with the pain patients and in my teaching.

I have a deep respect for the sensitivity of the Aboriginal people and I want to show their culture all my respect; but I also see the possibility of bringing their story to Denmark, learning Danish pain patients ways to cope, where the soul and spirituality is a natural and important part of pain coping.

For further information contact Anette Skriver at anetteskriver@gmail.com

NEW BEGINNINGS - PSYCHO-SOCIAL CARE FOR CHILDHOOD LEUKAEMIA IN BEIJING CHILDREN’S HOSPITAL

Each year, there are about 200 newly diagnosed leukaemia children treated in the Haematology Oncology Center of Beijing Children’s Hospital (BCH). There are at present almost 1000 of leukaemia patients who have survived at least 5 years, 25 of them have got married and had 22 healthy babies. We started the psycho-social care program for leukaemia patients and their family from 2001. Our doctors and nurses are not only responsible for the medical treatments, but also provide psycho-social supports for leukaemia patients and their parents. The psychologists from other institutes come to our hospital to serve psycho-social intervention voluntarily.

For each kid admitted in our hospital, the duty nurse gives a brief introduction about the circumstance, and then duty doctor talk to parents about the diagnosis, treatment and prognosis of the disease, highlights their hope to overcome the disaster. During their treatment in hospital, our doctors and nurses also involve in many activities with leukaemia children and their parents, such as birthday cake party, clown playing, park field trip, free lectures to parents and so on. Celebration party has been held every two years for survival children. A comprehensive, dynamic and multi-disciplinary supports with psycho-social care has been given during the many years of their childhood. Our doctors and nurses have developed a strong relationship with the children and their parents. It is very important for the children to get social supports. We also involved some parents in our hospital to serve psycho-social intervention voluntarily.

Preliminary analysis suggests that the experience of an environmental retreat provides a welcome contrast from the hospital setting. There is time to reflect, think and renew creative energy, partly inspired by the physical environment. Women report feeling empowered and supported by the care and generosity provided by staff and volunteers. They feel valued just for “being” - and find themselves reflecting on the meaning of their experiences. They also reported renewed understanding of self and others (such as intimate relationships), as well as taking up activities such as gardening, art and physical activity. Thereby, the time at Otis provides not only a physical space, but an emotional space for healing.

For further information contact Dr Huyong Zheng at zhenghuyong@vip.sina.com

In reference to an “International Perspectives” article exploring the relevance of psycho-social insight to geography and landscape theory (Vol. 1 Iss. 2), Dr Jan Pascal and research students Mr. Gabi Bini and Mrs Emma Mc Caulley from Latrobe University, Bendigo campus wish to share insights from their similar research experiences. In collaboration with the Otis Foundation, the research explores psychosocial experiences of women with breast cancer at an environmental retreat.

The Otis foundation provides respite services to those living with breast cancer. It allows opportunities for women and men with breast cancer to enjoy a time of restoration, relaxation and rejuvenation in a country environment. The Otis foundation provides two fully furnished self contained units, free-of-charge within a bush setting for visitors and their carers.

This study focuses on the holistic being-in-the-world. It is interested in exploring the connections between place, wellness and healing. Interviews with the women explore their sense of self through time since diagnosis, their connection with the landscape and environment at the Otis foundation (the retreat), their relationships (professional, social and family), as well as their emotional and cognitive state of mind. In keeping with phenomenological ideas of temporality, the study was interested in women’s wellbeing before, during and after their time at Otis.

In response to the continuing interest and ongoing requests for our book, Indigenous Palliative Care Service Delivery: A Living Model (ISBN 0977545002) we are now pleased to announce that an updated, second edition is now available.

Haematology and Palliative Care: Towards an Integrative Practice - FREE HARDCOPY

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Next Issue: I will finish the list and get back to Asynchronous collaborative online software and services.

I will talk to all interesting stuff. Well, to paraphrase Plato, “beauty is in the eye of the beholder,” and for some of us technology and related uses and advances can be made out of it – particularly for practitioners and researchers involved with psycho-social research. This issue I will highlight innovative use of information technology products for the Psycho-Social Health Industry.

SOARING TOGETHER - SHARED EXPERIENCES FROM THE “SPIRIT OF EAGLES”

The International Program of Psycho-Social Health Research (IPP-SHR), in conjunction with the Queensland Cancer Fund, recently hosted Native American Oncologist, Professor Judith Kaur, for a day of information sharing on Indigenous cancer issues.

Dr Kaur is the director of the Native American Programs at the Mayo Clinic Comprehensive Cancer Centre, Minnesota, and is one of only two Native American oncologists in her country today.

During her Australian visit she shared valuable insights into the cancer issues faced by American Indians and Alaska Natives, many of which are highly relevant for Australia’s Indigenous populations.

According to Dr Kaur, cancer care and cancer control strategies can effectively work for Indigenous populations only when communities are able to take control of their own health issues. By encouraging community input into research and planning, and fostering community leadership, Dr Kaur believes that sustainable and appropriate strategies aimed at lessening the burden of cancer can be developed. Dr Kaur showed how her program, the Spirit of Eagles, has successfully done this by granting funds for community-based cancer control projects to Native population groups and working in close alliance with community leaders.

R-E-SEARCH

HIGHLIGHTING INNOVATIVE USE OF INFORMATION TECHNOLOGY PRODUCTS FOR THE PSYCHO-SOCIAL HEALTH INDUSTRY

For the last two issues we have been exploring technology, Internet applications and communication devices. Of course, depending upon who you talk to - all interesting stuff. Well, to paraphrase Plato, “beauty is in the eye of the beholder,” and for some of us technology and related instruments are such “beauty.” However, we are not all “star crossed lovers” or seeing pink when it comes to such issues. Much technology is seen as a burden, forced upon the user with an “adapt or perish” stamped firmly on the front. However it need not be like that, real practical uses and advances can be made out of it – particularly for practitioners and researchers involved with psycho-social research. This issue I will look at some technological steps that IPP-SHR has taken which has had huge advances in our research output, ways of conducting research and research efficiency. So please forgive me if you were expecting an issue concerning Asynchronous collaborative online software and services – I will promise to get back to it next issue!

1. Digital Dictation and Transcription – Originally IPP-SHR used audio tapes and transcribers for its interviewing requirements. Such recording devices do work well, however they have the burden of a physical medium to transport, loose and suffer damage. Not to say that this does not happen with digital medium, however, moving to digital dictation and transcription has increased turn around time and decreased costs associated with transcriptions. Files are easily sent to the transcriber, sound quality is higher and physical damage or deterioration is avoided. Although there are some ethical issues that need to be implemented due to the easy duplication of files, the switch to digital has a significant cost and time savings for research staff and enabled IPP-SHR to conduct research projects over diverse geographical areas. One practical note – if purchasing a digital recorder, ensure that the transcriber can accept the files, and purchase an higher-end model for increase battery life.

2. Online Collaborative Calendar – Fantastic tool for coordinating and scheduling interviews. Particularly handy if the research team is in different locations and time zones. Google produces an excellent example and best of all its free. For outlook users out there - Google Calendar interacts with its scheduling and calender services. www.google.com/calendar

3. IP Video Conferencing – The clarity and price have an inverse relationship in the right direction. Clarity and ease of Internet Protocol (IP) video conferencing has increased whilst price has substantially dropped. In some cases this can be up to 20% of the cost of traditional (ISDN) video conferencing. And with such quality – compared to the cost of travel……need i say more?

4. Scan to PDF - Another tool that has revolutionised our work. Using a specifically designed scanner with email connectivity, this scanner has the same function as any photocopier. However, a user can choose to have the document traditionally copied or delivered to an email inbox as a PDF. This has enormous advances for backup and storage as it removes the physical medium from the equation. Additionally, there are environmental benefits to creating PDF backups compared to hard copies. Although, as with all environmental audits - there is a trade off - one needs to explore how much electricity needs to be used (and how much electricity is produced) compared to how much paper is saved.

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