

January 2010  
Volume 5, Issue 1

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Detailed Insights into Psycho-Social Health Research  
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**About the Psycho-Social Review**

The PSR is an international review that covers issues pertaining to psycho-social aspects of health care. The PSR provides a forum and opportunity for service providers, researchers and policy makers to connect between issues on the ground and theory relevant to practice. The PSR aims to connect those interested in psycho-social health care issues.

ISSN: 18335659 Circulation: 6200+  
www.ipp-shr.cqu.edu.au



# Psycho-Social Review



## Integration into the Australian Health Care System: Insights from International Medical Graduates

 **Off the Press at IPP-SHR**

International medical graduates (IMGs) now comprise a significant part of the Australian workforce. However, their perspective, on strategies to facilitate their effective integration into the Australian health care system, have not been adequately explored. This article presents the findings from qualitative research that explored IMGs experience before, during, and after their involvement in the Observer Program (OP)- a hospital based pre-employment program for IMGs conducted in the Department of Medicine, at the Redland Hospital (RH), Queensland, Australia.

The Observer Program provides opportunities for IMGs to explore clinical and health systems knowledge and practice, as an unpaid 'observer' in a supported hospital learning environment. It provides the Redland Hospital with an opportunity to closely monitor IMGs progress and assess their suitability for full time employment.

In addition to comments on the Observer Program, the IMGs detailed eight strategies that, from their perspective, would improve both, the efficiency and effectiveness of the process of integration into the Australian health care system. These strategies included; providing information to IMGs before departure from their country of origin; improving the information available on relevant websites; providing more support for bridging courses; funding more OPs similar to that conducted at RH; provid-

ing an IMG liaison officer at hospitals; reducing the difficulties associated with passing the Australian Medical Council (AMC) examination; providing support for IMGs families, and relaxing the rules about when and where IMGs can practise medicine. It is stressed that these findings represent the perspectives of IMGs only, and that any and all changes to the process of integration of IMGs must have, as a primary benchmark, the aim of ensuring that the highest quality of medical care is provided to the Australian population.

The suggestion for the IMG liaison officer was to provide information and support to overseas trained doctors during the initial stage of their entry into the Australian health care system. The liaison officer would support the IMGs by providing advice, information support, direction and contact with other IMGs. Participants reported that an IMG who had successfully entered the system would be the most appropriate person for such a position.

The strong recommendation from the present findings is that the integration of IMGs be streamlined with clearly defined, coordinated, and easily accessible processes.

Publication details: McGrath, P, Henderson, D & Phillips, E (2009) 'Integration into the Australian health care system: Insights from international medical graduates', *Australian Family Physician*, Vol 30(10): 844-847

 **Access this article online at**  
[www.ipp-shr.cqu.edu.au/publicatons](http://www.ipp-shr.cqu.edu.au/publicatons)

## Editorial

Dear Reader,

Welcome readers to 2010, I look forward to hearing your stories and psycho-social insights as we move into the new decade of the 21st century!

In the last couple of months I have had the great privilege of being invited to speak to a number of audiences where there has been strong practitioner representation. It has been deeply satisfying to experience the enthusiasm, dedication and energy generated by a wide range of practitioners involved in the psycho-social industry. Increasingly, this enthusiasm embraces a desire by practitioners to be involved in research. As a consequence, I am often asked to elaborate on IPP-SHRs Practitioner Researcher (IPR) scheme. The IPR scheme bridges the gap between health professionals wishing to undertake research on issues pertinent to their professional practice, whilst maintaining clinical practice. The IPR works closely with the IPP-SHR team to refine the project and is supported to maintain a sense of ownership that drives the completion of the project. The scheme operates on a Memorandum of Understanding (MOU) with the practitioner's organisation which details the agreement for research time for the practitioner and the process of collaboration and in-kind support. The expectation is that on completion of the project the findings are translated into a report for the practitioner's organisation and peer-reviewed publications. For further information on this scheme and IPP-SHRs collaborative research strategy, click on 'Collaboration' at the base of our home page ([www.ipp-shr.cqu.edu/collaboration](http://www.ipp-shr.cqu.edu/collaboration)).

As always, the review brings you glimpses of the important psycho-social research conducted around the world. This time we hear of the humanising of childbirth from Sao Paulo, Brazil; of the barriers to Aboriginal peoples accessing renal transplants from Canada, and the end-of-life care experiences of relatives of individuals declared brain-dead in ICUs in Manchester, United Kingdom.

Every volume of the review is a salute to all those involved in providing, understanding and documenting psycho-social care. We now know you do make a difference!

Happy reading!



Dr Pam McGrath

IPP-SHR Director,  
NHMRC Senior Research Fellow

We would like to hear from you!

IPP-SHR is keen to hear your thoughts on the Psycho-Social Review. If you are interested in any particular topics or would like to see any new sections introduced please let us know.

Letters to the editor, news or articles that you wish to share can be sent to [ipp-shr@cqu.edu.au](mailto:ipp-shr@cqu.edu.au) or [www.ipp-shr.cqu.edu.au](http://www.ipp-shr.cqu.edu.au). Articles or news items can be either a full version or abridged.

We look forward to hearing from you.

**Email: [ipp-shr@cqu.edu.au](mailto:ipp-shr@cqu.edu.au)**

## What's Happening at IPP-SHR?

### **Book Release - Eight Seasons - Our Family's Journey with Childhood Leukaemia**

IPP-SHR wishes to congratulate Sandra Evans for the publishing of her book detailing her family's experience with paediatric leukaemia. The book will be published under an IPP-SHR special initiative, and will be available to purchase in early February, 2010.

### **Leukaemia Foundation of Queensland (LFQ) and IPP-SHR explore Survivorship Issues**

LFQ and IPP-SHR will begin a research project exploring Survivorship Issues in haematology patients for 2010. Findings are expected to be used by LFQ to support better service provision.

### **IPP-SHR @ PONZ**

IPP-SHR wishes to congratulate the Psycho-Oncology New Zealand collaborative on the success of their conference. IPP-SHR will be posting audio files from presenters at the conference. Stay tuned to IPP-SHR Podcasts for updates.

### **Austral-Asian Journal of Cancer (AJC) launches In Cyprus**

IPP-SHRs affiliated journal, the AJC, has recently opened an editorial office in Cyprus, Greece. Editorial and academic leadership will be informed by Professor Constantinos Deltas, and Professor Constantinos Chirstofides at the University of Cyprus.

### **International Research Promotion Council (IRPC) and IPP-SHR explore HIV/AIDS in India.**

Starting in 2010, and lead by IPP-SHR Adjunct Fellow, Dr Sue Rice, this joint research collaborative will explore the health care needs of female HIV/AIDS patients accessing newly established Community Care Centres within India. It is hoped the research will be used to identify the health care needs of such populations and provide better service.

### **MOU signifies research collaboration between IPP-SHR and Kenya**

IPP-SHR welcomes Gideon Odhiambo (Vol 4 Iss 3) as an IPP-SHR Practitioner Researcher. Gideon will be exploring psycho-social issues associated with International Displaced Persons (IDPs) within Kenya.

# The easy option? Australian findings on mothers' perception of elective Caesarean as a birth choice after a prior Caesarean section

## Off the Press at IPP-SHR

As the rate of primary and repeat Caesareans (CS) around the world increases, obstetricians, midwives and primary care providers are expected to provide counsel to women seeking information regarding birth choices for delivery after a prior emergency Caesarean. In Australia, CS accounts for more than one-in-five births. Reasons for this exponential increase are varied. This article seeks to contribute to the knowledge on this topic by presenting research findings from a qualitative study designed to explore, from the mothers' perspective, the decision-making experience with regards to subsequent birth choice for women who have previously delivered by Caesarean section. In Australia, 35% of Caesarean deliveries are repeat Caesareans. Specifically, the findings in this article present the perspective of the mothers who opted for an Elective Caesarean (EC).

Current research has focused on the clinical outcomes of EC and VBAC and the psycho-social implications are not as well researched. The majority of EC mothers in the IPP-SHR study perceived VBAC as having the highest risk for delivery, particularly because of concerns about the rupturing of the prior CS scar. After obstetrical and medical factors, the major reasons for a choosing Caesarean were psychological and safety concerns. Also of significance is that many of the mothers made firm and unalterable decisions in favour of an EC, either prior to conception or early in the pregnancy, and were not receptive to any subsequent information or discussion of risks associated with EC. This group of mothers reported that the psycho-social factors were more significant in determining their birthing choice, rather than relying on clinical advice or information on the risk.

The majority of mothers in this study



chose EC for reasons of fear and the desire to retain control over the birthing process. These findings strongly emphasise the importance of understanding and taking into consideration the mothers' psycho-social perspective on birth choices as a key to providing counsel and support.

Publication details: McGrath, P & Ray-Barruel, G (2009) "The easy option? Australian findings on mothers' perception of Elective Caesar as a birth choice after a prior Caesarean Section", *International Journal of Nursing Practice*, 15(4):271-279

 Access this article online at [www.ipp-shr.cqu.edu.au/publicatons](http://www.ipp-shr.cqu.edu.au/publicatons)

## Research that Connects

### IPP-SHRs Collaborative Research

IPP-SHR provides research leadership on psycho-social issues relevant to health care. As part of IPP-SHRs commitment to the psycho-social enterprise, IPP-SHR offers a variety of options to integrate research into your practice or institution.

IPP-SHR has many flexible options available for individuals or institutions to collaborate and work with us, including: research; researching training and higher degrees; program development, and evaluation or consultancy.

IPP-SHR offers collaboration opportunities which are designed to meet individual needs or those of an organisation.. IPP-SHR offers, research training through the IPP-SHR Practitioner Research Scheme, Adjunct Appointments, Collaborative and Contract Research.

Full details of IPP-SHR collaborative research programs can be found at [www.ipp-shr.cqu.edu.au/collaborate](http://www.ipp-shr.cqu.edu.au/collaborate)



# The Toolshed for Men's Grief

 Programs & Practitioners

Grief affects us all, but for men it can be silent and invisible, not only to the griever but to others as well. This might be the reason it is so hard for men to seek out support during this often difficult time. Acknowledging such difficulties, The Leukaemia Foundation Queensland conducts workshops for men who have lost a loved one to leukaemia, lymphoma, myeloma, amyloidosis or cancer. Titled "The Toolshed for Men's grief", the program is tailored to comprehensively address the importance of key roles and key goal-planning for men during the grieving process. More importantly, it shows that a lot of expectations put on men who are grieving are myths, i.e. big boys don't cry. The workshops provide a motivating, reassuring and open framework towards understanding the grief process from a masculine perspective.

- "It also reassured me that I was on the right track on my own journey with grief."
- "It was also special to be able to share the day as a men's group."
- "It provides a safe environment to share experiences without judgement."

**Shirley Cunningham**

Support Service

Leukaemia Foundation of Queensland

[www.leukaemia.org.au](http://www.leukaemia.org.au)



# The Compassion Cart - Simple yet Effective Psycho-Social Support

 Programs & Practitioners

Visitors and staff at the University of North Carolina (UNC) Hospitals can easily visualize the support offered by the hospital to families in need of comfort. Compassion carts stand in front of the rooms of patients nearing the end of life and offer nourishment and information on grief support services to the patients family and friends.

A collaboration between bereavement support services and nutrition and food services, the carts offer hot and cold water, coffee and tea, soda, juice, a bucket of ice and other condiments including, pretzels and crackers, blank note cards, and information on bereavement services.

After a three month pilot, the compassion cart program has been operating successfully hospital-wide since July 2006, with positive results garnered from a survey demonstrating increased satisfaction from the family, with the efforts of the healthcare team. Benefits were not only derived from patients, with staff indicating that the program offered a great sense of joy; "It is like a kind word from us that says, We are really sorry... We provide them nourishment, physically and spiritually." Angelo Mojica, Director of Nutrition and Food Services at UNC.

The daughter of a patient said, "It was such a thoughtful gesture of empathy and comfort to have someone think of basic things like food and water. It was so supportive, so caring, and totally unexpected."

For further information or enquires please email:

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Chapel Hill, North Carolina, USA



# Integrating the Personal Story in the Context of Pain



*Staff working at the Hunter Integrated Pain Service (HIPS), are exploring holistic methodologies of treatment for acute and persistent pain, which can significantly impact on an individual's quality of life. HIPS offers an evidence-based multidisciplinary approach to pain management in the public hospital system in Newcastle, NSW. Dr Chris Hayes provides some insights into current emerging theories on pain and its management.*

The traditional bio-psychosocial approach to pain is often expressed in such a way that people with persistent pain are told that their pain will inevitably continue, and that the best they can do is simply learn to manage it. Pain is seen primarily as a biological entity and psychological and social factors have only a secondary modulating influence. This model, in fact, leads us to think of sepa-

rate biological, psychological and social compartments, albeit with a modest degree of inter-compartmental impact.

As the broader health care system moves toward more holistic models of care, the Hunter Integrated Pain Service (HIPS) team has been exploring concepts of meaning and personal story in the context of persistent pain. This exploration has been influenced by our coal-face experience of seeing many people in pain, since the service began in 1997. Part of the HIPS evolution has involved development of a website aimed at providing appropriate educational information to people in pain and health professionals. Articles of interest from the Community Information section include "Understanding Pain", "My Story" and "Spirituality and Pain".

We recognise that in the health system, the personal story can sometimes become separated and effectively kept

in a different room to the presenting health problem. If this happens there is a danger that the treatment approach narrows down to focus on the presenting problem in isolation. Therefore a major challenge is to allow both the health problem and the surrounding story to coexist in the same room. When this happens the meaning of the health problem can be explored and a balanced treatment plan begins to emerge.

In integrating story with other pain management approaches we have anecdotally found improved results. We have a small number of cases in which the person in pain has been willing to explore deeper meaning and found that persistent pain has resolved. Our team is currently accumulating outcome data related to this broader approach.

**Dr Chris Hayes**  
Hunter Integrated Pain Service  
[www.hnehealth.nsw.gov.au/pain](http://www.hnehealth.nsw.gov.au/pain)

## ▶ Working with the Story

*Exploring a personal story can be an important part of a broad pain management plan. Here are some steps to consider:*

### 1. A timeline

Drawing a timeline can show potential links between life events and the development of health problems. Draw a line across the page representing your birth, from the left hand side through to the present moment on the right. Put a series of marks along the line to represent every 5 or 10 years. Next, plot the times when stressful life events occurred on the upper side of the line (divorce or work stress for example). Then show when health problems began on the lower side. Are there any links between life events and pain?

### 2. Journaling

Writing a journal can be a good way to connect more strongly with the emotions of your story. You may choose to spend a short time each day writing down details of significant life events and the feelings that went with them.

### 3. Support

The support of another person, or group, is often fundamental to the story. Stories are for telling. Being able to tell a "safe" person may be a key to releasing deep tension and moving ahead with the process of healing.

### 4. Stillness

Stillness brings us to a reflective place from which we can consider the events of life, interpretations we have made and how we have responded. Stillness invites us to release any stress that we have held within. Stillness teaches us to respond peacefully to events that previously triggered stress. Some like to use specific relaxation or meditation techniques, others prefer a less structured approach. There is no single way, but many.

# Supporting those that Support Others



## Programs & Practitioners

Millions of people are severely affected by natural disasters and conflict in some of the harshest and most complex environments on earth. Many are caught in ongoing conflict, while others require aid assistance for the first time. Regardless of the cause, those affected are highly vulnerable, displaced and uncertain about their future.

Responding to, and sharing these, challenging environments are humanitarian aid workers who provide support to those requiring assistance. They supply basic necessities through the delivery of food, administering medicine, providing shelter and infrastructure, and protection of the most vulnerable.

Aid agency, RedR Australia, runs an extensive training program to prepare relief workers for the realities of field

work. Two core training courses, the Essentials of Humanitarian Practice (EHP), and Personal Security and Communications (PSC), provide an introduction to the humanitarian sector, and detail how to manage safety and operate communications equipment.

The live-in courses provide a range of learning experiences, including, scenarios and field exercises to equip participants with the skills to respond quickly and effectively during complex humanitarian crises.

Participants on the EHP are introduced to cultural awareness, gender issues in humanitarian work, personal health preparations and managing stress in emergencies. Returned aid workers host a group session discussing their personal experiences on assignment. The con-

fronting scenarios played out during the PSC are designed to mentally prepare aid workers for challenging experiences including, dealing with angry crowds, kidnapping and hostage survival, sexual assault, vehicle checkpoints and road blocks, negotiation and field preparedness, and evacuation. A counsellor is present during the course to support participants through one-on-one debriefings and personal reflection.

Training courses are developed to complement the responsibility of aid agencies to care for their staff while in the field, and post-assignment through counselling and debriefing sessions.

**Belinda Johnson**  
RedR Australia  
[www.redr.org.au](http://www.redr.org.au)

# Psycho-Social Support for Children of War



## Programs & Practitioners

Fifteen years ago, World Vision, Uganda, established a rehabilitation centre, the World Vision Uganda Children of War Rehabilitation Centre, in Gulu, to care for the psycho-social needs of child soldiers escaping from the Lord's Resistance Army (LRA).

The centre assists children who have experienced high levels of trauma with resulting high levels of physical and mental morbidity. The centre runs psycho-social interventions such as, art, music and sports therapy, individual counselling sessions and interpersonal

psychotherapy groups to assist with recovery.

One of the main barriers, faced by children who have escaped from the LRA, to recovery, is re-integration into their communities, and families. Children returning home can face stigma and rejection from their communities due to the violent acts they have been forced to commit against these families. Often, when a child is abducted, they are forced at gunpoint to kill a family member. The centre works with such children and their community, offering

counselling and education to assist with reintegration.

Children who have been reintegrated back into the community can assist others through a community based organisation called, Children & Youth as Peace-builders (CAP). One of CAPs main objectives is for the community to accept former child soldiers upon their return and to encourage reintegration with their community.

**Megan McGrath**  
Policy and Programs  
World Vision Australia

# Bridging the Gap- A Call to Address Childhood Cancer in Developing Countries



Childhood cancer is a major health threat in developing countries. An estimated 250,000 children develop cancer each year, and 80% of them live in developing countries (BBC 2002, American Cancer Society, 2007). Eight out of ten of the world's children die without receiving treatment. 80% are either not diagnosed, or are denied potentially life-saving treatment (BBC, 2002). Four in five are from low and middle income countries where child cancer is just one of many priorities struggling for resources (World Child Cancer, 2009). In poorer countries, childhood cancer is too often detected too late for effective treatment, and appropriate treatment is too often not available or affordable. Many children are never diagnosed at all, and when a diagnosis is made the treatment options may be limited (UICC, 2006).

The survival scenario in developed countries is quite different. Diagnostic and treatment protocols in developed countries have effectively improved childhood cancer survivorship by 75-80%. In developing countries, by sharp contrast, more than 80% of young cancer patients die (World Child Cancer, 2009).

The childhood cancer situation in Bangladesh is similar to other developing countries. Cancer is one of the

major causes of morbidity and the sixth leading cause of mortality in Bangladesh (MOHFW, 2008; BBS, 2008). The annual incidence of paediatric cancer in Bangladesh is estimated to be 7000-9000 cases per year; with less than 500 children receiving hospital treatment (Islam S, 2009). Indeed, the founder of "World Child Cancer" was shocked during his visit to Bangladesh in 2007, when he saw one child with an incurable brain tumour being given only paracetamol to ease the pain (World Child Cancer, 2009).

Major disparities in access to very limited services, between rural and urban areas, are also distinctively visible. Bangladesh does not have a childhood cancer registry to help inform planning decisions across the country. Clearly, there is a large unmet need in the community, and the Bangladesh health system faces significant challenges in coping with the burden of childhood cancer (MOHFW, 2008).

Most childhood cancer patients die without a proper diagnosis and adequate medical treatment; more than half of properly diagnosed children still die within five years (MOHFW, 2008). If diagnosed at an early stage, and if treatment is available, most childhood cancers are highly curable (Raul et.al, 2008). It is

high time for international development partners to come forward to conduct appropriate research and intervention programs to save deprived children in developing countries like Bangladesh. As a first step, the British Columbia Cancer Agency, in Canada, has a plan to set up a Childhood Cancer Forum in Bangladesh, in collaboration with experts from the UK, Japan, USA, Canada, and Bangladesh.

The main objective of the forum is to investigate the scale and nature of the problem; generate financial and technical resources, and to design and implement research and intervention programs to combat childhood cancer in developing countries, starting in Bangladesh. This call is for international communities to join together to achieve the goal of bridging the gap.

## Syed Rahman

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Complete reference list is available at  
[www.ipp-shr.cqu.edu.au/enews](http://www.ipp-shr.cqu.edu.au/enews)



## The Amaranth Foundation



The Amaranth Foundation is a new charity based in rural New South Wales, Australia, established to provide holistic, psychosocial support and care for people living with a serious or life limiting illness. Amaranth has developed an evidence-based model of psychosocial support, with a strong focus on working with

patients, their family and care givers, on conserving dignity, finding hope and meaning whilst living with uncertainty. Amaranth provides an innovative model of psychosocial palliative care, utilising concepts of packaged care planning, and emphasising the importance of a professional approach to assessment and intervention, based on social work values and standards.

The foundation does not provide direct nursing assistance, but through their PallCare Packages® offer counselling, support, case management, brokerage for equipment and services, assistance with financial allows and referral.

## Julianne Whyte Director

The Amaranth Foundation  
<http://www.amaranth.org.au>



# Headspace Central Australia

## Programs & Practitioners

Headspace Central Australia provides youth friendly primary health care to young people aged 12-25 years, experiencing mental health and related substance use disorders. We work through early identification and effective, evidence-based intervention, in an accessible and integrated service.

Through a multidisciplinary focus, and networked collaborative youth services, we engage with issues such as mental health, alcohol and other drugs, general clinical care, sexual & maternal health, education, employment & training, and housing.

Our aim is to provide curative, preventative, promotive and rehabilitative comprehensive primary health care, through working in collaboration across Central Australia, for sustaining approaches to serving all young people, their families and communities.

In addition to medical care and psychological care, Headspace Central Aus-

tralia operates as the hub for a network of school and social support services. We assist young people to recover from mental illness or addictions, and then to find appropriate education and training programs, accommodation and employment. The Alice Springs Wellbeing Hub has been established among all schools, health and community agencies, to create cultures of wellbeing and restorative practice across the whole community.

In creating a positive intervention for the social and emotional wellbeing of young people, we offer a range of collaborative projects designed to assist young people to find their sense of identity and purpose, while recovering their health, so that they make positive choices for future life development. Such activities include, creative arts expressions (music, dance, art etc.), linked to therapeutic narrative work, hands-on projects with cars, emergency service training, and relating with supportive independent community elders in our

Elders–Youth Group.

Supporting this community-based work is an environment where appropriate, comfortable and accessible facilities make young people feel at home. This speeds early detection of problems, and targeting of brief interventions, thus reducing the need for more intensive community based rehabilitation plans for addictions and mental health problems.

Combining Principles of Youth Empowerment and Clinical Excellence, our services work together in a seamless, coordinated way. Treatment, recovery and development for young people rely on reciprocal access, communication and support between our services.

### **Robbie Lloyd**

Manager

Headspace, Central Australia  
[www.headspace.org](http://www.headspace.org)



# Perinatal Hospice and Palliative Care:

A comprehensive model of care for families continuing a pregnancy following a terminal prenatal diagnosis

## Programs & Practitioners



Perinatal hospice and palliative care is an innovative and compassionate model of support that can be offered to parents who find out during pregnancy that

their baby has a fatal condition. Perinatal (around the time of birth) hospice incorporates the philosophy and expertise of hospice into the care of this new population of patients. As prenatal testing continues to advance, more families are finding themselves in this difficult situation. For parents who receive a terminal prenatal diagnosis and wish to continue their pregnancies, perinatal hospice and palliative care helps them embrace whatever life their baby might have, before and after birth.

This support begins at the time of diagnosis, not just after the baby is born. Under the conventional hospice model, services do not begin until the baby is born or is discharged from the hospital, which is of little help when a baby has a life expectancy of hours or even minutes. A perinatal hospice and palliative care approach, in contrast, is a model of caring for the family before, during, and after birth.

It can be thought of as “hospice in the womb” (including birth planning and preliminary medical decision-making before the baby is born) as well as more traditional hospice care after birth (if the baby lives longer than a few minutes or hours). This approach supports families through the rest of the pregnancy, through decision-making before and

after birth, and through their grief. Perinatal hospice also enables families to make meaningful plans for the baby’s life, birth, and death, honouring the baby as well as the baby’s family.

Perinatal hospice is not a place. Ideally, it is a comprehensive team approach that includes, obstetricians, maternal-fetal medicine specialists, midwives, labour and delivery nurses, neonatologists, NICU staff, chaplains and pastors, doulas, social workers, genetic counsellors, paediatricians, therapists, and traditional hospice professionals. It is a continuum of supportive care.

### **Amy Kuebelbeck**

[www.perinatalhospice.org](http://www.perinatalhospice.org)

**Global Update: Manchester, United Kingdom**

## The End-of-Life Care Experiences of Relatives of Brain Dead Intensive Care Patients

Brain death usually occurs suddenly as a result of a traumatic event such as an acute brain hemorrhage or severe accident. The majority of patients spend their last days in an intensive care unit (ICU) and during this time family members are often approached to consider organ donation.

This study explores the palliative care needs of families of patients with brain death. Family members expressed satisfaction with the physical care of their relative whilst in ICU; however, communication and the breaking of bad news were areas of concern. The facilities for family members were seen as insufficient, as many expressed a need to have a break from the ICU environment and to have a place that was comfortable to relax and unwind in. The lack of privacy within the ICU was difficult as participants felt they would have liked time alone with their loved one before the machines were switched off.

Communication about death was seen as difficult as participants stated that staff were not appreciative of the suddenness of the event that brought them to the ICU, and there was confusion about when the patient actually died – was it when the brain death occurred or was it when the machines were turned off?

The results of this study show a need for the use of a palliative care team within the ICU, to assist family members with the traumatic time of deciding to cease life-sustaining treatment and also during the bereavement process.

Publication Details: Lloyd-Williams, M., Morton, J & Peters, S (2009) The End-of-Life Care Experiences of Relatives of Brain Dead Intensive Care Patients, *Journal of Pain and Symptom Management*, 37(4): 659-664. Précis by IPP-SHR

**Global Update: Alberta, Canada**

## Barriers Facing Aboriginal Patients Accessing Kidney Transplant

Disproportionately fewer Aboriginal Canadian patients experiencing end-stage kidney disease (ESKD) receive transplants in comparison to non-aboriginal patients. ESKD is a preventable chronic condition with kidney transplantation being considered the optimal treatment approach. Kidney transplantation is very complex, involving patients in several steps including: being deemed medically suitable; being referred into programme; receiving transplant education; completing pre-transplant work-up; becoming wait listed, and then receiving the donor kidney. This study explores the perspectives of Canadian kidney health professionals on the barriers facing Aboriginal ESKD patients accessing kidney transplants.

Data gathered from health professionals, working over six Canadian provinces, showed the emergence of multi-faceted barriers, which were found on, both, the systemic and individual levels, that reduced Aboriginal patients' ability to access transplant and dialysis. These challenges included, system complexity,

remote living location, low-socioeconomic status, and language and cultural differences. The most commonly cited barrier to Aboriginal patients receiving a transplant was living in a remote location. Living in a remote area results in displacement from specialist services for work-up and dialysis services. Oftentimes, dialysis treatment necessitates a move into an urban area for the Aboriginal Canadian patients, which results in difficulties associated with loneliness.

Identifying the experience of Aboriginal patients was noted as the next step in gaining a better understanding of how these issues affect patients ability to interact with the health care system, and how best to deliver appropriate and effective care.

Publication Details: Anderson, K., Yeates, K., Cunningham, J., Devitt, J & Cass, A. (2009) *They really want to go back home, they hate it here: The importance of place in Canadian health professionals' views on the barriers facing Aboriginal patients accessing kidney transplants*, *Health & Place*, 15(1): 390-393. Précis by IPP-SHR

**Global Update: Sao Paulo, Brazil**

## The Meaning Given by the Healthcare Professional to Labor and Humanising Delivery

The humanisation of a significant event, such as childbirth, can make it a positive and rewarding experience. Qualitative research was conducted to gain an understanding of the meaning, the healthcare professional in charge of women in childbirth, gave to labor and humanising delivery.

Seven physicians and four nurses, from a public hospital in the city of Sao Paulo, participated. The results showed that many professionals possessed an understanding of the benefits of humanising childbirth, but a gap existed between the concept and the reality of this service delivery model. Barriers such as, rigid hospital routines, a lack of human contact, and the loss of autonomy for the birthing women, hindered the humansing of this significant event. In addition, it was noted that there was a need for more

educational courses on this topic for professionals during their medical training.

Recommendations such as, introducing the Program for Humanisation of Prenatal Care and Childbirth (PHPN) policy in the prenatal period, and making efforts to include the patient's family members in the care plan, were made.

The research revealed that the government's PHPN policy is excellent in principle but difficult to apply due to underlying financial and infrastructural deficits.

Publication Details: Mabuchi, A.S & Fustinoni, S.M. (2008) The meaning given by the healthcare professional to labor and humanizing delivery, *Acta Paulista de Enfermagem*, 21(3): 420-6. Précis by IPP-SHR

## Journal & Book Profile

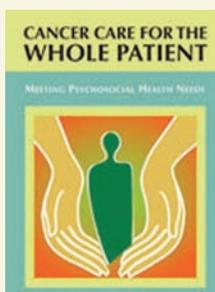


### The Patient: Patient Centered Outcomes Research

The Patient, publishes research that seeks to move the patient perspective from one that is typically considered anecdotally, to one that is grounded in scientific methodologies, and thus ensures that patient-centered evidence is utilised appropriately to inform and enhance health care decision-making.

The Patient deals with the full range of patient centred studies, reviews and commentary, ranging through techniques such as, conjoint analysis, patient reported outcomes, studies on compliance and satisfaction, through to patient directed health plans and patient literacy.

<http://www.ovid.com/site/catalog/Journal/3709.jsp>



### Cancer Care for the Whole Patient Meeting Psycho-Social Health Needs

This is a seminal and important work for those involved in the psycho-social industry. It encompasses a wealth of recent research, practical insights and clear recommendations, on a broad range of topics that embrace the full spectrum of psycho-social needs of cancer patients.

Institute of Medicine of the National Academies, *Cancer Care for the Whole Patient: Meeting Psycho-social Health Needs*, The National Academies Press, Washington DC, ([www.nap.edu](http://www.nap.edu)), 2008

<http://www.iom.edu/en/Reports/2007/Cancer-Care-for-the-Whole-Patient-Meeting-Psychosocial-Health-Needs.aspx>

Do you have a book to review?

If you have a book or journal that you would like to display in this profile, please send a copy to PSR REVIEWS, PO BOX 796 TOOWONG Q 4066 AUSTRALIA

## Upcoming Events

| Event   | Dates                | For more information  |
|---|----------------------|---|
| 10th Annual Nursing Conference-Current Perspectives in Oncology Nursing.<br>Tampa, Florida, USA             | 03-05 February, 2010 | Visit: <a href="http://www.moffitt.org/continuinged/nsg2010">www.moffitt.org/continuinged/nsg2010</a>                   |
| WCIM World Congress of Internal Medicine 2010<br>Melbourne, Australia                                       | 20-25 March, 2010    | Visit: <a href="http://www.wcim2010.com.au">www.wcim2010.com.au</a>   |
| 3rd International Nurse Education Conference<br>Sydney Australia  | 11-14 April, 2010    | Visit: <a href="http://www.netnep-conference.elsevier.com">www.netnep-conference.elsevier.com</a>                       |
| 7th Biennial International Conference in Organisational Behaviour in Health Care (OBHC)<br>Birmingham, UK   | 11-14 April, 2010    | Visit: <a href="http://www.hsmc.bham.ac.uk/events/SHOC.shtml">www.hsmc.bham.ac.uk/events/SHOC.shtml</a>                 |
| Midwifery Today Conference. Trends and Traditions in Midwifery and Birth<br>Philadelphia, Pennsylvania, USA | 14-18 April, 2010    | Visit: <a href="http://www.midwiferytoday.com/conferences/Philly2010">www.midwiferytoday.com/conferences/Philly2010</a> |

# Podcast Picks

IPP-SHR Podcasts - Bringing you the latest in psycho-social health research from around the world. [Listen online at www.ipp-shr.cqu.edu.au/podcasts](http://www.ipp-shr.cqu.edu.au/podcasts)

## 'You are the first person who's asked me...': The Importance of Understanding Loss and Grief in People with Schizophrenia

People with schizophrenia are five times more likely to commit suicide than those in the general population, and their suffering, due to delusions, hallucinations, impaired cognition and impaired social functioning, is well documented. However, no studies to date have looked specifically at the lived experience of loss and grief in schizophrenia. Dr Maria Mauritz, says people with schizophrenia have normal grief reactions, but their prolonged experience of loss can lead them to lose self-confidence, autonomy and ambition, and to develop a sense of meaninglessness. Hallucinations cause people to lose trust in their own senses, for

example, wondering, "Am I actually hearing this", and she identifies a sense of not belonging as a common ongoing, painful experience. Maria believes it is crucial to ask people with schizophrenia about their feelings and look at what is motivating their behaviour. She says, like all people experiencing grief, they need comfort and consolation, so it is important to find out what it is that comforts them. Maria says small things like asking people how they are, and offering a cup of tea, are important-- just treating them as human beings.

**Published 04 December, 2009**  
**Interview with Dr Maria Mauritz**

## 'An Inescapable Reminder': Understanding the Distress of Living with a Malignant Wound

People living with malignant wounds, and those who care for them in their final months of life, are often deeply affected by the overwhelming demands of wound care. Some patients are so embarrassed by their wound's odour and appearance, they avoid contact with friends, and some delay seeking medical help. Carers are often left to cope on their own, their lives dominated by the demands of wound dressing, showering and laundry. Researcher Susan Alexander believes that many carers experience posttraumatic stress disorder after their loved ones have died. She says the wounds also serve as a constant reminder

to patients that they are dying. Her research shows nurses can feel frustrated, inadequate, guilty and angry that they were not able to care for their patients to the standard they felt was required. Susan says that knowing about their patient's social isolation, and experiencing traumatic situations during treatment, can traumatise not only the nurse involved, but whole teams of community nurses. Susan says the psycho-social effects of malignant wounds have been almost totally overlooked in the literature.

**Published 27 November, 2009**  
**Interview with Susan Alexandra**

## Sex after Surgery: Helping Nurses Talk to Colorectal Cancer Patients about Sexuality

Colorectal, or bowel cancer, is the second leading cause of cancer-related death in the United Kingdom, and the third most common form of cancer in the western world. Research shows that after surgery for colorectal cancer, patients often experience altered body image, low self-esteem, poor self-concept and psycho-sexual problems. Erectile dysfunction, retro-grade ejaculation, vaginal dryness and painful intercourse are also common. Spouses of men, who have had surgery, report their partners feel less masculine and become emotionally withdrawn, which has a massive impact on relationships. Marie Beck, the study's

author, found that nurses have very limited discussions with colorectal patients about sexuality and sexual dysfunction. Nurses said hospital wards lacked privacy for discussions, and they felt embarrassed and ill-equipped to discuss sexual issues. For patients to receive holistic nursing it is critical for nurses to talk to patients, about altered body image and sexual dysfunction. Marie says she hopes that if nurses are better informed, they will be more confident discussing psycho-sexual issues, in both, ward and clinic environments.

**Published 27 November, 2009**  
**Interview with Marie Beck**



Detailed Insights into  
Psycho-Social Health Research

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## Latest Podcasts

- **Cancer Beliefs of Australian Indigenous Peoples'**  
Published 18 December, 2009
- **'Catch me before I fall': Supporting Young People with Mental Illness as they Become Adults**  
Published 11 December, 2009
- **'Should we restore the tooth or extract it?': Ethical Challenges Involved in Spending the Public Health Dollar.**  
Published 06 November, 2009
- **'It cuts both ways': Understanding the 'Almost Normal' Life of Adolescents with Defibrillators**  
Published 30 October, 2009
- **'Incomprehensible shock': How Patients Make Sense of Acute and Unexpected Spinal Injury**  
Published 23 October, 2009

# Does Bereavement Support Save Lives?



## Work-in-Progress at IPP-SHR

IPP-SHR has currently finished primary data collection for a project which aims to examine the effect that Bereavement Support has on the lives of those that have recently lost a significant other.

The research was instigated by anecdotal evidence collected by a Queensland hospice service, Cittamani Hospice Services, who noted that clients of their bereavement service were experiencing

an unusually low mortality rate compared to other people experiencing a similar bereavement.

The increased risk of mortality following bereavement of a spouse has been well documented in the literature, and is particularly pronounced in the period immediately following the loss of a loved one. Recent studies suggest that the use of hospice care may have a benefi-

cial impact on mortality rates following bereavement.

Data is currently being analysed and will be cross referenced with the National Death Index at the Australian Institute of Health & Welfare. It is hoped that data will provide some insight into the provision of bereavement support and the effect it has on mortality rates of recently bereaved people.



## research

**Hamish Holewa**  
**IPP-SHR**  
**Program Manager**

With increased focus on accountability and efficiency the need to record telephone calls is rising. Despite this increasing demand, there is little in the way of dedicated, non-enterprise, phone recording products available. Whilst this is slowly changing, for most users, telephone recording still requires some planning and know-how. For this issue of R-e-Search we will have a look at some of the recording paradigms currently in use.

### At the end of the line

End of the line recording refers to recording audio as you would hear it. Normally achieved with a speaker phone and a dictation device, it is generally reliable and easy to use but does have some privacy and sound quality drawbacks. As the device captures audio from the telephone speaker, there be a substantial interference and discrepancy between the phone and your voice, causing possible issues during transcription. If most of your interviewing is done close to your computer, consider using your computer or a webcam. Audacity, is an intuitive and open source sound recorder that is perfect for this purpose.

### From within the phone

Recording from within the phone captures the audio signal before it is converted to actual sound waves and requires either a 'Soft-phone' or an add-on device. This method generally produces a higher quality recording due to less interference and external noise. On most desktop phones this can generally be achieved using an inline adapter that connects between the wall and phone, however it is worth checking with tech support first, as inline adapters are not always compatible with some newer phone systems.

An alternative to hardware based solutions is to use a software phone, or 'Soft-phone', which enables phone calling over an internet connection using Voice- Over-IP (VOIP) technology, e.g. Skype. Although you will need a computer, recording quality is generally good (and getting better), calls are inexpensive, and the software is generally free. An added bonus is there is generally less file management issues, as files are stored locally on the computer and do not need to be transferred between devices.

### Switch or exchange recording

This is a fairly new and exciting technol-

## Phone Recording

ogy which has just become available to individual users. Basically, your phone provider channels all calls made from your phone through a central server which you are able to access and control. The server will record phone calls and make them available through a secure website. The advantage of this service is that recording is simple; it is not tied to one phone; is secure and provides exceptional sound quality. However, due to the relevant infancy of this technology, there are few companies that currently offer or support it. Podference, a web based service, allows automatic recording of conference calls which can then be emailed or accessed through a website. Another notable service is GoogleVoice (previously GrandCentral), which converges all phone calls to a central location and features in-call recording. Whilst only available to users within the USA, this product is touting automatic transcription of messages. Whilst automatic transcribing holds promise, the length of time before it can be reliably used for research may be longer than some on-hold queues.

Happy recording!

### Contact Details:

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