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Psycho-Social Review

A Quarterly Review, International Program of Psycho-Social Health Research
CQUniversity Australia

Off the Press @ IPP-SHR

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IPP-SHR
International Program of Psycho-Social Health Research
CQUNIVERSITY AUSTRALIA



Ethical Reflections in an Accident and Emergency ward

A shift is occurring in health care research which broadens the focus on ethical decision-making to that of the organisation, as opposed to just the individual in the system. Such focus recognises that ethical behaviour happens at, both, the individual level and the organisational level, giving impetus for health organisations to actively foster ethical behaviour and move away from simply reacting to ethical conflicts, to employing approaches designed to reduce their occurrence. In response to this paradigm shift, a program of research was initiated between IPP-SHR, CQUniversity and the Bayside Health Service District (BHSD), Queensland, Australia, with the aim of developing an innovative organisational model for responding to ethical concerns at the Hospital. Findings from this study, conducted within the Accident and Emergency ward complement pilot work conducted within the Acute Medical ward.

Findings echo previous pilot work, in which, participants indicated that the topic of defining the notion of ethics was difficult to articulate, and ethical decision-making at times was a struggle. Whilst differences existed between different health professional groups (medicine, nursing and allied health), at the core of both sets of findings was the notion that ethics was the service delivery notion of providing the best possible care for patients. The participants reported an 'ethics-as-process' view of moral reasoning. This view is expressed as acting in accordance with the patient and families' wishes, rights, and expectations and in providing a high level of care. The definitional consensus of ethics as patient-centered care moves the focus of ethical reflection from abstract philosophy to sociological concerns about the ongoing processes involved in patient and family care. From such a perspective, concerns about power, communication and multi-disciplinary co-operation are as important as philosophical reflection.

Based on the sociological view posited by the participants, the research explores and documents strategies for dealing with professional conflict and tension. The findings from the project cover a wide range of relevant organisational processes including notions of 'a stand off', not 'rocking the boat', collegial support, patient and family consultation, seeking the advice of superiors, and multi-disciplinary team work. However, it was noted that with effective, multidisciplinary respect and communication most patient-care issues can be dealt with pro-actively before ethical problems arise.

OA OPEN ACCESS

McGrath, P & Henderson, D (2008) "Oh, that's a really hard question" : Australian findings on ethical reflection in an Accident and Emergency ward, *HEC Forum* 20; 4: 357-373

editorial

Dear Reader,

In this issue we are sharing with you the results from one of our recent studies on ethical reflections in an Accident and Emergency ward. The work builds on previous research we conducted in a medical department at the same hospital. The results of both studies affirm the difficulty health professionals have with defining the notion of ethics, and point to the fact that ethical behaviour happens at both the individual and organisational level. As these issues touch all professionals involved in health care, and are at the core of a new direction in understanding ethical decision-making, we are very keen to hear of your experience and thoughts on this matter. We always appreciate your feed-back - let us know what you think about these ideas!

I am often asked about the location of our central office. We are based at Milton in Brisbane, Queensland, Australia you can find a site map on our website at: http://www.ipp-shr.cqu.edu.au/visitus. So now you know, please feel free, when you are passing our way, to drop in and catch up.

As always we bring you a wide range of research from around the world: from the USA, research on newborn screening; from Scotland, insights on birth choices; from NZ, findings on decision-making to obtain medical help during stroke, and, from the USA, research on how race and ethnicity impact on surrogate decision-making.

Happy reading!

Dr Pam McGrath

IPP-SHR Director,
NHMRC Senior Research Fellow

We would like to hear from you!

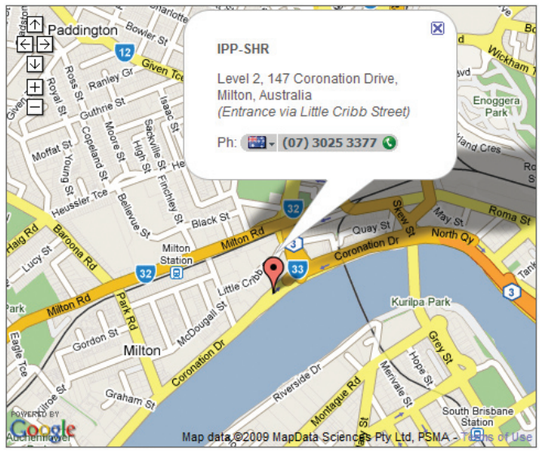
IPP-SHR is keen to hear your thoughts on the Psycho-Social Review. If you are interested in any particular topics or would like to see any new sections introduced please let us know.

Letters to the editor, news or articles that you wish to share can be sent to ipp-shr@cqu.edu.au or 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





Map Data ©2009 MapData Sciences Pty Ltd PSMA
Courtesy of Google Maps

Catastrophic Bleeds: Controversies from Australian Research

Off the Press @ IPP-SHR

As part of a two-year, National Health and Medical Research Council (NHMRC) funded research project, focusing on the integration of palliative care services into haematology, IPP-SHRs researchers have found that there is a lack of information on managing catastrophic bleeds (CBs) for haematology patients. To address this dearth of information this article seeks to document the experience of managing catastrophic bleeds, from the perspective of health professionals involved in the care of these patients.

The research indicates that although CBs are rare, such episodes are very traumatic for all involved, including, the patients, their carers and family, and the health professionals. Participants reported considerable disagreement as to whether predicting a CB event was possible. This unpredictability was viewed as a major contributor to the shock and distress associated with a CB experience. Findings indicated that there was considerable controversy about the provision of clinical and supportive care to haematology patients who were vulnerable to catastrophic bleeds. Controversy arose from: actually identifying at-risk individuals; the role of blood products in supportive care; and pre-emptive warnings to family and friends. Participants stated that prior knowledge of a CB was seen as beneficial, as it could reduce shock due to the speedy onset of some CBs. Statements to the contrary focused on whether it is unnecessarily frightening, or stressful, for those involved, particularly due to the unpredictability of CBs.

Ambiguity also existed regarding the appropriate response associated with the CBs impact upon home-based palliative care , ranging from, the CB being a major obstacle for haematology patients to receive in-home care, to, indicating that by providing carers with appropriate strategies for managing a CB, the possibility of its occurrence would not prevent home-based care. Haematologists' insights indicated that although the possibility of a CB shouldn't prohibit a patient's choice to die at home, in-patient care was the usual option in this situation.

However, all health care professionals were in agreement on providing sedation and pain relief to patients experiencing a CB. Insights provided by the health care professionals highlighted a number of practical suggestions including: the use of dark towels to minimise the distressing visibility of the bleed; the importance of advanced planning for care; accepting the situation has limits; reassuring the family that the patient was likely to lapse into a lack of consciousness and would not suffer, and the use of sedation.

The major recommendation emerging from this research was the need for further research work on this topic, in order to provide clear guidelines for best practice in clinical and supportive care.

McGrath, P., Leahy, M. (2008) Catastrophic bleeds during end-of-life care in haematology: Controversies from Australian research, *Supportive Care in Cancer,* Online First

what's happening @ IPP-SHR

IPP-SHR Welcomes New Adjunct Research Fellow – Dr. Sue Rice

Dr. Sue Rice has been appointed Adjunct Research Fellow, and will further IPP-SHRs Australia/India, psycho-social health research program, by exploring the interface between AIDS patients and women's rights within Kerala, India.

A/Prof Thomas Koilparampil Visit

Further to Dr. Rice's appointment, IPP-SHR was pleased to welcome Associate Professor Thomas Koilparampil to Australia in December, 2008. A/Prof. Koilparampil was in Australia to further Australia/India research collaborations, and to promote the Austral- Asian Journal of Cancer.

Congratulations Dr. Judi Parson

IPP-SHR wishes to congratulate, Dr. Judi Parson on the award of her PhD. Judi, completed her doctoral studies exploring the integration of procedural play for children being treated for cystic fibrosis from a nursing perspective.

New Book Announced – Ms. Sandra Evans

IPP-SHR welcomes Ms. Sandra Evans new book titled: "Dream to Hope". A first hand account of enduring paediatric leukaemia", due for release in May, 2009.

ChemoClub

IPP-SHR, in collaboration with Dr. David Joske from Sir Charles Gairdner Hospital, Western Australia, and Steve Smith from Aspire Fitness, will explore the benefits gained by patients participating in group exercise whilst undergoing treatment for haematological malignancies.

Bereavement Research

Cittamani Hospice, and IPP-SHR, have teamed up to evaluate Cittamani's Bereavement Program. With funding awarded by CQUniversity's Merit Grant, the collaboration hopes to explore the, anecdotally reported, low mortality rate of clients of the Cittamani bereavement program.

50th Podcast

IPP-SHR celebrated its 50th Podcast! Published on the 5th December, 2008, the podcast featured Professor Brenda Happell, and explored the effectiveness of mental health services from the consumers' perspective.

global update

A look at psycho-social health research around the globe

Location: Auckland, New Zealand

Help-Seeking at the Time of Stroke: Stroke Survivors

Researchers from New Zealand used open-ended interviews, with 20 participants, to explore the factors involved in making the decision to obtain medical help at the time of stroke. Participants were enrolled from three hospitals; a community-based stroke support service, and a primary health care service focused on health care for Maori.

The research revealed four main themes which affected the participant's decision to obtain medical help. Firstly, almost all the participants reported struggling with making sense of their symptoms, often putting the symptoms down to ageing, muscular problems, pre-existing health conditions, or other illnesses. Even when some participants identified their symptoms as being caused by a stroke, they still delayed seeking medical treatment. Secondly, participants expressed a desire to maintain a sense of normality as being influential in not seeking immediate medical assistance. Participants spoke of the choice to self-manage as the norm, rather than seeking out medical assistance. Thirdly, the presence of another person played a major role in the decision-making process at some point. This either delayed or expedited the process, with participants reporting on the tension between holding onto their independence, whilst, taking into account the concern of others. Lastly, the perception of medical services such as, when they should be accessed (during business hours), their perceptions of the accessibility of services, and previous encounters with medical services all influenced the decision-making process.

These findings highlighted the complexities involved in an individual's decision-making process to seek medical help whilst undergoing a stroke.

Publication Details Moloczij, N., McPherson, K., Smith, J., Kayes, N. (2008) Help-seeking at the time of stroke: stroke survivors' perspectives on their decisions, *Health and Social Care in the Community*, 16(5): 501-510

Listen Online 3rd April, 2009, 9:05 am EST

Location: Bronxville, New York, United States of America

Is My Sick Child Healthy? Is My Healthy Child Sick?: Changing Parental Experiences of Cystic Fibrosis in the Age of Expanded Newborn Screening

Newborn screening (NBS) began more than 20 years ago and is now experiencing a rapid growth across the United States, with more than four million babies annually undergoing such tests. This study explores how the NBS program influences parents' lives whose asymptomatic baby screens positive for a genetic disease (e.g. cystic fibrosis), and compares these experiences with parents who received a diagnosis after symptoms emerged.

Parents reported that the early diagnosis impacted deeply upon their feelings of competence towards adequately care for their newborn. Having a newborn baby to care for can be a daunting experience for many parents and in particular if it's a first baby. In addition, the early diagnosis of a non-treatable genetic disease makes it even more difficult for the parent to cope. It places the disease at the forefront rather than allowing the focus to remain on "falling in love" with their newborn baby.

Parents commented that the early diagnosis of cystic fibrosis put the medical professionals in the best position of understanding the situation and employing the best care for their newborn baby. Parents' found it vital to have contact with the health-care providers, as they were unsure of whether their own care giving was adequate; they relied on medical staff for expertise, advice and reassurance. Practical recommendations were made such as: asking parents how much information they needed about the normal course of the diagnosed condition; and if there were no serious health consequences, to the baby, the NBS could be delayed for two to three months, thus allowing time for the critical bonding between parent and newborn to occur.

Publication Details: Grob, R. (2008) Is my sick child healthy? Is my healthy child sick?: Changing parental experiences of cystic fibrosis in the age of expanded newborn screening, *Social Science & Medicine Journal*, 67; 1056-1064

Listen Online: 24th April 2009, 9:05 am EST

Location: Leicester, United Kingdom

"Choice" and Place of Delivery: A Qualitative Study of Women in Remote and Rural Scotland

One-fifth of the population in the United Kingdom, and one-third of the population of Scotland, live in rural and remote areas. Research into the birthing choices for women in rural and remote locations is greatly lacking. To address this absence of information a study was conducted to explore women's perceptions of "choice", and place of delivery, of their babies.

The research findings revealed that the perception of choice was heavily influenced by the women's perceived safety during birth. Women in these remote areas have three choices: a mid-wifery led unit, a home birth, and a consultant based birth.

Consultant based care was viewed as the safest option as they were seen as covering every eventuality. Mid-wifery based care was seen as offering a higher level of psycho-social care, but perceived safety was still given priority. Women living in rural and remote areas would rather travel the long distance to receive this type of care, before the birth process begins, in order to avoid being taken via ambulance or air during active labour. The way in which the "choices" were presented by health professionals greatly influenced this decision-making process, which was further compounded by the notion that many women hadn't even realised that they actually had a "choice".

Women engaged in making choices did so in a variety of ways ranging from, "acceptors" to "active choosers". Further influencing rural and remote women were pregnancy complications and geographical accessibility, and its influence on their social support networks.

The findings from this research raised many questions about the meaning of "choice" within recent policy recommendations which advocated the right for women to have a choice. More research is needed to investigate this complicated and important issue.

Publication Details: Pitchforth, E., van Teijlingen, E., Watson, V., Tucker, J., Kiger, A., Ireland, J., Farmer, J., Rennie, AM., Gibb, S., Thomson, E., Ryan, M. (2009) "Choice" and place of delivery: a qualitative study of women in remote and rural Scotland, *Quality and Safety in Health Care*. 18(1):42-48.

Location: Houston, Texas, United States of America

Voices of African American, Caucasian, and Hispanic Surrogates on the Burdens of End-Of-Life Decision Making

Scant research exists on the experience of end-of-life decisions made by a patient's surrogate, and on how race and ethnicity impact upon this decision-making process. Researchers recruited 44 experienced surrogates to explore the role of ethnicity, race and culture within the surrogate's decision-making processes.

Data was analysed using qualitative methodologies with a focus on themes that might be endemic to each of the three groups. All groups reported a similar experience when exploring the burden of end-of-life decision-making processes. Participants reported that the uncertainty surrounding the patient's prognosis, in conjunction with the need to explore the patient's preferences, whilst in the context of the medical, personal and familial areas, compounded the decision-making process.

The participants indicated a number of variations in the decision-making process, which were seen in the following areas: physician–family relationship; religion and faith; past experiences with race/ethnicity, concordant versus non-concordant physicians.

The research indicated that physicians might be unaware of the burdens associated with being a decision making surrogate and suggested that physicians became attuned to these strategies, adopted by surrogates, to alleviate the burden and uncertainty which surrounded this difficult end-of-life process.

Publication Details: Braun, U., Beyth, R., Ford, M., McCullough, L. (2008) Voices of African American, Caucasion, and Hispanic Surrogates on the Burdens of End-Of-Life Decision Making, *JGIM: Journal of General Internal Medicine,* 23(3):267-274

Listen Online: 17th April 2009, 9:05 am EST

international perspectives

How psycho-social research is used around the world

Meeting both Physical and Psycho-Social Care in Ethiopia: The Fistula Foundation



Dr. Catherine Hamlin and her late husband Dr. Reg Hamlin, established the Addis Ababa Fistula Hospital in 1975 to assist Ethiopian women experiencing the debilitating condition of obstetric fistula. A fistula develops when a pregnant woman experiences a prolonged, obstructed and unassisted labour. The pressure of the baby's head against the pelvis bone cuts off blood supply to the bladder tissue and sometimes the wall of the rectum. This leaves the women permanently incontinent. The foul smell makes them social outcasts from their families and villages, with little or no support. Pregnant women living in remote areas are particularly vulnerable, as they have little or no access to medical intervention. To address this health issue the Hamlin's developed a surgical procedure which has a success rate of 93 percent. The Hospital, and its four outreach centres, can treat up to 3,000 women every year.

The psychological impact upon these women is significant. They arrive at the Hospital crippled, and often very depressed, as a result of the injuries and shame they have suffered. The nerve damage caused by a protracted labour, and long periods of lying curled up in the hope that this will stop the leaking, causes their leg muscles to atrophy. The isolation and the sense of shame the women feel often results in deep depression. It can take months of physiotherapy and psychological counselling before a patient is well enough to have her fistula repaired. Patients often arrive thinking no one else has the same problem. Soon they find they are not alone; they feel welcomed and accepted.

In addition to psycho-social rehabilitation, gained from the surgical restorative procedure and from normalising the experience, the beauty and tranquillity of the gardens surrounding the Hospital help restore the body, as well as the mind. Such settings provide a perfect opportunity for the women to receive literacy and numeracy lessons which assist greatly with the healing process.

Since the establishment of the Hospital, many innovative outreach programs have been added to assist with this problem, including: a mobile medical team; a course to teach women parenting skills; and a college to train Ethiopian women as midwives.

Large Barriers Psycho-Social Research in India

I am presently working on a thesis on the psycho-social spirituality of the terminally ill at the University of Madras, which is located in Chennai, Southern India. The objective of my thesis is to learn about the psycho-social spirituality of cancer patients, and to explore existential questions of patients within the exchange of biomedical science and faith. This study is based upon experiences recorded while working at Adayar Cancer Institute and the Jeevodaya Hospice in Chennai. In addition to my academic work, I also provide guidance and counselling to cancer patients in neighbouring areas.

However, pursuing a career in psycho-social studies and spirituality in India can be quite challenging. Apart from the high costs of post graduate studies, practical barriers exist, such as, computer access and intermittent internet availability. As there is very little government or industry support for such academic exploration, support from family and friends is needed to complete any study. Although faced by limited opportunities, I am striving to further my studies and have a strong passion for the welfare of humanity.

E Sandiyagu
PhD, Chennai, India

Give us a buzz, drop a line or flick us an email !

International Perspectives aims to give an insight into all aspects of psycho-social issues around the globe. Whether it is recent advances in programs addressing psycho-social issues, musings about psycho-social practices, or an update on the relevance of psycho-social issues within your town or country. We are keen to hear from you.

email: ipp-shr@cqu.edu.au

chat back

Teaching Spiritual Care to Health Care Professionals

In 2006, the Mid North Coast Division of General Practice (MNCDGP) received a grant, from the Department of Health and Ageing, to increase local health care providers' levels of understanding and skills, in relation to the non-religious spiritual care needs of palliative care clients.

To increase such understanding, to date 96 workshops have been conducted, covering a diverse range of service providers and organisations including: hospitals; residential aged care facilities; community organisations; volunteer groups, and carer support networks. Participants ranged from personal carers and volunteers to professional staff, involving, general nursing staff, social workers, palliative care nurses, facilities managers, General Practitioners, and patients facing life threatening illnesses.

The workshops were designed to be interactive, and to facilitate, rather than guide the conversation into specific directions. In the beginning, most workshops focused on talking about spirituality and discussing theoretical concepts of spirituality and religion. Although this was usually easy and safe for the facilitator and participants, it did not touch on the intimacy of one's own experiential spiritual process. As a result, the very first workshops were predictable, and not always entertaining enough to keep tired staff engaged, between shifts.

Gradually, it became clear that to fully engage participants in the understanding of spirituality, it is paramount to invoke a sense of the spiritual aliveness or presence in the workshops, so health care professionals could truly connect with their own and, where appropriate, each others spirituality. To run workshops about spiritual care, in essence, means to recognise and teach practices of nurturing and developing one's own spirituality first. Therefore, it is important that the facilitator of such an interactive process is familiar, at ease, in touch, and able to share from their personal spiritual experiences.



Of course, such an inquiry is always approached gently and at no time were people obliged to participate. Spirituality and spiritual care, after all, is not a thing, a commodity, or technology of healing; it is about respect, nurturing and wholeness.

Anna Bloemhard, M.A.
Spiritual Care Project Officer
Mid North Coast Division of General Practice,
New South Wales, Australia

The Spiritual Care Project finishes on 31st March, 2009 and is run by Anna Bloemhard. Anna's book "Spiritual Care for Self and Others" can be found online at www.mncdgp.org.au/node/210
For further information please contact Anna on 02 66515774 or email: bloemhard@mncdgp.org.au

TLC: Innovative Respite Options

The TLC Volunteers service began in 1990 after a few local people recognised the need for palliative care support in our community.

The group provides free care for those deemed palliative, living with life limiting illness and respite for their carers. In providing this service and respite for carers, we enable families to stay together for as long as they can manage and give them the realistic option of dying at home.

The services is provided and managed through a group of volunteers who undergo a nationally accredited palliative care volunteer course. Further training is provided through a buddy system which works well in early days, assisting in gaining confidence and providing companionship and mentoring.

In addition to care and respite offered within an at-home setting, volunteers also provide respite in the local public hospital. Rostered to visit patients over two shifts a day, this support assists both staff and patient's families. Patients who do not have immediate family located within the area are brought to the groups' attention as a priority to reduce isolation.

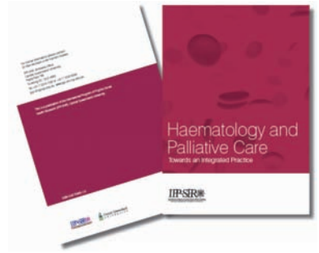
Currently we are researching ways to reinvigorate our transport/ companionship service that provides a unique service of collection of a person (& carer if they wish or they may choose the time for respite) for their chemo or radiation treatments. The service is unique as the volunteer stays with the person throughout their treatment and brings them back home. Treating centres located in the city are a 84 km round trip.

It is exciting to think we shall celebrate 20 years in the community in 2010. It is an aim of mine for this service to become more convenient and flexible by making it available to the community 5 days per week, instead of the presently funded 3 days.

Judith Robinson
Coordinator
TLC Volunteers Maitland Inc., NSW
www.tlcmaitland.org.au

from the coalface

Programs and Practitioners



Haematology and Palliative Care: Towards an Integrated Practice.

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Dogs at Work!





Grace: A Cocker Spaniel demonstrates skills learnt through training to become a service dog.

Canine Helpers train assistance dogs for people with a disability. An assistance dog can dramatically improve the life of a person with a disability, from increasing mobility and independence, to preventing accidents and injuries. An assistance dog provides many different kinds of support, all of which enables a person with a disability to live their life more fully, more confidently and more independently.

Excluding benefits associated with physical assistance, recipients also note additional psycho-social benefits including, relief from anxiety or depression, and increases in exercise levels and social interaction. Assistance dogs are highly trained, and are certified to accompany their handler in public, in the same way as Guide Dogs.

There are different types of assistance dogs:

- Service Dogs work with an individual with a physical disability, and can perform tasks, such as, opening and closing doors, helping with household chores and retrieving the phone;
- A Therapy Dog works with an individual with other disabilities, such as, autism or mental illness;
- Facility Dogs work in a group setting, like a special education unit or a hospital. These dogs work with a range of children and adults with different disabilities;
- Hearing Dogs work as the ears of their owner, e.g. telling them when a doorbell rings, kettle boils or alarm sounds.

Canine Helpers is currently the only non-profit organisation in Brisbane that provides assistance dogs free of charge; and it continues to work towards providing better services, and more highly trained dogs, at the lowest possible cost to recipients.

For more information please visit www.caninehelpers.org.au or Call 07 3350 2090

CANINE HELPERS
FOR THE DISABLED INC

The Journey Beads Program

A diagnosis of childhood cancer, or other related disease, begins a long, emotionally and physically difficult journey into a world of treatment. In November, 2001, the Journey Beads Program was incorporated into the Legacy Emanuel Children's Cancer and Blood Disorders Program, to help provide children and their families with another form of recording their treatment experience.

Journey Beads begins with a piece of cord, with the child's name, in which coloured beads are added, each representing a different aspect of the treatment. Journey Beads is a tangible way, for patients to document their progress and to share their feelings in a code that will be understood by their families, caregivers and by other kids who have cancer. The beads are a measure of how far they have come and represent some personal challenges the patients have faced throughout their treatment. Benefits include, helping children understand what they have been through, and gives the social workers a chance to sit with the parents, or child, to talk about each bead, the procedures, and feelings that accompany them.

The Journey Beads program aims:

- To provide a way for children to document and honour the experience of the treatment;
- To provide an opportunity for each child to tell their own unique story and record it in some tangible way;
- To help children create meaning out of the numerous procedures they must endure;
- To provide a way for children to symbolise their disease related experiences visually, playfully and artistically;
- To provide children and parents a unique way of communicating the experience of childhood cancer or other related disease.

In January, 2008, we also started the Sibling Bead Program. We found that siblings



became interested in having their own necklace and so we began the program for them. It's a way for them to record the effects of their sibling's cancer on their own day to day life. The goals of this adjunct program are:

- To provide a way for children, who have siblings with cancer, to honour their experience as a brother or sister;
- To provide an opportunity for each sibling to tell their own unique story and record it in a tangible way;
- To help children honour and create meaning out of the changes in their life, due to having a sibling with cancer.

The program is flexible and children do not have to participate, or, they can stop at any time. Journey Beads are meant to be FUN!! The bead boxes are located in several different areas including: The hospital, the Children's Cancer Program Clinic and the Children's Day Treatment Unit.

Legacy Emanuel Children's Hospital Cancer and Blood Disorders Center Portland, OR, USA

Frequent Users of Health Services Initiative

The Frequent Users of Health Services Initiative (FUHSI) funds programs in six Californian communities to address the needs of "frequent users", defined as individuals who repeatedly cycle through hospital emergency rooms due to acute or unmanaged chronic health conditions, often complicated by psycho-social issues.

Frequent users' multiple and complex needs are not effectively addressed by costly and episodic care provided in hospital settings, so, the FUHSI was designed to promote the development of integrated, community-based care to address patients' comprehensive needs and to decrease avoidable emergency department visits and hospital stays. Ultimately, the Initiative aimed to relieve pressure on overburdened hospital and emergency care systems and promote effective use of resources.

The six FUHSI programs redirected care from emergency departments to lower cost community-based facilities. In addition to providing acute medical care at presentation, FUHSI, assisted users' in navigating multiple systems—primary care, mental health, substance abuse, and social services. The six programs varied from, intensive case management provided by licensed clinical staff to, less intensive para-professional staff-driven interventions; but all used a multidisciplinary approach. In some cases, a team that included a physician and/or nurse practitioner, a licensed clinical social worker, a case manager, and a benefits advocate, directly provided the services; in other cases, a case manager referred the client to required services.

Barriers to serving the population included: difficulty with client outreach and engagement, since many clients were not receptive to receiving services; technological challenges that impeded easy identification of eligible clients, as well as, real time notification of their emergency room use. Despite these challenges, the multidisciplinary approach used by the Initiatives programs produced positive results, including: connecting 66 percent of clients to California's health insurance for the poor; increased referrals to community clinics and primary care providers; 53 percent were eligible for disability insurance; 42 percent with mental health issues at enrolment were connected to services; 34 percent of clients, who were homeless, were connected to permanent housing; and 20 percent of clients, with substance use issues, were connected to services.

In addition to being able to provide holistic and sustainable health care for users, the programs were also able to significantly reduce emergency department and hospital inpatient use.

The FUHSI is a six-year California-based effort funded by two philanthropies: The California Endowment and the California Health Care Foundation.

www.frequenthealthusers.org







what's on ?

- 5th World Congress
  World Institute of Pain – WIP
  When: 13 - 16 March, 2009
  Where: New York, NY, USA
  For more information visit:
  www.allconferences.com/conferences/20071230075236

- 11th Congress of the European Association for Palliative Care
  When: 7 - 10 May, 2009
  Where: Vienna, Austria
  For more information visit:
  www.eapcnet.org/Vienna2009/index.html

- Midwifery Today Conference
  "Preserving the Spirit of Midwifery"
  When: 13 - 17 May, 2009
  Where: Copenhagen, Denmark
  For more information visit:
  www.internationalmidwife.com/conferences/Denmark2009/Denmark09program.pdf

- 7th International Interdisciplinary Conference on Communication, Medicine and Ethics
  When: 25 - 27 June, 2009
  Where: Cardiff, UK
  For more information visit:
  www.cardiff.ac.uk/encap/research/hcrc

- Bioethics and Health Law Conference. Future Offers, Future Threats
  When: 9 - 12 July, 2009
  Where: Queenstown, New Zealand
  For more information visit:
  www.events4you.co.nz/abaanzihle.html

- 9th Biennial Rural Social Work Conference
  When: 30 - 31 July, 2009
  Where: Geelong, VIC, Australia
  For more information visit:
  http://www.aasw.asn.au/

- Inaugural Whole Person Care National Symposium
  When: 30 - 31, October 2009
  Where: Sydney, Australia
  For more information contact:
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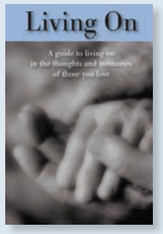
journal and book profile



The Social Context Of Birth

The Social Context of Birth brings together a collection of informative essays on issues of importance to the lives of women in the 21st Century. Situated within a socio-cultural perspective, this book traverses a diversity of topics relevant to the core theme of childbirth. It offers contemporary views on issues as broad and timeless as "women and society" and "the family", whilst also addressing more specialised, post-modernist concerns, such as, new reproductive technologies, foetal surveillance and the medicalisation of childbirth. This collection, written in lay language, will appeal to students and practitioners of midwifery and the caring sciences, along with those interested in issues surrounding women and birth.

Squire, C. (ed.). (2007). The Social Context of Birth
Oxon, UK: Radcliffe Medical Press



Living On: A Guide To Living On In The Thoughts And Memories Of Those You Love

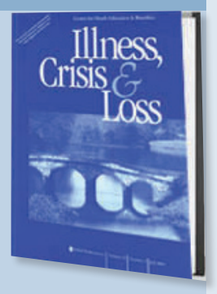
Most people make a conventional Will to pass on their material possessions. Award winning Australian health journalist Jill Margo, and her daughter Emily, have extended this notion to include the act of passing on an emotional legacy through messages to family and friends. The purpose of this emotional legacy is to provide comfort and support for those who remain.

To assist this process they have written a book that draws on the real-life experiences of many people, and offers pragmatic guidance about how to leave something of yourself that will live on after you have gone. Readers are provided a wealth of practical suggestions and ideas on how to communicate messages through a wide range of mediums including, written, audio and visual presentations.

Margo J. & Margo E. (2008) Living On: A guide to living on in the thoughts and memories of those you love, Brandl & Schlesinger, Blackhealth, NSW, Australia

feature journal

Illness, Crisis & Loss



Illness, Crisis & Loss is the resource that furthers your understanding and knowledge of the psycho-social and ethical issues associated with life-threatening illness, traumatic human crises, grief, and loss. The broad focus of the journal makes it relevant to a wide range of professionals and scholars, such as, grief counsellors, therapists, social workers, thanatologists, physicians and nurses, medical ethicists, and anyone else who works with people in crisis situations.

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podcast picks

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Terminal Dehydration: The Experience and Perceptions of End-Of-Life Palliative Care Nutrition and Hydration

Most palliative care patients, at the end-of-life, will have a significantly decreased food or drink intake, if any at all. Such cessation can be due to lack of energy, anorexia, dysphasia or nausea, and this absence of nutrition leads to isotonic dehydration: the loss of salt and water from the body. Whilst potentially distressing for the families and health professionals, isotonic dehydration can be beneficial for the patient. To discuss the reactions and perceptions, of families and health professionals, to medically administered nutrition and hydration, Dr. Pamela van der Riet talked with Hamish Holewa for IPP-SHR podcasts. Noted were benefits associated with reduced issues with fluids, less incontinence and vomiting and some documentation relating to decreased pain. Despite such benefits, decreasing of medically administered hydration and nutrition, to a palliative patient, can be distressing to the family. Education, open discussion and a team approach for staff in acute care and families, as well as basic care for the patient, was seen as very important in easing the experience and burden on all in palliative care..

Published:
30 January, 2009

The Combating Civilian: Suicide Risk Factors in Combat Veterans

Recent theories state that a person's tendency to suicide is dependent on three factors: acquired ability, burdensomeness and failed belongingness. This, added with a repeat exposure to painful stimuli, can lead to a habituation to pain. To discuss her study on how this theory applies to combat veterans, Dr. Lisa Brenner spoke to Michael Bouwman for IPP-SHR podcasts. Lisa talked about how soldiers are trained to use their military values and skills in a combat situation, and how this highly violent environment can lead to a numbing of feelings and a high tolerance of pain, which was found to be a major influence towards suicidal attempts. When veterans return home they have feelings of dissociation, disconnectedness and of not belonging; this can lead to feeling they are a burden on others, and feel a loss of self sense and purpose. It was found that veterans felt that family and friends were the reason why they were still alive, however, this was coupled with a feeling of distress if they were not able to provide financially for their family. The goal from this study was to increase more work with veterans and revise traditional rehabilitation systems, which in turn, would help veterans return to work that was meaningful, and help veterans adapt military values to positive experiences in civilian life.

Published:
06 March, 2009

Social Well-Being: The Therapeutic Values of Urban Public Spaces

For IPP-SHR podcasts, Dr Vicky Cattell talked to Hamish Holewa about her study on improved understanding of the use of public spaces. This study looked into people's interactions within their everyday public spaces, and how these spaces promoted well-being – the main focus being on what promoted/protected health, rather than what caused illness. It was noted that quiet, green and peaceful places were chosen by people as places of privacy and solitude. However, it was noted that the active, community spaces of urban life were also what people sought– to use these public spaces to interact with others. Some also felt it enough to be able to sit back and observe interactions going on around them. It was also noted that public spaces, such as, local markets and shopping streets, had a higher potential for encouraging inter-ethnic understanding. This study showed that busy spaces had therapeutic qualities, people felt comfortable, could mix and observe with others in their own urban environment.

Published:
06 March, 2009

IPP-SHR PODCASTS

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Psycho-Social Health Research

IPP-SHR podcasts explore the latest in the world of psycho-social health research. With thorough commentary, convenience of access and global coverage, catch up on the latest in psycho-social health news.

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4. Listen through the PSR - Click on the podcast title of the electronic version of the PSR and it will automatically play on your computer!

Decision Making for Live Renal Transplant Donors

work in progress @ IPP-SHR

Although the benefits for the recipient of a kidney donation have been well documented, the psycho-social risks to the donor are less understood. Research is needed to ensure appropriate decision-making that will lead to positive outcomes for potential live donors.

IPP-SHR researchers have reached the half way milestone for this longitudinal research project. The study follows a group of 20 participants through their donation process, from the first point of contact through to one year post transplant. Preliminary findings indicate a high level of satisfaction with the donors' decision to provide a live kidney to a family member or significant other, and are starting to provide detailed information on factors that contribute to success.



IPP-SHR PAH Live Donor Research Team
From Left- Julie Haynes, Maine Liles, Melinda Jesudason, Dr. Paul Pun, Dr. Pam McGrath.

research

Web 2.0 and Research?



Hamish Holewa
IPP-SHR Program Manager

Although as its name suggests, Web 2.0, does not hold any fundamental difference in its construction to Web 1.0. It still uses the same programming languages, (perhaps with an extra level of abstraction), the same method of transferring data, and although upgraded to deliver faster information flow, the same pipes and machinery. What has changed is the way people interact with websites and the Internet.

The main difference between Web 1.0 and 2.0 is interactivity and content control. Web 1.0 largely reflected the same business models of "offline" businesses; the Internet was largely viewed as an extra medium for advertising. Companies offered content in a similar way to commercial television or newspapers. Content was professionally written and editors controlled what was posted. Information was hierarchical and not individual; communities of users were controlled by single entities. However, such paradigms of information control seemed to evaporate, as did wealth of investors, during the 200/2001 DotCom crash. Whilst the industry was picking itself up and dusting itself off, entrepreneurs, designers and programmers began to realise the powerful potential of the massive network that the Internet is.

Fast-forward to 2009, and Web 2.0 is the new paradigm: websites now facilitate the easy sharing of user generated information and content; communities of users can share thoughts, music, videos and photos. Social networking sites which assist in keeping contact with friends, family and acquaintances, appear to be unstoppable. Finding interest groups, subjects and communities of users has never been easier.

The advent of user created content, social networking and Web 2.0 paradigms provides researchers with additional opportunities to gather ideas, contact and recruit participants, disseminate results and manage research. Researchers are able to enter the conversational world, or community, of a particular topic. A quick search brings up numerous consumer forums covering any number of health topics. Although analysis requires the same methodological procedures and research design as "traditional" research methods, Web 2.0 provides a different avenue for participant expression and participation.

Another option worthy of exploration would be to use a social networking site for project information, dissemination and participant recruitment. Social networking seems to have an inherent snowballing effect: like-minded users continuously sharing with other interested parties. Through these forums, participant recruitment, or research cross-checking and validation, could be obtained.

However, as with all research there is a caveat. The Internet is not the all inclusive, democratic, social, global entity that it is commonly portrayed as. Positive response bias, would be on ones short list, in regards to research design. Also, people go to different websites for different reasons. Just because it is on the Internet doesn't mean it's an international representation: the majority of users might come from developed English speaking countries, and MySpace might be the most popular social networking site in America, but in Australia it's Facebook, in Brazil it is Orkut, in Japan it's Mixi, and in China it's Xiaonei.

IPP-SHR: Research that connects

IPP-SHR is dedicated to working with those at the coalface of health care and providing 'research that connects'. In additional to academic research, IPP-SHR has extensive experience in knowledge creation, conducting domestic and international research projects, program evaluation, topic exploration, workshops and consultation. Please do not hesitate to contact us if you require any further information regarding IPP-SHR's services.

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