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Detailed Insights into
Psycho-Social Health Research

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Psycho-Social

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

Review

"I was never like that"

Australian findings on
the psychological and
psychiatric sequelae
of corticosteroids in
haematology treatments



Corticosteroid treatment is at the core of most treatment protocols for haematological malignancies. However, the treatment efficacy often comes at the cost of distressing emotional side effects such as insomnia, euphoric moods, mood disorders, mania and visual hallucinations, severe depression, irritability, violence, neuropsychological deficits and psychotic states.

There is a dearth of published data documenting the emotional and psychiatric sequelae of corticosteroid use for haematology patients and its connection with pre-existing mental history. In response to this, IPP-SHR researchers conducted a study that explored prior mental illness health history and the effects of corticosteroid use on haematology patients in Australia.

The participants reported no prior need for any psychiatric or counselling services. All participants reported being well supported by a network of friends and family. Consequently, most participants were shocked and surprised by the emotional difficulties experienced whilst taking the corticosteroids during treatment. A wide range of symptoms were reported by the participants. These included insomnia, disturbing thoughts, depression, agitation and irritability, hyperactivity, mind wandering and forgetfulness, anxiety and panic, slurred language and hallucinations. All the participants clearly stated in their

Off the Press @ IPP-SHR

interviews that their symptoms were directly associated with the corticosteroid use. Some participants documented this by writing down their experience with corticosteroids so they could track when they were most likely to experience these emotional side effects.

Special mention was made of the difficulties associated with the week long withdrawal process experienced after the corticosteroids were ceased. The withdrawal process was characterised by symptoms such as social withdrawal, emotional flatness, agitation, anxiety and a foggy or fuzzy feeling in the head.

These findings provide evidence that emotional disturbances associated with corticosteroid use in haematological malignancies are directly related to the drugs used and not a symptom of the individual's prior emotional well being.

McGrath, P, Patton, M & James, S (2008) "I was never like that": Australian findings on the psychological and psychiatric sequelae of corticosteroids in haematology treatments", *Supportive Care in Cancer* 17; 4: 339



Online Version is available at
www.ipp-shr.cqu.edu.au/publicatons

editorial

Dear Reader,

Although IPP-SHR has its origins in psycho-oncology, in recent years the research program has extended to embrace the full spectrum of the psycho-social industry from birth to death and in areas as diverse as renal transplantation and mental health. One of the great advantages of such an umbrella program is that it provides a birds-eye-view of the development of the many areas associated with psycho-social health research. Therefore, the strong focus on paediatric oncology in this issue of the Psycho-Social Review is a timely reminder to us of the great success in this area.

Journals now abound that are devoted entirely to the publication of psycho-social research to help us understand and respond to issues faced by children with cancer and their families. The peer-review processes on these journals are now informed and respectful of the contribution of qualitative research. There is increasing evidence that the insights from psycho-social research in the area of childhood cancer are being effectively translated into service delivery improvements and health policy consideration. These exciting developments have only happened over the last few decades – an inspiration for what can be achieved!

It is a good time for all those who have made a contribution to putting the psycho-social agenda on the map in oncology to stop and reflect positively on the major achievements of their collective efforts. While many other disciplines are only starting out in this area of psycho-social research, they too can be inspired by a vision of the future that is now on the horizon of a health industry driven by a knowledge base that appreciates and responds to the human experience (including the psychological, social and spiritual dimensions) of serious illness.

As always the quarterly review brings you psycho-social research from around the world. In this issue we hear of work from Canada on international medical graduates; from Brazil, research on family refusal to donate organs and tissue for transplantation; from Norway, insights on the psycho-social dimensions on acute and dramatic spinal cord injury; and, from New Zealand, research on Maori Men and the grief of SIDS.

Happy reading!



Dr Pam McGrath

IPP-SHR Director,
NHMRC Senior Research Fellow



IPP-SHR Research That Connects

IPP-SHR is a collaborative initiative jointly funded by the National Health and Medical Research Council and CQUniversity, which aims to examine and document the human experience of significant physical and mental conditions.

The program is concerned with contributing to the development of psycho-social services that assist people to deal with the many challenges associated with significant physical and/or mental conditions or episodes.

IPP-SHR's research program continually expands to address issues across the psycho-social continuum, including: haematology/oncology, mental health, palliative care, acute medicine, bioethics, rural and remote health, Indigenous health, spirituality, paediatrics, birth studies and service delivery evaluation.

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

The Medicine Is To Get Me Better Findings on paediatric patients' responses to play with medical equipment

Off the Press
@ IPP-SHR

Children diagnosed with a haematological malignancy undergo a long and arduous treatment experience which involves frequent hospitalization, repeated intrusive procedures, and side-effects from prolonged chemotherapy. This article presents findings from recent qualitative research which documents through an unstructured play-based interview, the insights and understanding of paediatric haematology patients about their disease and its treatment. This data was compared with a control group of healthy preschoolers who experienced similar play-based interviews.

The material in this article has been gathered as an extension of the first stage of a longitudinal Australian study that looks at the psycho-social issues associated with the treatment of paediatric Acute Lymphoblastic Leukaemia (ALL) and associated haematological disorders. It is an exploration of the experience of treatment for paediatric ALL and related haematological disorders from the perspective of the child patient, their parents and well siblings.

The play-based interviews were transcribed verbatim and analysed using qualitative methodologies. The findings from the interviews were in direct contrast with the earlier findings with the healthy pre-schoolers. Whereas the healthy preschoolers had a very short-lived, naïve and joyous curiosity about the medical equipment, the child patients either played intensely for extended sessions or avoided the medical play completely. Unlike the healthy pre-schoolers who resorted to imaginative constructs to help explain the purpose of the medical equipment, the child patients used appropriate terminology and provided scientifically based thinking in their understanding of their diseases and treatments. The child patients could name the equipment, were aware of its use and were able to mimic the health professionals through direct and realistic use of the equipment.

In relation to their explanations about their diseases, even the young pre-school child patients provided sophisticated insights. This understanding extended to their knowledge of the treatment

and its side effects, procedures and protocols, and the rationale for the use of different technologies.

The findings point to the distressing emotional sequelae associated with invasive medical procedures for children undergoing treatment for ALL as revealed by their responses to medical play. Responses such as obsessive play and avoidance resonate with the literature on posttraumatic stress and are dramatically different to children not exposed to such treatment experiences. The study highlights the need to respond therapeutically to such procedural distress and demonstrates the efficacy of play as a medium for communication about such distress with child patients.

McGrath, P & Huff, N (2009) "The medicine is to get me better: Findings on Pediatric Patients' Responses to Play with Medical Equipment." *Austral-Asian Journal of Cancer* 8: 2; 83-91.



Online Version is available at
www.ipp-shr.cqu.edu.au/publications

what's happening @ IPP-SHR

IPP-SHR Welcomes New Adjunct Research Fellow – Dr Marie Theresa Proctor

IPP-SHR welcomes Dr Proctor whose appointment heralds a close collaboration between IPP-SHR and Westmead Children's Hospital, Sydney.

Psycho-Social Profile of Head and Neck Cancer Patients

IPP-SHR Practitioner Researcher at the Princess Alexander Hospital has recently completed her data collection on 300 newly referred patients. The full report will be released shortly.

CQUniversity Excel Award Mr Hamish Holewa

Awarded for his work with IPP-SHR podcasts – if you haven't heard IPP-SHR podcasts – go to www.ipp-shr.cqu.edu.au/podcasts

CQUniversity New Vice Chancellor

IPP-SHR welcomes Prof Scott Bowman to CQUniversity. IPP-SHR also thanks Prof John Rickard for his vision, support and leadership.

75th Podcast

IPP-SHR Podcasts reach another milestone with the release of the podcast featuring Professor Anthony Jorm: Desire for Social Distance from People with Mental Disorders. Podcast #69 with Dr Jane Grassley has been re-released as an extended version due to popular demand.

OSWA Website Launch

IPP-SHR wishes to congratulate its affiliate, the Oncology Social Workers of Australia for the public release of their website. The website will provide an important resource and link for social workers involved in haematology and oncology settings. Also visit: www.oswa.net.au

AJC

The AJC: An open access, multidisciplinary cancer journal has recently implemented online article submission and editorial process tracking. This enables greater flexibility and transparency in the peer review process. Interested authors can submit their articles at www.ajcancer.org

● Location: Ontario, Canada

Recertifying as a doctor in Canada: international medical graduates and the journey from entry to adaptation.

Approximately 23-28% of the doctor workforce is now represented by international medical graduates (IMGs). These physicians are practising medicine in countries where they did not graduate from medical school. Globalisation and severe doctor shortages have jointly contributed to the increasing levels of IMGs currently practising medicine around the world. Data does exist on IMGs; however most of it examines the credentials, competency, demographic characteristics and their distribution. Little is known about the IMGs recertification training experience within recipient countries.

This study aims to address this gap in knowledge of the IMGs experience of recertification within a recipient country. Four main themes typified the recertification experience.

The first major theme captured with the training entry barriers. The IMGs described the process as logistically difficult, impersonal and stressful. The other three themes emerged as

a 3-phase process of loss, disorientation and adaptation. The IMGs described the theme of loss on two levels: personal (loss of personal identity, financial autonomy and ability to fulfil familial roles) and professional (loss of professional identity and status). The participants reported a feeling of disorientation due to cross-cultural differences in medical practice. The loss and disorientation phases need to be resolved before the IMG can successfully navigate through the final phase of adaptation to the recipient countries' medical system.

It is the hope of the researchers that the findings from this study will better inform future medical training programmes to improve IMGs integration into recipient medical communities.

Publication Details: Wong, A., & Lohfeld L. (2008) Recertifying as a doctor in Canada: international medical graduates and the journey from entry to adaptation, *Medical Education*. 42; 1: 53-60.

● Location: Sao Paulo, Brazil

Family refusal to donate organs and tissue for transplantation

Deciding to donate a loved ones organs and tissues for transplantation is a complex process which begins with the identification and maintenance of a potential eligible donor. The act of donation involves the following steps: identifying potential organs, family notification, informing the Center for Organ Sharing (COS), ascertaining the eligibility of the organs, and performing diagnostic exams to confirm brain death. The Center for Organ Sharing (COS) must then notify the Organ Procurement Agency (OPA) who assesses the clinical conditions of the potential donor, eligibility of the organs and gains family consent. A study was conducted in Brazil to explore the perceptions of potential donor family's decision making process to refuse organ and tissue donation for transplantation.

The data analysis indicated that the situation was perceived as being shocking and despairing. The participants reasons for donor refusal were: religious beliefs; the hope for a miracle; distrust regarding organ donation; denial or a lack of understanding of brain death; grief and weariness due to the loss of the loved one; a fear of organ trafficking; and family

conflicts for making the decision The research also noted that many people in this position often do not have the necessary information for making the decision or do not clearly understand the donation process.

The presence of several factors such as an awareness of the patient's wishes, emotional support, and information provided to the family about the donation process, contributed to encouraging the act of donation. An accurate appraisal of the patients condition upon hospitalization and informing family members immediately when procedures are begun to confirm brain death also facilitated family members ability to engage in the decision making process.

It is hoped that the knowledge gained by this research will provide support for professionals who work in the challenging area of organ and tissue donation and transplantation.

Publication Details: Moraes, E.L., & Massarollo M.C.K. (2008) Family refusal to donate organs and tissue for transplantation, *Revista Latino-Americana de Enfermagem*. 16; 3: 458-64.

A look at psycho-social health research around the globe

global update

● Location: Oslo, Norway

The incomprehensible injury – interpretations of patients' narratives concerning experiences with an acute and dramatic spinal cord injury

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 caring 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: Lohne, V. (2009) The incomprehensible injury – interpretations of patients' narratives concerning experiences with an acute and dramatic spinal cord injury, *Scandinavian Journal of Caring Sciences*. 23; 67 -75.

● Location: Auckland, New Zealand

Maori Men and the Grief of SIDS

The sudden and unexplained death of an infant as in Sudden Infant Death Syndrome (SIDS), represents one of the most traumatic events a family can experience. For New Zealand's Maori peoples, this trauma has been shown to be exacerbated by the imposition of statutory investigation processes which have been shown to ignore Maori grieving rituals. Whilst interventions to work with SIDS families have been documented to improve grieving outcomes for Maori mothers, the needs of Maori fathers are still not well understood or catered to by existing services.

In response to this significant dearth in knowledge, New Zealand researchers have collected narrative data from Maori fathers who have lost a baby to SIDS and analysed these narratives in the context of traditional Maori constructs about grief. Their findings indicate that Maori fathers are not well supported through the grieving process and that significant service and personal barriers (e.g. beliefs about the importance of being staunch for other family members) inhibit them from accessing and utilising supports.

The stories of the Maori SIDS fathers interviewed in this study provide stark accounts of relative disconnection from community and extended family and an array of isolating, self-destructive coping mechanisms. Furthermore, these narratives highlighted the challenges imposed upon fathers by a lack of financial and other resources upon which to call at the time of an infant's death and a largely insensitive coronial investigation process.

The findings of this study point to a clear need to effectively facilitate Maori fathers' experiences of grief, recognising the intrusive, oppressive and overly forensic activity around a SIDS death. This research also highlights the need for Maori men, their families, their organisations and their communities, with their unique set of cultural values and practices around grief, to reclaim and/or adapt them to facilitate the journey through the alienating, painful, grief-producing experience of losing an infant to SIDS.

Publication Details: Edwards, Shane, McCreanor, Tim, Ormsby, Manga, Tuwhangai, Nick and Tipene-Leach, David (2009) 'Maori Men and the Grief of SIDS', *Death Studies*, 33:2, 130 — 152

Featured Section: At-the-coalface

Using the Internet for Psycho-Social Support

For this issue, At the Coal Face showcases some of the new psycho-social programs that are utilising innovative technology to offer support in the area of paediatric and young adult cancer.

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

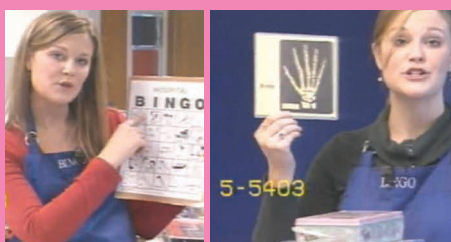
International Perspectives aims to give an insight into all aspects of psycho-social issues around the globe. Whether it is recent advances in programs addressing psycho-social issues, musings about psycho-social practices, or an update on the relevance of psycho-social issues within your town or country.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

email: ipp-shr@cqu.edu.au

A Little Bit About Hospital Bingo

Hospital Bingo is a health and medical themed Bingo game which has been played at Johns Hopkins Paediatric Hospital since the mid 1980's. Broadcast over the Closed Circuit Television system, Hospital Bingo is intended to provide community and social interaction for the hospital's paediatric patients. Patients can physically attend or claim their Bingo using the internal phone system. Winners are able to select a prize which is delivered to their bedside and provided by private and corporate sponsors. The appeal of Hospital Bingo is enduring -despite being in operation for over 20 years, it is still the most anticipated event of the week.

See a Video demonstration of Hospital Bingo at <http://vimeo.com/4202628>



Providing Hope and Support

Programs & Practitioners

Staff working at the Child Life Department did not let the opportunities presented by the opening of the new Charlotte R Bloom Children's Hospital at Johns Hopkins in 2010 to pass by. The department realised that the new hospital provided the opportunity to implement internet connectivity, computing and gaming by the bedside and to provide a fertile ground for research exploring such issues. Patrice Brylske provides some insight into the process at Johns Hopkins Child Life Department.

Many children's hospitals across the US are currently evaluating the optimal method to bring access to the internet for patient computing and playing video games to the bedside. The value for patients and families is clear, instant communication with family and friends via email and web pages, decrease in frustration with wait times for computers or gaming consoles, as well as the potential for a decrease in nosocomial infections from sharing systems on the paediatric units. The challenges for hospitals to implement the changes in the delivery of these services are significant. The costs to purchase and maintain a fleet of PC/gaming systems, the dramatic increase of the time from IT departments to support the systems, and the difficulty in bringing guest access to the internet in a clinical environment without compromising network security and risking patient care are a few of the huge hurdles to overcome.

The Child Life department is responsible for providing play and preparation to normalize the healthcare experience. The department recognizes the influence

technology has on children today, and has propelled these issues forward and created an environment ripe for pilot projects in computing and gaming at the bedside. The department has partnered with non-profit HopeConnectsKids whose intent is to give chronically ill children the opportunity to escape the stresses inherent in their conditions by providing distraction and comfort through gaming and peer contact. We are set to research the impact of social gaming for hospitalized children. Where does the use of technology fall on the continuum of play: normalization, distraction or therapeutic expression?

The process has already begun with Hospital Bingo, a traditional game played via closed circuit TV has been integrated into a multiplayer video game. No longer will patients at Hopkins need to wait until Wednesday at 2:30 pm to enjoy their favourite hospital game.

Patrice Brylske
Program Director
Johns Hopkins Hospital
Baltimore, Maryland, USA

Dr Arun Mathews MD
Director Research Fellow
HopeConnectsKids
Johns Hopkins University School of Medicine
www.hopeconnectskids.org



international perspectives

How psycho-social research is used around the world

Livewire

Connecting young people with a serious illness, chronic health condition or disability

Livewire.org.au, is a new online community designed specifically for young people aged over 10 and under 21 living with a serious illness, chronic health condition or disability. It has been developed to provide a safe and supportive online network where members can connect and share experiences wherever they are – at home or when undergoing treatment in hospital.

An estimated 450,000* young Australians aged between 10 and 21 are currently living with a serious illness, chronic health condition or disability. These conditions can profoundly impact their everyday lives, leading to frequent absences from school, sport and other social activities. Young people living with an illness or a disability frequently experience significant



isolation. Livewire can be considered part of a holistic healing approach to help them feel less isolated, receive more social support, overcome anxiety and stress, alleviate boredom and feel an increased sense of community participation.

Livewire combines youth culture content, interactive games and a full suite of social networking tools including chat, blogs and forums where a team of chat hosts and moderators trained in adolescent health ensures that Livewire remains a supportive, safe and fun place.

(*Children's Hospital Education Research Institute (CHERI) Report, September 2008)

Cinnamon Pollard
Partnerships and Marketing Director,
+61 411 432 143
www.livewire.org.au

International Psycho-Oncology Society

The International Psycho-Oncology Society (IPOS) was established in 1984 as the only international, multidisciplinary organization dedicated to fostering the science of psychosocial and behavioural oncology and improving the care of cancer patients and their families throughout the world. The vision of IPOS is that all cancer patients and their families throughout the world receive optimal psychosocial care at all stages of disease and survivorship. IPOS hosts an annual World Congress of Psycho-Oncology to aid in fulfilling its mission and vision.

www.ipos.org.au

Keeping Up with Current Issues Social Networking Websites for adolescents with cancer

Adolescents diagnosed with cancer experience a significant decrease in their social lives. This period of isolation occurs at a time in their development when socialization with peers is of the utmost importance. A small body of literature is emerging which is documenting adolescents' use of internet based support during cancer treatment; adolescents gain benefits such as a feeling of social competence by staying in contact with peers, self-expression, and information access.

To further document adolescents' use of website based support a team of researchers at McMaster Children's Hospital are conducting research which aims to explore how adolescents diagnosed with cancer use social networking websites during and after cancer therapy, to identify the positive and negative elements of this form of support and finally, to investigate the reasons why adolescents perceive this type of support as helpful or not.

Jane Cassano,
McMaster Children's Hospital
Ontario, Canada

Fusion 5 Website

Although leukaemia can occur at any age, children aged fourteen years and younger account for nearly sixty percent of all cases according to the Leukaemia Foundation. While there is a wealth of information available for adults and teenagers, there is little in the way of online information produced specifically for children to aid in their understanding of leukaemia.

This website intends to fill this gap by producing age specific material and to also extend the traditional medical environment by providing a fun, informal, informative, safe and therapeutic educational tool. The interactive website is based around a key central character with whom children can relate, who explains in a first-person narrative their journey from diagnosis through to treatment. Other characters include medical personnel, a portacath-fitted ragdoll friend, and a metaphorical chemotherapy superhero.

The resource aims to empower children with leukaemia with knowledge about what is happening to them, and in turn ease some of their fears of the unknown. It is also designed to reduce social isolation, stigma and misunderstanding by allowing children to easily explain to their peers their leukaemia, treatment and possible side-effects. The website's target audience includes not only children with leukaemia but also their siblings, friends, family, carers, educators, medical personnel and psycho-social specialists.

<http://fusion5.micaelita.com>

For further information or enquiries, please contact Michelle Thompson and Joe-Anne Kek-Pamenter at: fusion5@micaelita.com



Fusion 5 Website Characters

The impact of steroid use in myeloma – insights from a support nurse

Chat Back Tracy King brings a wealth of practical experience as a Myeloma Support Nurse to her response to IPP-SHR's published research on the topic of the psycho-social impact of steroid use in haematology.



Steroids feature commonly in the management of Myeloma and perhaps more so than other blood malignancies. In reference to your article concerning Dexamethasone treatment protocols in paediatric oncology patients, Decamethasone is also used with all of the newer agents (Velcade, Thalidomide, Revlimid) and indeed high dose 'Dex' alone is a treatment for Myeloma. Despite such usage, steroid toxicity and adverse events are underreported and undermanaged in my experience with

those with myeloma.

Internationally there is much interest in the nursing community around informing patients as to the adverse events associated with a range of common Myeloma treatments and 'steroid effects' feature in the top 5: Peripheral neuropathy; myelosuppression; thrombotic events; steroid effects; and gastro effects. Following this, in June 2008 the International Myeloma Foundation of Nursing Leadership Board published a consensus statement on managing the side effects of steroids.

Anecdotally I find it is the side effects of steroids to be one of the most overlooked and under-managed toxicities. I manage a telephone helpline and run support groups and educational days for consumers and we always have cause to discuss steroid effects. Perhaps it is the complex nature

of steroid effects on all body areas that makes it so tricky to manage? Perhaps it is the perception that steroids are the more 'gentle' of treatments with chemotherapy and immune-modulators being the ones to manage first? Perhaps it is the systemic nature of the toxicities? Whatever the reason, I believe we do an injustice to our patients in not proactively managing toxicities of steroids.

I had one patient who wore a red badge to work on her steroid days – she was a nurse, and her badge showed her colleagues that she was a woman not to be messed with on steroid days! Another patient got out of his car on the M25 in London and abandoned it! Another was up knitting all night. Others are moribund, the list goes on. There are so many interventions and strategies that can be applied to help live better with steroids, if only we applied them.



Information on the published consensus statement managing the side effects of steroids can be found at: International Foundation of Nursing Leadership Board (2008) Steroid-Associated Side Effects in Patients With Multiple Myeloma: Consensus Statement of the IMF Nurse Leadership Board. Clinical Journal of Oncology Nursing, 12;3; Supp: 53 -63

Psycho-Social Care In A Day Surgery Center

Programs & Practitioners

Facing surgery is a daunting experience, which due to high caseloads, increasing workloads and fewer staffing options, patients' emotional and psycho-social needs might not be adequately met. To address this unmet need, the Asheville Surgery Centre, North Carolina has created a unique position called the Patient/Family Liaison Officer.

The Patient/Family Liaison Officer identifies these needs and finds a way to make their surgical experience as positive as it can be. This may be through informal actions such providing a cold drink, a reassuring hug, conversation or through more formal actions such as organising a tour and providing play therapy.

Particular attention is focused on

children who are at high risk of trauma post surgery. Tailor made tours of the Surgical Center are regularly conducted with the assistance of a therapeutic puppet called Gertie, who explains in developmentally appropriate level what will happen on the day of surgery and shows the children all the equipment and the Operating Room for familiarising purposes. Pre-operative teaching experiences such as these provide a vital link for paediatric patients in gaining confidence and coping skills which help to dramatically decrease any lingering trauma as a result of surgery.

Although this role initially begun to increase customer service satisfaction, the role has quickly grown and has resulted in positive implications including, improving communication between staff, patients and their families before, during and after surgery.



Patti Campbell
RN Nurse Manager
Asheville Surgery Centre
Mission Hospital
Asheville, North Carolina

The Life-Limiting Conditions Project

Programs & Practitioners



Diagnosis of a paediatric life-limiting condition profoundly changes family life. Across the illness journey the affected child and his or her family can experience a range of psycho-social, developmental, educational, relational, spiritual and healthcare needs. Appropriate and timely support of families is facilitated when healthcare professionals (HCPs) acquire an understanding of the effects of a serious illness upon the entire family. This process is enhanced when research makes available information to assist HCPs in making best practice decisions.

The Life-Limiting Conditions Project is a qualitative study exploring Australian families' experiences of caring for children and adolescents diagnosed

with life-limiting conditions with a view to understanding how: (i) they cope, adapt and manage the challenges they face when caring for ill children; (ii) they experience care systems around them; and (iii) they make choices about the services they use. Ninety-one family members spoke about how conditions such as leukemia, cerebral tumor, Wilm's tumor, bone tumor, cystic fibrosis, neuromuscular disorders, severe congenital abnormalities, biliary atresia and various rare metabolic disorders impacted their family life.

As the Project Officer for the Life-Limiting Conditions Project I was privileged to listen to the families' stories and to observe their care in action. Working with a group deemed to be vulnerable; discussing sensitive issues and at times distressing experiences such as the death of an ill child; interviewing currently ill children and adolescents and their well siblings of varying ages and developmental stages was challenging

and deeply rewarding. Extensive time was dedicated to building rapport with family members with prolonged contact maintained during the interview phase, with post interview support and follow-up provided. Family members reported the process to be cathartic, many indicating their participation was fuelled by a desire to help families yet to have a child diagnosed.

Currently we are conducting thematic analysis with findings being considered from the perspectives of couples; intergenerational relationships; a nuclear family unit; extended family systems; and within and cross family experiences. Findings are currently being presented at conferences and through peer-reviewed journals.

Dr Marie-Therese Proctor
Psychologist & Researcher
For further information about the LLC Project, contact Dr. Marie-Therese Proctor at mtproctor@optusnet.com.au

The Psycho-Social Support and Integrated AIDS Project (PSIA)

Chat Back Gideon Odhiambo, a psycho-social health facilitator from Kenya, writes to explain some of the support programs he is facilitating.

I am a psychosocial health facilitator and behaviour change consultant working in the war torn area of Southern Sudan. I am currently working with the Psychosocial Support and Integrated AIDS Project (PSIA) that seeks to integrate HIV/AIDS prevention, care and treatment services with psychosocial support for orphaned and at risk children.

The children PSIA works with are exposed to difficult and harsh social, physical economic conditions as a result of parental loss or loss of caregivers and the destruction of family support systems by either HIV/AIDS or war. These children face a complex situation of unbelievably severe

life challenges, including:

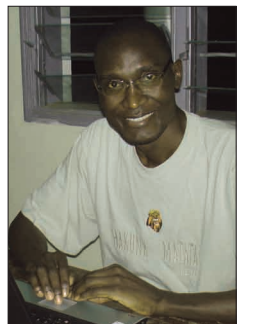
- The trauma of war and constant abductions.
- A heavy responsibility to care for sick parents, caregivers and/or siblings made vulnerable by HIV/AIDS.
- Stigma from people and other children leading to discrimination in basic needs provision and the enjoyment of basic rights.
- Hunger – these children simply struggle to find food. A number of them are able to only eat one meal a day!
- School drop-out, due to diminished ability to pay school fees and access other educational requirements.

In responding to these extreme issues, PSIA has two main objectives. Firstly we seek to improve access and utilisation of facility and community based HIV prevention, treatment, care and support services

amongst the child and adult population.

Secondly, the program aims to support and improve the emotional, behavioural and psychological wellbeing of orphans and vulnerable children identified to be struggling with psychosocial challenges.

Within this program, my role is to work towards the realization of the later objective, by facilitating activities aimed at improving resilience and recovery amongst orphans and vulnerable children affected by depression and emotional or psychological trauma. Although a peace agreement was signed in 2005, the psycho-social needs of children within Sudan are still very high.



Gideon Odhiambo

journal and book profile



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



Play as Therapy: Assessment and Therapeutic Interventions

This book makes a contribution to the important work of all professionals who understand and focus on the medium of play as a way of engaging therapeutically with the world of the child. It is an easy-to-read, technical book with a wealth of referenced information on play assessment and therapeutic options.

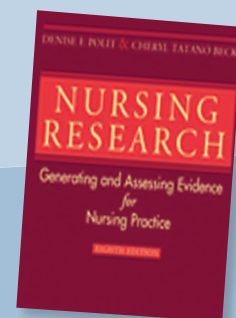
Stagnitti K. & Cooper R. (2009) Play as Therapy: Assessment and Therapeutic Interventions, Jessica Kingsley Publishers, London



Managing Quality in Qualitative Research

The issue of quality in qualitative research is one that is often neglected. In this comprehensive book attention is given to the fundamental question of how to define and assess the quality of research. Uwe Flick examines how to distinguish between good research and bad research when it comes to the areas of teaching, evaluating, planning and publishing of qualitative research.

Flick U. (2007) Managing Quality in Qualitative Research, Sage, London.



feature book

Nursing Research: Generating and Assessing Evidence for Nursing Practice

This is a comprehensive textbook on methodological issues in regards to nursing research by authors who have well established reputations in the area. An ambitious textbook that provides an overview of up-to-date knowledge associated with generating and assessing evidence for nursing research – the contents have an appeal to a wider audience. It is a well organized textbook with topics that range from conceptualizing, designing, collecting and analyzing data for research to inform an evidence-based approach to nursing practice. This is a useful book for any researcher's library.

Denise F. Polit & Cheryl Tatano Beck, (2008) Nursing Research: Generating and Assessing Evidence for Nursing Practice, 8th Edition, Lippincott Williams & Wilkins, London

upcoming events

Event	Dates	For more information
2009 World Congress of the World Federation for Mental Health Athens, Greece	02 - 06 September, 2009	Visit: http://wfmh.org/09WCongress.htm
Palliative Care 2009 Combining the 10th APCC & The 8th APHC Perth, Western Australia	24 - 27 September, 2009	Visit: http://www.conlog.com.au/palliativecare2009/
Mind to Care. 35th International Conference Australian College of Mental Health Nurses Sydney Australia	29 September - 02 October 2009	Visit: www.acmhn.org
7th International Conference for Emergency Nursing. Balancing the Art and Science Gold Coast, Australia	07 - 10 October, 2009	Visit: www.cdesign.com.au/cena2009-03-23
Inaugural Whole Person Care in Clinical Practice – “Responding to the Challenge of Whole Person Care in Clinical Practice.” Sydney, Australia	30 October, 2009	Visit: www.iceaustralia.com/wholeperson09

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

A Mother's Guidance: Grandmother Breastfeeding Support For Mothers

Jane Grassley talks about her study on grandmothers' breastfeeding support for mothers. It was found that a grandmother's own infant feeding practices influenced mothers' decisions to initiate and continue breastfeeding. Open encouragement and support from grandmothers assisted a mother's decision to breastfeed and helped protect the mother from ongoing justification of breastfeeding. This was particularly important in cultures that have sanctions against public breastfeeding and unfriendly breastfeeding workplaces. It was also noted that some grandmothers felt that breastfeeding was a barrier to bonding with the grandbaby, including, being able to feed the baby, allowing the

baby to stay overnight and concern for the mothers well being. It was also shown that there were numerous myths that persisted in relation to breastfeeding; including: concern that a mother is not making enough milk, that exclusive breastfeeding did not deliver all dietary requirements and that breastfeeding "just did not work anymore". Practical implications suggest including grandmothers in breastfeeding conversations with health professionals, encouraging grandmother's to tell stories about their experiences, and providing additional information to grandmothers.

Published:
15 May 2009

We Did Not Choose This Life: The Stigmatisation of Poverty

Stigmatisation faced by people living in poverty contributes to social exclusion and poor health outcomes. Through interactions with others, including, staff of welfare agencies, people in poverty believe they are seen as free loaders whose poverty is due to laziness, irresponsible spending, and choosing an easy life. These beliefs are legitimised by media and government policies but are in conflict with peoples' personal identities. Participants described their resourcefulness, budgeting and survival skills in the face of chronic stress and anxiety, being unable to afford food, medication, and health services. Strategies people used to reconcile differences between their personal

and social identities included: hiding their poverty, confronting discrimination, and making a difference by helping others. While some participants were able to ignore comments by others, many internalised the stereotype, becoming depressed and further withdrawn. It is recommended that welfare agencies become more supportive, policy changes be made so that income inadequacy is not perpetuated, and evidence of the structural causes of poverty be disseminated to counteract the belief that this is an individual responsibility.

Published:
26 June 2009

The Final Shock?: What Prevents Physicians From Discussing Deactivating Defibrillators at the End-Of-Life

An Implantable Cardioverter Defibrillator or ICD can save a person's life by correcting a potentially lethal heart-beat. But what if a patient, who is nearing the end of life, just wants to die peacefully? It is rare that a patient is asked if they would rather the shocks stop, and they were allowed to pass away. To discuss his study on the barriers that prevent physicians from having this discussion with their patients, Dr Nathan Goldstein, talked to Michael Bouwman for IPP-SHR podcasts. Nathan discussed how physicians found it difficult to place these devices in the same context as other vital decisions that had to be made at the end of a patient's life. Physicians also noted the magnitude and sense of finality of turning a

defibrillator off, versus the easiness of taking a patient on and off their medication. In addition to this was the size of the device itself: a small nearly unseen bump under the collar bone was often not thought about, according to some physicians, as there was no physical reminder. However, it was stated the most significant aspect of this issue was the difficulty in predicting a patient's cardiac rhythm at the end of life, and when a defibrillator was going to shock. Due to this unknown entity, some patient's might not die soon after a defibrillator is removed, rather death would occur weeks or months later.

Published:
27 March 2009



IPP-SHR PODCASTS

Detailed Insights into 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!

Extended versions of IPP-SHR podcasts are commonly available. If you or your organization would like to request a topic for exploration, please email: The Director, Dr. Pam McGrath at ipp-shr@cqu.edu.au

International Medical Graduates Integration Study

*work*ⁱⁿ*progress*
@ IPP-SHR

IPP-SHR is pleased to announce that important milestones have now been reached in our program that explores the integration of the International Medical Graduates (IMGs) into the Australian healthcare system.

While there has been an increasing reliance on the employment of IMGs to staff hospital and healthcare services in Australia, to date, there has been

scant work that has explored the factors associated with their integration into the Australian healthcare system.

The program documents the experiences of IMGs in regards to their integration into the Australian medical workforce through three separate but related research projects.

The first project examines the Observer Program run by Redland Hospital in Brisbane, Queensland, Australia, which was developed to facilitate the training and employment of IMGs in the Australian health care system.

The second project involves in-depth interviews with 30 IMGs that have entered the Australian workforce. The data collection for this project has now been completed.

To ensure a complete view of the issues, it is pleasing to report that a third study has now been funded to examine the experience of Australian-trained doctors with IMGs.

IPP-SHR would like to thank the Redland Hospital for their support in initiating this exciting and important research program.

*r*esearch



Hamish Holewa
IPP-SHR Program Manager

Open source software (OSS) refers to software which is generally license free, can be modified and tailored towards unique needs and is, most significantly, available free of charge. OSS encompasses a design philosophy which is open, transparent and inherently peer-reviewed. The movement has been greatly enhanced by the massive connectivity, project management tools and distribution tools that are offered through the internet. The breadth of software offered by open source developed software is staggering. You can get open source operating systems, office suites, video and audio recording products, email and file transfer clients. Indeed, if you are reading this column through a web-browser, the server that delivered this file probably runs an OSS operating system. However, for this issue of *r-e-search* we would like to give mention to an OSS project named the Open Journal System or for those of us who prefer TLAs (three letter acronyms), OJS.

OJS is an open source software project that

Open Source for Open Access

aims to enable easy set-up, administration and operation of online journals. This enables groups, societies or individuals to set up an online journal, without expensive costs, overheads or the need to collaborate with publishers. Whilst there are other software packages available, these are generally quite expensive and/or exclusive to a publisher. The open source paradigm levels the publishing playing fields. It gives groups who may not have deep pockets access to technology and publishing processes once only available to larger publishers or with deeper pockets. The technology also removes a large component of the administrative cost enabling easier justification for open access publishing models.

Although OJS is open source, it doesn't lack any features. Authors can submit articles online and track their progress through peer-review to publication. Journal editors and managers can assign articles to reviewers, publish into online first editions, submit content to indexation agencies and automate communication processes. Additionally, menial tasks such as progress and deadline checking and subscription managements can be automated. Although using OJS

doesn't automatically make a journal good, it does take a lot of the administrative burden from originators and editors so they can concentrate on the policy and content.

Such benefits do come at a price. Firstly, you will need a little technical knowledge to first install and set up the system; although this may be minimal compared to purchasing a similar off-the-shelf product. Secondly, you need to be a little more resourceful when it comes to troubleshooting. Most OSS projects do not have the resources of a dedicated support team. Whilst this leaves you without a single port of call and a responsible entity, OSS projects generally have a strong community of users that are willing to lend a hand. And thirdly, the administrative layout and interface is not intuitive and may take some getting used to.

With a little bit of patience and resourcefulness, these hurdles are easily surmountable and shouldn't heavily bias a decision to explore open source software. Most experiences will be as good if not better than commercial software, particularly if, like most people, you consider finance to be a factor.

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 addition 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.

Contact Details:

IPP-SHR, CQUniversity, Brisbane Office, PO BOX 796 TOOWONG Q 4066 AUSTRALIA

Telephone: + 61 7 3025 3377 Email: ipp-shr@cqu.edu.au

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